

**Social Representations of Diabetes in Ghana: Reconstructing
self, society and culture.**

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ABSTRACT

Diabetes is a significant cause of adult disability and death in Ghana. Current research leaves significant questions unanswered about the integrated ways in which psychological and socio-cultural factors mediate chronic illness experiences and practices. This thesis develops a social psychological approach to address conceptual gaps in the field and outline practical possibilities for improving diabetes care. It draws on and expands the conceptual framework of social representations theory by incorporating socio-cultural theories of emotions, phenomenological perspectives on chronic illness experience, and the social psychology of participation.

Rural and urban accounts of health, illness and diabetes (experiences) were elicited through semi-structured individual and group interviews with 68 people with diabetes, 62 lay healthy individuals and 23 health professionals working in the biomedical, ethnomedical and faith healing spheres. Further, six-month ethnographies were carried out in the life-worlds of 3 people with diabetes and 11 significant others. Using Atlas-ti, a systematic analysis identified the nature and inter-relationship between (1) cognitive-emotional polyphasia – shared/contested thinking, feeling and embodied action on health, illness and diabetes; (2) biographical disruption – life changes caused by diabetes and inter-subjective meanings evoked; and (3) illness action – coping strategies and styles in response to biographical disruption.

Three sets of social representations of diabetes were identified: (1) the social representation of diabetes as a life-changing or life-threatening disease which emerged at the level of self; (2) the social representation of diabetes as a ‘sugar disease’ which circulated in the public sphere and (3) the social representation of diabetes as a spiritual disease which drew on cultural thought and practice. Each had positive and negative consequences for illness action. Informed by the social psychology of participation, the thesis outlines possibilities for transforming negative dimensions of social representations as a basis for improving diabetes care.

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GLOSSARY

Ethnomedicine

A variety of terms have been applied to indigenous African healing systems such as ‘folk medicine’, ‘traditional medicine’, ‘ethnomedicine’, ‘popular medicine’ and ‘popular health culture’. Following critical anthropological discussions on the legitimacy of these varied terms, I refer to the indigenous Ghanaian healing systems as Ghanaian ethnomedicine and to healers interchangeably as ethnomedical practitioners and health professionals. The choice of ‘ethnomedicine’ aims to draw attention to the roots of local medical and pharmacological perspectives within Ghanaian cultural traditions, but move beyond the dominant idea that they are traditional, static or less professional. The ‘health professional’ label used simultaneously aims to reflect the legitimacy conferred to this group, as healthcare experts, by lay Ghanaian society. Within these broad terms, the distinct specialties, such as herbalism, spiritualism and divination, are clearly distinguished where appropriate.

‘People living with diabetes’

The medical sociologist Conrad (1990) notes: “People who are sick spend only a small fraction of their time in a patient role. While being a patient may be an important aspect of being ill, it is by no means the only one nor necessarily the most important. We need to study how people manage their illness in their everyday lives much of which has no relation to their status as a patient. In this light I suggest we self-consciously reconceptualize our respondents as ‘sufferers or people with...’ rather than patients” (p. 1260). Conrad’s view captures the guiding ethos within critical health psychology. Theorists avoid using ‘patients’ in descriptions of their research participants. The use of ‘sufferer’ has generated some controversy recently. Some theorists argue that imposing the term ‘sufferer’ emphasizes pain and suffering to too great an extent, when illness experiences can encompass a broad range of productive and disruptive socio-psychological states. ‘People with...’ seems to be the most acceptable term within the field. Close attention is paid to these discussions. The term ‘people with diabetes’ is

predominantly used to acknowledge the complex nature and psycho-emotional responses of illness experience. However, where participants, including 'people with diabetes', use the term 'patient' or 'diabetics', or where people with diabetes define their experiences in terms of overwhelming pain and suffering I apply their own terms to legitimize their experiences and views.

Illness/disease

Critical health psychologists distinguish between illness and disease. Illness refers to the subjective experience of pain and disability, while disease refers to the biomedical emphasis on organic pathology. Theorists note that these distinctions are not that clear-cut: the biophysical, psychological and socio-cultural context of illness/disease are intricately linked. More, crucially, in the Akan language – the dominant language used in non-English interviews for this research – there is no distinction between illness and disease. The Akan term '*yare*' applies to a holistic integration of disease and illness. Therefore, 'illness' - in the critical health psychology sense - is predominantly used as it characterises biophysical and socio-psychological dimensions of disease. Where participants refer explicitly to distinct terms, these will be highlighted.

INTRODUCTION

AIMS OF THE THESIS

This thesis has two primary aims. First, it aims to develop a critical social psychological framework, which addresses the conceptual gaps in African-based chronic illness research. Current research focuses exclusively on cultural determinants of health and illness on the one hand and individual determinants on the other. This leaves significant questions unanswered about the way psychological and socio-cultural dynamics intersect and frame illness experiences and illness practices. The thesis draws on social representations theory as a conceptual framework to examine the interplay of psychological, socio-cultural and material factors mediating the experiences and responses of Ghanaians living with diabetes.

Second, the thesis aims to contribute to the policy challenge of improving the diabetes care in Ghana. Diabetes is under-funded and under-researched despite the fact that it has been high on the list of priority health interventions outlined by Ghana's Ministry of Health since the mid-nineties. There is consensus among local clinicians and policy makers that diabetes care is poor and requires robust research and intervention. The thesis sets out to provide people with diabetes, health professionals and policy makers with a systematic explanation of the ways in which people with diabetes experience and respond to their condition. This will facilitate the development of practical interventions that draw on existing economic and human resources.

BACKGROUND

It has become essential within the critical social psychological framework to make explicit one's position as a researcher, and the impact of this position on the research process, from the definition of the research question, through method(s) of inquiry employed, to analysis and theory building. This practice is based on the premise that all knowledge is socially situated and research is always carried out from a particular subjective and epistemological standpoint

(Ladson-Billings, 2001; Richards, 1997; Mama, 1995; Banister et al., 1994). It is important therefore to highlight the values underpinning one's intellectual work, by acknowledging the motivations, commitments, and conditions that influenced its production. Taking these perspectives on board, I provide a brief account of the ideological and motivational underpinnings of the research.

My interest in an African-centred social psychology of health was shaped by two definitive experiences. The first began during my Masters degree, a course that doubled up as a conversion degree for graduates with a non-psychology background. I had an undergraduate background in Pharmacology, but had decided a switch to clinical health psychology. I was particularly keen to explore ways in which my undergraduate interest in psychopharmacology and drug use behaviour could be expanded within a health psychology framework. While carrying out coursework and engaging with both mainstream and critical literature in abnormal psychology and health psychology, I began to identify particularly with social constructionist perspectives on psychiatry and mental health. Issues debated within anti-psychiatry discourse, such as the social construction of mental illness, the overemphasis of drug therapy in the treatment of mental illness, the problematic application of psychotropic drugs, and the compromising relationship between psychiatry and the pharmaceutical industry, constituted some of the key reasons I had abandoned a career as a bench pharmacologist for clinical health psychology. Ironically, as my engagement with critical social science perspectives grew, I became increasingly aware that the clinical health psychology ethos mirrored that of pharmacology, rooted as it was within mainstream medicine and psychiatry. My sense of unease deepened during work on my dissertation, when it became evident that mainstream psychological theories provided very limited analyses of health beliefs and practices within multi-cultural communities in the UK. The dissertation explored drug treatment of mental disorders and involved qualitative work with members of three voluntary mental health organisations in the Greater Manchester Area, one of which was African-Caribbean. Analysis of the data from African-Caribbean respondents touched upon the social construction of 'race', and

the complicity of mainstream psychology and psychiatry in the construction and maintenance of this problematic notion. Crucially discourses and practices around this notion underpinned the labelling of black patients with the more serious mental illnesses demanding social and legal restraint. This work shifted my research interests from a creative synthesis of pharmacology and health psychology to applied cultural and social psychology.

The second defining experience came post-Masters when I gained a voluntary internship with a medical school department in Ghana. The plan was to spend a few months working in mental health or health research, and draw on this practical experience to develop ideas for doctoral work. Months stretched to two years and the voluntary internship led to paid positions for a number of Ghana-based and US-based European and American international health organisations. I worked in various capacities - as research fellow, consultant, research co-ordinator and technical writer - on a range of short-term national and international health projects. I gained some expertise on diverse health areas in Ghana, such as community mental health, substance dependency in rural communities, drug use in hypertension and diabetes, as well as health areas in Asian and Latin American contexts.

With each project it became increasingly apparent that international health ideas - which constituted the main driving force of formal healthcare practices in Ghana and similar low-income non-industrialised countries - were as problematic as the mainstream clinical psychology and mental health ideas I had been uncomfortable with in my UK work. Research development in this arena was informed by notions of lay health beliefs and practices as resistant to biomedical intervention. This stemmed largely from the objectification of African communities as 'traditional' and 'developing', usually in implicit juxtaposition to an idealised developed, modern West. The goal of the majority of international health projects was to reshape 'faulty' cultural beliefs and practices - albeit in 'culturally sensitive' ways - in order to improve compliance to biomedical therapies and reduce the burden of disease. This epistemological stance perhaps was unsurprising since international health work was at its core driven by modernisation theory. What was more surprising was the wholesale and seemingly uncritical adoption of these ideas by Ghana's healthcare professionals. Given a socio-political

context where the double bind of economic dependency and the concomitant loss of local political decision-making power was widely debated and criticised, this non-reflexive expression of local ideas through the framework of international health discourse was unexpected.

During my internship at the medical school and subsequent projects, doctors I spoke to both formally and informally blamed non-compliance largely on traditional beliefs and practices. Lines of argument were often polarised. For example biomedicine was perceived as scientific, modern, and progressive in direct contrast to Ghanaian ethnomedicine labelled as non-scientific, traditional, and backward. Ghana's elite healthcare users were perceived as rational in comparison to non-elite groups (usually implying rural and/or uneducated) seen as non-rational and superstitious, and so on. A corollary to these lines of argument was a dominant perception of biomedicine as the sole agent through which 'progressive and modern' health attitudes and practices could be attained.

Through my work I was aware that patient practices and ethnomedical practices in Ghana could be problematic. Some individuals did shop around for treatment, within public and private biomedical facilities, between biomedical and ethnomedical systems and within ethnomedical systems, and in some cases used different drugs simultaneously. Some ethnomedical practitioners pushed forward a highly visible and sophisticated agenda as health experts. Their ability to cure a broad range of acute and chronic conditions was advertised not only via the mass media and local advertising outlets, but also (quite brazenly) on hospital grounds. However, coming from a recent history of intellectual engagement with critiques of race discourse in Psychology and Psychiatry, I was unconvinced of the polarised traditional-modern framework within which the relationships between biomedical practitioners, lay people and ethnomedical practitioners were conceptualised. To my mind biomedical non-compliance and accessing treatment within alternative medical spheres was not a problem reserved for 'traditional' societies and born out of the 'traditional' nature of socio-cultural practices, it was

as much a problem for people living with long-term illness in affluent 'modern' Western societies.

A critical look at Ghana's contemporary social realities highlighted the fundamental flaws in splitting social groups along traditional (non-westernised)-modern (westernised) lines and making broad assumptions about distinct socio-cultural practices on this basis. Ghana's history was intricately linked to European history, as a former Portuguese, Dutch, then British colony. There was a visible modernisation process sweeping through the country, fuelled both by the international community and the state. However, the Ghanaian contemporary reality was influenced not only by western ideas and cultural products, but also by cross-ethnic, cross-border influences. More importantly, the lives of most Ghanaians I read about, met, or knew, straddled the traditional and contemporary in very fluid ways. For example, in the health arena, the educated 'rational' elite was as likely to consult a traditional religious healer for answers to 'spiritual' problems, as was a rural uneducated dweller. The post-independence wave of evangelical Christian churches - highly publicised as contemporary religious systems of social, moral and spiritual support - had added a new dimension to medical pluralism in the country. While the media (especially print and radio) had a long history in Ghana, the nationwide growth of a private media sector since the early nineties had broadened the sources and content of social debates - blending global with local concerns - as well as the range of social groups engaged in these debates. Yet few of the informal discussions I had - and none of the formal health policy debates - took on board these shifting social and cultural relations when making sense of lay constructions of health and illness and the impact of these on illness experience and treatment practices. Neither were there any formal discussions on the extent to which the modernisation project shaped the knowledge systems and practices of healthcare professionals themselves, a crucial factor I felt, since they held local power over formal health issues.

It seemed evident that as long as Ghana's healthcare was shaped by medical pluralism, biomedical and ethnomedical systems, as well as all other alternative medical systems would continue to act as resources in the world of the ill. Furthermore, just as people with chronic

illness in a variety of social settings made sense of their illness by accessing a broad range of available information, resources and modalities of knowledge, Ghanaians with chronic illness were likely to draw on eclectic resources from their particular social and medical pluralistic contexts for their diverse needs. The economic context of care – in a low income social setting such as Ghana with its poorly resourced public health services and expensive private alternatives – was also likely to have a huge impact on treatment choices made not only within the biomedical sphere but decisions made to try cheaper alternatives elsewhere. Further, given the lack of a social welfare system, the socio-economic burden of illness would fall not only on people with long-term illness but also on their significant others. Placed within this broader context, issues of non-compliance and poor self-care took on more complex shades that went beyond simplistic dichotomies of traditional versus modern ways of thinking and living.

The role of culture in health and illness could not be overlooked. However, the questions asked of lay health beliefs and practices, in my view, needed to engage more critically with the way psychological, social and material factors intersected in illness experiences. These broad concerns informed the development of this thesis.

CHOOSING GHANA AS A CASE STUDY

Ghana was chosen as a case study for three reasons. First, like many African countries, Ghana suffers from what the World Health Organisation (WHO)(2003) terms, an “epidemic of non-communicable diseases”. However, the rise of chronic conditions co-exists with the problem of communicable diseases, and more recently the AIDS pandemic, which continue to claim the lives of large sections of African societies. Researchers note that the ‘double burden of disease’ constrains health systems operating with limited economic and human resources, leading to a policy context within which a significant proportion of healthcare budgets¹, human resources, and research, focuses on communicable diseases with comparative neglect of chronic non-communicable diseases.

¹ It has been estimated for instance that over 80% of the health budget in Africa is concentrated on communicable diseases (Pobee, 1993).

Secondly, my Ghanaian work experience showed that the success of research in the African setting is largely determined by critical attention to logistics. Essential infrastructure that facilitate the research process and are taken for granted in more affluent Western settings such as communications (especially postal communications and telecommunications) and transport systems, are problematic in both rural and urban African settings. It is not uncommon for a research project to run twice over scheduled time without appropriate logistical preparation and support. Given the time restraints of carrying out academic fieldwork, attention to logistics was crucial. During my two years work experience in Ghana, I developed useful professional and social contacts as well as adequate geographical knowledge of the country. Therefore, it made practical sense to carry out empirical work there.

The third reason for choosing Ghana was my knowledge of the local language and culture. The empirical and theoretical focus of this thesis is to examine the link between social knowledge, illness experience and practice. Language and communication are integral parts of the production, dissemination and transformation of knowledge, as well as social interaction and practice (Easton, 2001). Also important, as contemporary cross-cultural researchers such as Fiske and colleagues (1996) note, is the researcher's level of familiarity with the socio-cultural context of the research setting. With a dual British-Ghanaian identity and with good working knowledge of two major Ghanaian languages, Fanti and Twi, and partial knowledge of a third, Ga, I felt a focus on Ghana would be invaluable to the research process.

Africa was chosen as an overarching unit of analysis for this thesis. The aim was to make an important distinction between responses to the region's health problems and responses to health problems in other low-income non-industrialised nations. A general case may be made that the empirical problems under study are common to the majority of low-income non-industrialised nations. However, while a strong body of critical social science work on health grows in Asian and Latin American regions, much of what is known about health, illness and treatment practices in Africa continues to stem from mainstream anthropological, sociological and international health work. Progressive elements have emerged within anthropological and

sociological work in recent years. However their strengths lie at the macro-social level of analysis. Chronic illness research requires an integrated approach to the psychological, and social-cultural dimensions of experience and practices, as well as keen attention to the socio-economic and structural context of health delivery. Africa is therefore quite unique in terms of the significant lack of context-specific conceptual tools with which to begin a social psychological analysis of chronic illness experience and action. It was important, therefore, to single out Africa as the broader context within which particular discussions relating to Ghana are situated firstly, and secondly, as the region to which research findings could make a practical contribution.

THE EMPIRICAL PROBLEM

Diabetes has become a significant cause of adult disability and death in Ghana. Despite being placed on the list of priority interventions outlined by the country's Ministry of Health in the early 1990s, it continues to be under-funded and under-researched. It is estimated that 4% of Ghanaians aged between 15 to 70 years have diabetes (MOH, 2000), although epidemiological work on chronic illness is patchy and unreliable like the rest of Africa (Cooper et al, 1998a,1998b), and experts speculate that current rates might be higher (F. Ofei, personal communication, 2000; Amoah et al, 2002). The most recent clinical research, for example, showed a doubling of hospital admissions over a ten-year period (Adubofour et. al., 1993).

There is consensus among clinicians and health policy makers that diabetes care in Ghana is poor. The list of problems include poor diabetes education, a lack of guidelines for diabetes care, erratic supply of essential diabetes drugs at health facilities and poorly trained diabetes health care professionals (Adubofour et. al., 1993; Ofei, et al., 1996;Amoah et al, 2000). Poor professional care, commentators note, is implicated in poor self-care. Calls have been made for increased research on socio-psychological determinants of diabetes (Ofei, et al., 1996) and robust policy interventions (Amoah et al, 2000). The research-policy interface of chronic illness

care in Ghana is intricately linked to the broader regional context. It is therefore important that the discussion is situated within the regional context.

Two bodies of work contribute to regional research on chronic illness. The first body of work, here called 'cultural studies' constitutes anthropological and sociological approaches to health beliefs and illness practices. The second, here called 'medical psychology studies', draws from an amalgamated medical and health psychology paradigm and applies psychological concepts to examinations of health behaviour and (biomedical) compliance. The empirical goals of both bodies of work have been to improve biomedical practice and to facilitate the development of context-specific and culturally sensitive educational programmes to improve knowledge and health behaviour among people with chronic illness and wider populations. As such they have generated much needed empirical information on structural inequalities in chronic illness care, as well as highlighted gaps in public education. Fundamentally these activities present an important step forward in the neglected arena of chronic illness.

However this thesis argues that the exclusive focus on cultural determinants of health and illness on one hand and individual determinants on the other, leave unanswered questions about the social psychology of chronic illness in the region. This has crucial implications on providing quality care for people living with chronic illness, as well as the feasible use of existing human and economic resources to facilitate such a process. I will briefly outline the conceptual problems to make a case for introducing a social psychological approach to the field.

The cultural approach to chronic illness research

Considerable anthropological evidence has been gathered to suggest that reality in many African societies spans both natural and supernatural worlds. Kirby (1993:238), for example, notes: "the spirit world – the ancestors, spirits of the 'wild', spirits of divination and ecstatic spirits of possession, personal guardian spirits, magical 'medicines' and mystical devices, witchcraft and God – though not part of the material base of Western science, are absolutely basic to African

experience and problem-solving”. Evidence gathered on disease categories also suggests that lay theories of health and illness, like theories of everyday social realities, span the natural-supernatural continuum. Some illnesses are deemed naturally caused, others supernaturally caused.

Cultural studies can be grouped under two approaches: dominant and alternative. The dominant approach has adopted split distinctions between traditional African practices (synonymous with indigenous practices before westernization) and modern African practices (synonymous with post-westernization) as a framework for analysis. The alternative approach has adopted a more fluid approach to the tradition-modernity distinction by focusing on social change through intra-cultural and cross-cultural processes.

Both groups of studies highlight two major themes. Firstly most studies present evidence to suggest that chronic illnesses are conceptualized as supernaturally caused. Secondly, researchers note that individuals living with chronic conditions which biomedicine cannot cure invariably turn to the phenomena of ‘healer-shopping’ (the sequential use of a range of treatments within and across medical systems) and ‘dual-use’ (the simultaneous use of different treatments). Both practices are perceived negatively within both approaches in the broad sense that they undermine biomedical goals. However each group adopts a different interpretive framework in outlining the socio-cultural dynamics of treatment practices.

The dominant approach operates under two key assumptions. First, researchers stress that a shared value system between lay individuals and health professionals is a prerequisite for treatment consultation and compliance. Individuals living with naturally caused illnesses will seek exclusive treatment within medical systems expert in naturally caused illnesses; those living with conditions deemed supernaturally caused will seek exclusive treatment within ethnomedical systems designed for supernatural dimensions of disease. Secondly, distinct areas of medical expertise are demarcated for biomedicine and ethnomedicine: biomedicine is conferred expertise in the treatment of naturally caused conditions, while most indigenous

medical systems are deemed expert in the treatment of supernaturally caused conditions. Implicit within this is the scientific superiority of biomedicine over a pre-scientific traditional ethnomedicine. As chronic illnesses are widely attributed to supernatural causes, it is assumed that ethnomedical services are the first and sometimes only port of call for people with chronic illness. Poor compliance and self-care is therefore attributed to faulty cultural beliefs. The body of work aims to change lay and ethnomedical beliefs towards more modern biomedical lines.

The alternative approach challenges these key assumptions. Theorists argue that practical and symbolic meaning influences treatment practices. Individuals will consult practitioners who they believe can answer *how* and *why* an illness came about and how best they can treat the illness (Mavi, Owen, Gelfand, 1983). Secondly they argue against the dichotomy of biomedicine as modern and scientific and ethnomedicine as traditional and pre-scientific. Theorists assert that both systems share commonalities. For example, both observe symptoms, dispense medications and produce therapeutic effects (Morris, 1986). And ethnomedicine is as competent in treating 'natural' conditions, as it is treating 'supernatural' conditions. More crucially, theorists note, chronic illness raises grave uncertainties within both systems with respect to cause and cure (Huertin-Roberts and Becker, 1993). The intersection of professional and lay uncertainties, in their view, drives the healer-shopping process.

Ultimately, the evidence from the alternative cultural sub-field suggests that responses to illness are not rooted in static traditional-modern ways, but are mediated by the interaction of socio-cultural theories of causation, severity and timeframe of illness as well as cost, availability and accessibility of pluralistic medical services (Rekdal, 1999; Ryan, 1998; Nyamwaya, 1987). Social psychological dynamics are implicated in this body of work, but remain to be systematically theorised.

The medical psychology approach to chronic illness research

There are two approaches within the medical psychology field. The first approach draws from the knowledge-attitude-belief-practice (KABP) model - hereafter 'KABP studies' - informing mainstream psychological approaches to health behaviour and popularised by current WHO health promotional work in low-income African, Asian and Latin American countries. This model makes causal links between knowledge, attitudes and behaviour, and assumes that better individual knowledge will lead to desired behavioural change. Thus, like the cultural studies, the KABP studies have made strong links between poor knowledge of chronic conditions and illness management regimes and poor compliance and self-care. They prioritise educational interventions for biomedical professionals and lay people as a means of improving compliance and self-care.

The second approach has broadened the empirical scope to examine the psychosocial context of illness management. Psychosocial studies have identified the interaction between economic deprivation and psycho-emotional disruption, as a key barrier to appropriate illness management. They discuss the impact of such disruption on relationships and care-giving capabilities within life-worlds and on the quality of doctor-patient relationships.

The medical psychology studies, like the cultural studies, have notable shortcomings. The conceptual framework of the dominant KABP subgroup has come under attack within critical health psychology as a limiting approach to complex illness experiences². Theorists charge as simplistic the direct links made between knowledge, attitudes and behaviour and the notion that greater and better individual knowledge will lead to behavioural change. Empirical findings suggest that contrary to the mainstream assumption that individuals are driven solely by a common desire to preserve health, behaviour can be guided by 'alternative rationalities'. These

² I should note here that critical health psychology critiques target application of KABP models in the west. However there are few exceptions such as Joffe (1996) and Campbell (2003), who conduct HIV/AIDS work in Southern Africa and critique the KABP approaches to global/African HIV/AIDS work. It is important to make this distinction since it has direct implication on the extent to which critical health psychology offers practical guidelines for chronic illness intervention in Africa.

alternative rationalities explain, for example, why despite full knowledge of long-term health-damaging effects of smoking, individuals make a 'rational' choice to smoke as a means of coping with adverse social and material circumstances (Graham, 1976; Jacobson, 1981); or why despite full knowledge and understanding of the protective value of condoms, individuals make a rational choice not to use condoms as a symbolic and emotional commitment to long-term relationships (Bennet & Murphy, 1997; Pivnick, 1993; Sobo, 1993). Moreover, theorists stress that an exclusive focus on 'rationality' neglects "'irrational', unconscious forces and emotions" (Crossley, 2000:38), which underpin complex human behaviours generally and surface with greater acuity during long-term illness.

Secondly, critics argue that the KABP approach erroneously presupposes that definitions and experiences of health and illness are rooted within the individual. Knowledge production and behaviours do not occur in a social or cultural vacuum, but are "moulded by social and cultural forces as well as the cognition of individual thinkers" (Stainton Rogers, 1991:62). Researchers such as Kleinman and colleagues (1992) argue that to reduce the chronic illness experience to one of individualised biophysical event is 'so inadequate as to virtually assure inaccurate diagnosis and unsuccessful treatment' (p.9).

Theorists examine 'insider perspectives' (subjective and intersubjective experiences) of illness, in order to situate individual experiences and responses to illness within their socio-cultural and material contexts. This shift in empirical focus has highlighted two important findings. First, the chronically ill have to cope simultaneously with the physical, social and symbolic context of illness. This sets up a quest for meaning that spans both everyday aspects of self-care as well as the implications of illness on one's social obligations and relationships and life trajectory (Bury, 1982; Crossley, 2000). Secondly, the illness experience is linked to one's broader life experience. Therefore it impacts not only on the life of the chronically ill person, but crucially also on the lives of individuals in their immediate social sphere: the chronic illness experience is "fundamentally inter-subjective" (Kleinman et al, 1992: 9). Thus, while biomedical knowledge and information may constitute a start to the process of interpreting the physical onset and impact of illness, it is the experience of 'living with and in spite of' illness

(Conrad, 1990: 1260) and the intersubjective meanings drawn from family and social relationships that frame both the context for 'good adjustment' (Radley, 1994:160) and the means through which this can be attained.

The psychosocial studies, which are more aligned with critical health perspectives, have two major shortcomings. First, although they highlight the psychological, social and material context of chronic illness experiences, they do not offer integrated analyses of the inter-relationship between these dynamics. Secondly, they suggest psychosocial and structural change but do not provide recommendations on how such change can be feasibly achieved.

Summary

The emphasis critical health psychologists place on socio-cultural and material context of illness experiences resonate with the regional psychosocial studies. Both bodies of work in turn offer empirical findings that lend weight to the core ideas expressed within the regional alternative cultural studies in relation to culture, society and health. A synthesis of these three approaches therefore provides a useful conceptual starting point for diabetes work in Ghana. However, each exists with shortcomings that necessitate the overarching social psychological framework proposed here.

The alternative cultural studies illuminate the openness and heterogeneity of some African socio-cultural systems and provide the context for examining socio-cultural knowledge production within a dynamic framework. However they are by nature limited by a macro-social bias; the ways in which individual and group practices shape socio-cultural systems do not feature in discussions.

The psychosocial studies highlight the psychological, social and material context of chronic illness experiences, but do not offer a critical synthesis of their interaction. Furthermore, they suggest psychosocial and structural change but do not provide practical guidelines for such intervention.

Critical health psychology approaches are compatible with the regional psychosocial studies. They provide a robust critique against KABP work and aim to offer an alternative framework. However, studies have, ironically, been accused of sociological reductionism, advocating the importance of an integrated 'biopsychosocial' model, yet overemphasizing the socio-political and material dimensions of illness experiences at the expense of the physical and psychological dimensions (Gervais et al, 1999; Crossley, 2000; Krause, 2003). Furthermore, while attempts have been made within the field to develop policy-oriented interventions (cf. Whitehead, 1995), these apply to affluent Western contexts and are unlikely to translate successfully to low-income settings like Ghana. Thus, like the psychosocial studies, they map out the complex context of chronic illness experience and responses, but require critical conceptual reworking in order to develop context-specific research and intervention.

In this thesis, the strengths of the three approaches are drawn on and developed within a social representations theoretical framework. This synthesis facilitates the development of a critical social psychological framework aimed at examining the inter-relationship between psychological, socio-cultural and material dimensions of diabetes experiences in Ghana.

THE THEORETICAL FRAMEWORK: THEORY OF SOCIAL REPRESENTATIONS

Social representations theory was chosen over other social psychological theories for three key reasons. First, the theory engages in critical discussion of culture and cultural production. Developed by Serge Moscovici in the 1960s as a 'psychosocial theory of thought and action', social representations theory aims to serve as a conceptual interface between psychology, sociology, anthropology and history (Moscovici, 1981). Theorists make three central arguments about cultural production pertinent to this thesis. First, culture frames practical social knowledge (Moscovici, 1973; 2000). Secondly, culture is characterised and transformed by 'competing versions of reality' (Rose et al, 1995) or different 'stocks of knowledge' (Flick, 1998) arising from everyday intersubjective experiences and communicative practices. This

explicit focus on the inter-relationship between society and culture and between the individual and society allows the theory to 'slot into the gap that lies between...individualist and socio-cultural analyses' (Joffe, 1996: 185-186). Finally, Moscovici placed strong emphasis on "studying the problems of our times and of dealing with them in their historical dimension" (1987: 523). Central to social representations work, therefore, is explicit focus on contemporary and historical dimensions of practical social knowledge.

While the theory has yet to realise its ambitious project to synthesise psychological, socio-cultural and historical phenomena, as further discussions will highlight, it nevertheless offers an open conceptual framework for incorporation of these phenomena. This 'openness' is crucial for the goals of this thesis. I have described briefly the ways in which ethnocentric assumptions about African societies undermine the usefulness of dominant health research approaches. For appropriate theoretical inroads to be made, epistemological sensitivity is a necessary prerequisite. This thesis is aligned with cultural critics such as Ladson-Billings (1999:257) who define epistemology as "more than a "way of knowing"" but also, a "system of knowing". Ladson-Billings argues that an epistemology constitutes a unique interlocking of "both internal logic and external validity" that carries "a crucial legitimating force" (p.258). An examination of Ghanaian diabetes knowledge, experiences and illness practices would be inadequate and inappropriate, without explicit setting in the broader Ghanaian context.

Secondly, while the theory has been applied to a wide range of social psychological phenomena, it has been particularly useful in contemporary social psychological studies of health and illness. It is important to note that critical health psychology is dominated by concepts and approaches drawn from sociology of health and illness. This in part has led to the charge of sociological reductionism leveled against the field. Classical and current social representations work and discussions on health and illness (e.g. Herzlich, 1973; Herzlich and Pierret, 1987; Farr and Markova, 1995; Joffe, 1996; Gervais and Jovchelovitch, 1998; Flick, 1998; Krause, 2003) contribute a distinctly social psychological dimension to the field.

Thirdly, unlike the majority of critical social psychological approaches whose empirical relevance continues to be tested largely within the Western context, social representations theory has been applied, with some success, to conceptual and empirical work in non-western contexts (cf. Wagner et al, 1999,2000; Krause,2002, 2003; Joffe, 1996; Joffe and Haarhoff, 2002) and non-western cultural groups based in the West (Gervais and Jovchelovitch, 1998; Howarth, 2000). The recently developed ‘social psychology of participation’ (Campbell and Jovchelovitch, 2000; Guareschi and Jovchelovitch, 2004) draws from the theory and informs highly successful participatory projects in Latin America (World Bank, 1996; UNESCO, 2003). These theory-driven, policy-oriented ‘psychosocial intervention’ projects, have been adapted to general health work in Africa (Onyango-Ouma et al, 2001) and thus offer possible solutions for chronic illness intervention work in low-income settings like Ghana.

Put together, these strengths of social representations theory set the stage for developing a robust conceptual framework. However, there are also inconsistencies and limitations within central aspects of the theory. Three core themes underpin the phenomena of social representations, all or some of which guide theoretical and empirical work in the field. All three themes have ambiguous or contradictory elements, which undermine the theory’s applicability to cross-cultural and chronic illness work cross.

The first theme centres on whether social representations are universal phenomena or specific to particular societies and eras. Theorists posit two views. The first view conceptualises social representations in a universalistic sense: here the phenomena constitute practical social knowledge produced through social relations and practices. It is assumed that such practical social knowledge exists in all societies and historical epochs. In the second view, social representations are described in particularistic terms, as unique to contemporary “de-traditionalised” societies (Jovchelovitch, 2001). Moscovici and others argue that science, technology and the mass media have changed the nature of common sense. For some theorists,

this ties social representations theory to a theory of modernity (Jovchelovitch, 2001). While both views co-exist the latter often takes precedence in theoretical discussions.

The particularistic thesis poses significant problems when transposed to work in contemporary non-western societies experiencing 'modernity' in different ways from the West. It would be unfair to assert that the notion of a unique 'modern western consciousness' is projected to the 'non-western' world – given that social representations work in contemporary non-western contexts constitutes an emerging, peripheral, sub-field. However, since social representations theorists implicitly buy into a tradition-modernity dichotomy when they adopt the 'particularistic' view of social representations, these dichotomous terms require deconstruction if the theory is to escape the ethnocentrism characterising mainstream social science discourse.

The second problem concerns why we socially represent. There is a recurrent taken-for-granted assertion within major theoretical texts that social representations emerge from a 'fear of the unfamiliar' and function to 'domesticate' or 'tame' the unfamiliar' (Moscovici, 1984; Wagner et al, 199b). This hypothesis is implicitly - and problematically – universalised. For example, Moscovici (2001) has asserted, that: ““principle of familiarity” underpins a large part of psychology and sociology (p.20)”. On this basis “individuals and communities resist the intrusion of strangeness (p.20).” African-centred anthropological work demonstrate that a variety of societies are 'open to the unfamiliar' thus challenging the overemphasis on 'fear of the unfamiliar'. Critical health work demonstrates that illness beliefs, experiences and practices are underpinned by a multiplicity of emotions. Put together, these perspectives suggest that social representations work needs to engage more critically in other possible motivational and emotional underpinnings of social representations.

The final problem centres on the socio-psychological functions of social representations. Theorists assert that social representations construct and transform social reality. There is general consensus that the construction and transformation processes involve a “dialectic relationship between individuals and culture” (Purkhardt, 1993:31) and are rooted in communicative action. Attention is paid, in some texts, to the embodied and material

dimensions of socio-cultural interaction and communicative practices (Purkhardt, 1993; Jovchelovitch, 1997; Markova and Wilkie, 1987; Gervais, 1997). These critical theoretical discussions have yet to translate to empirical work. The practical dimensions of knowledge, which are central to the theory, are excluded from empirical examination. These dimensions call into explicit view the embodied and material aspects of social interaction and human productive activity, and are central to the examination of illness experience and practice.

Critical re-conceptualisation of these core themes will be necessary to adapt the theory to diabetes work in Ghana. I draw on and develop Moscovici's (1961/1976) hypothesis of cognitive polyphasia as a mediating concept. Moscovici's earliest definition characterised cognitive polyphasia as "the dynamic coexistence ...of distinct modalities of knowledge, corresponding to defined relationships between human beings and their surroundings"(Moscovici, 1961/1976; p.186; translated by Gervais,1997). He asserts that the tendency for groups and individuals to draw eclectically and often in opposing ways on different modalities and contents of knowledge is fundamental to everyday life. Second, he draws attention to the emotional underpinnings of polyphasic thought. The hypothesis captures key elements of critical social psychological perspectives on the dynamic and heterogeneous nature of human thinking, feeling and productivity. It facilitates the clarification of ambiguities within the theory. It also provides a mediating context within which to incorporate key ideas from critical health psychology and applied social psychology, firstly to examine diabetes experiences and illness practices in Ghana and secondly, to explore possibilities for intervention.

OUTLINE OF THE THESIS

The thesis is presented in two parts. Part One provides the empirical, conceptual and methodological background. Chapter One introduces Ghana. The institutional, socio-economic and cultural contexts of healthcare are outlined to situate the problem of diabetes care. Chapter Two focuses on regional and non-regional chronic illness research. Cultural, medical psychology, and critical health psychology approaches are presented. The strengths and limitations of each approach are treated to in-depth discussion, as are areas of conceptual and practical overlap between approaches. The socio-economic context of chronic illness intervention is tackled, by juxtaposing current regional health intervention approaches with multi-disciplinary discussions on participation. The usefulness of a 'social psychology of participation' is highlighted. The aim of this chapter is to prepare the empirical and conceptual ground for introducing the usefulness of social representations theory, subject of Chapter Three.

Social Representations Theory has three core themes. These relate to: (1) the particular or universal nature of social representations; (2) the motivations underpinning the representational process; and (3) the constructive power of the phenomena. All three themes have limitations, which undermine the theory's applicability to cross-cultural and critical health work. The limitations are discussed. Drawing on anthropological perspectives on cultural production, socio-cultural theories of emotion and phenomenological perspectives on illness experience, conceptual ways forward are outlined. A case is made for conceptual development of cognitive polyphasia as cognitive-emotional polyphasia.

Chapter Four describes research design and implementation. The interaction between culture, society and illness action is complex, multi-determined and virtually unexplored within the Ghanaian context. A multi-method qualitative design was applied to the examination of the complex psychological, socio-cultural and material contexts of diabetes. Data was gathered from three sets of participants: (1) from people with diabetes and their significant others through individual interviews, group interviews and the ethnographic method; (2) from lay healthy individuals through group interviews; and (3) from health professionals from Ghana's

biomedical, ethnomedical and alternative health systems through individual interviews and group interviews. The first part of the chapter makes a case for choice of methods. The second part focuses on the field work process: the process of selecting research settings and participants is described; ethical aspects of field relations are discussed. The final section discusses data collection and analysis; the development and application of the coding frame is described. The thesis is aligned with qualitative researchers who stress that credible research, whether quantitative or qualitative, is framed by rigorous and critical application of appropriate methods. Within this framework issues of validity and reliability are core to this process. The incorporation of validity and reliability checks in the development and application of the research design is a central theme that runs through Chapter Four.

Part Two presents and discusses results. Following from theoretical discussions on cognitive-emotional polyphasia, an introductory section outlines six modalities of knowledge underpinning accounts on health, illness and diabetes: cultural, political, scientific, 'scientized', religious and emotional. This provides the context for mapping out sources and functions of participants' knowledge on health, illness and diabetes. Chapter Five presents narratives of people with diabetes, lay healthy individuals (including significant others of people with diabetes) and health professionals on health, illness and medical pluralism. The aim is to highlight the dynamic nature of socio-cultural knowledge production and processes of social legitimation in the Ghanaian public sphere. Chapters Six to Nine focus on diabetes. Narratives of people with diabetes are presented in Chapters Six and Seven, the former on interview accounts, the latter on ethnographic accounts and practices. Each chapter ends with a synthesis of the nature of interaction between diabetes knowledge, experience and practice. Chapters Eight, and Nine focus on lay and health professional narratives, respectively. The ways in which these accounts merge and/or clash with views, experiences and practices of people with diabetes are critical points of focus in each concluding synthesis.

Chapter Ten ties together key strands from Parts One and Two. In the first half, three sets of social representations are outlined: the social representation of diabetes produced at the

level of self; the social representation of diabetes as a sugar disease produced at the level of society; and the social representations of diabetes as a spiritual illness, produced at the level of culture. Sources, socio-psychological functions and implications for diabetes care are discussed. The second half of the chapter revisits perspectives from social psychology of participation, to work through possibilities for diabetes intervention. The strengths and limitations of the thesis in relation to its stated aims are discussed in conclusion.

PART ONE

OVERVIEW OF CHAPTER ONE

This chapter introduces Ghana and outlines the empirical problem and research questions. I begin with a background to the country's socio-economic, cultural and health policy context. Part Two describes Ghana's pluralistic medical context. The dominant systems - biomedicine, ethnomedicine and faith healing systems - are profiled and their role in chronic illness care discussed. Part Three outlines the problem of diabetes care drawing together existing research and policy findings. A summary of findings from regional and international health psychology work on diabetes, which shed useful light on the psychological, social and cultural dimensions of diabetes experiences, is incorporated here. The Ghanaian research and policy information, coupled with the cross-cultural diabetes work, inform the research questions which are outlined in the concluding part of the chapter.

CHAPTER ONE

STRUCTURAL, SOCIO-CULTURAL AND MEDICAL CONTEXT OF

DIABETES CARE IN GHANA

1.1. GHANA: SOCIO-ECONOMIC, CULTURAL AND HEALTH POLICY CONTEXT

Ghana is situated on the west coast of Africa, between Cote D'Ivoire to the west, Togo to the east and Burkina Faso to the north. A relatively small country, in comparison to most African countries, Ghana has a population of 18.8 million. Capturing global attention by becoming the first African country to gain independence from its British colonists in 1957, the country has, in the last decade especially, cemented its status as the 'poster country' for the international development project, due to its relative intra-cultural stability, the state's embrace of international development ideologies and active engagement in world trade (Anane, 2002; World Bank, 2002).

Over 55% of Ghana's population is engaged in agricultural production, which accounts for 50% of the country's GDP (World Bank, 2002). 18.7% of the labour force is engaged in industrial activities in the areas of mining, lumbering, aluminium production and food processing. A burgeoning technology sector has recently embraced information technology outsourcing, already a multi-billion dollar business in Asian and Latin American countries (New York Times, 2002; Zachary, 2004). Civil service and private businesses taken up by 15.2% of the population, continue to remain the domain of the elite and a growing middle class. Official statistics suggest that unemployment levels peak at 20%, with 31% of the population estimated to live below the poverty line (Republic of Ghana (MOH), 1996).

Like the majority of African countries, Ghana is rich in mineral and natural resources – gold and timber being two of its main exports – but financially bankrupt. Its global debts are in excess of \$5 billion, and the country relies heavily on foreign economic aid. The International Monetary Fund (IMF) and World Bank inspired Structural Adjustment Programmes (SAPs), embraced by Ghana's last government, are reported to have had a considerable detrimental

impact on the country's educational and health systems (Anane, 2002). The introduction of a 'Cash and Carry' (payment at point of service delivery) system for healthcare, for example has had a devastating impact on accessibility to public health services particularly for low-income health service users. Recent reports from the Ministry of Health indicate that healthcare expenditure continues to be largely funded by the international donor community (Government of Ghana (MOH), 2001). These reports indicate that dependency on international aid undermines the ability of local policy makers to set the parameters for health research and intervention (Government of Ghana (MOH), 2001).

The country is currently a member of the Heavily Indebted Poor Countries (HIPC) Initiative developed by the IMF and the World Bank's International Development Association (IDA) to address 'Third World' debt reduction. It received a comprehensive debt reduction package in February 2002 and government plans are to redirect relief funds to education, health and structural improvements in rural regions (World Bank, 2002). A key aspect of health reform proposed and still under development by the new government is to replace the unpopular Cash and Carry system with more flexible alternatives, such as health insurance, prepayment schemes and exemption policies, to address the needs of low-income and rural health service users who are hardest hit by this system (Government of Ghana (MOH), 2001)³.

For administrative purposes the country is divided into ten regions, which are further grouped under northern and southern sectors. The northern sectors comprise Ashanti, Brong Ahafo, Northern, Upper East, and Upper West regions, while the southern comprise Greater Accra, Eastern, Central, Western and Volta regions. The regional divisions also demarcate Ghana's major ethnic and language groups which include the Akan, Ewe, Mole-Dagbani, Guan and Ga-Adangbe (see Appendix A for map of regional and ethnic demarcations). Each ethnic group has

³ It is important to note, to provide the broad context for the development of interventions, that being a member of the HIPC initiative essentially confers a status of state bankruptcy. The government can no longer borrow money and relies more heavily on foreign aid, with significant implications for public services. Media reports, public debates and informal discussions during and since fieldwork suggest deterioration of the economy and of public life. The national currency – the Cedi – continues to depreciate at a considerable rate, against the pound and dollar. Private businesses, particularly those with little access to foreign partnership, are in states of decline.

further subdivisions, which share cultural heritage, history and geographical origin; approximately 100 linguistic and cultural groups have been recorded (Ghanaweb, 2004).

The Akan language, and in particular the dialect Twi, is the country's lingua franca. However, English remains the official language, a legacy from Ghana's history as a former British colony, and is the primary language of educational instruction. Education generally mirrors the British educational system with primary, secondary and tertiary education being the main levels of formal education served by a mix of public and private institutions. The country's literacy rate is among the highest on the continent at 64.5%, with male literacy (75.9%) higher than the female rate (53.5%) (World Bank, 2002;Ghanaweb, 2004).

Rural-urban distribution studies⁴ show Greater Accra Region, home to the capital city Accra, to be the most urbanised and also the most densely populated with almost 2 million inhabitants. Accra is also the most culturally and socially diverse city, with a dynamic mix of people from Ghana's four ethnic groups and ten regions and from diverse educational, economic and religious backgrounds. Accra is the city of choice for the majority of non-Ghanaians living in the country. The city is also home to the majority of the nation's institutions and the elite social group, which runs them. In the arena of healthcare in particular there is over-representation of both formal, private and ethnomedical health facilities. The Northern, Upper East, and Upper West regions constitute the least urbanised areas.

Sociological writers note that Ghana's social fabric is permeated strongly by a variety of religious beliefs and practices (Twumasi,1975; Nukunya,1992; Clarke,1986; Opoku,1978). Christianity, the religion of state, is practiced by 69% of the population, a great proportion of these in the southern regions. In the post-independence years a proliferation of African independent churches (most constituting local branches of American and Europe based evangelical churches) have eclipsed orthodox churches statistically and in terms of social relevance. The growing popularity of these new churches has been attributed to the fact that

⁴ Urban centres - also referred to as 'non-traditional' centres - have populations of 500,000 or more, while rural 'traditional' communities correspond to villages, which have a population of 5000 or less (Ofori-Atta & Linden, 1995). Transitional societies are noted to range between these two and are characterised by their adoption of a blend of traditional and urban lifestyles.

they provide “an important means of obtaining divine help in solving everyday problems of work, family relationships, health and so on” (Clarke,1986:200). Islam is practised by 15.6% of the population, a majority of which are northern ethnic groups.

The remainder of the population practices a variety of traditional religions⁵. Social theorists note that the philosophies underpinning traditional religions of the main ethnic groups continue to shape social relations and practices within wide sections of society whether Christianized or Islamized. Indigenous marriage ceremonies, christening ceremonies, funerals and the celebration of centuries old festivals for example run parallel to, or are incorporated into, Christian and Muslim versions and all are perceived as legitimate (Nukunya, 1992; Clarke, 1986; Opoku, 1978). This research suggests however, that it is important to distinguish between public and private legitimacy of the contemporary role of traditional religions and customs. This distinction allows a better understanding of the complex role of culture and religion in health and illness practices. These issues are taken up further in Part Two.

1.2. THE PLURALISTIC MEDICAL CONTEXT

1.2.1. The formal healthcare system

Formal healthcare delivered by the government’s Ministry of Health, is organised at national, regional, district, sub-district and community levels delivered through a network of hospitals, clinics, health centres, health posts and maternity homes. The primary focus at all levels is the provision of public health, clinical and maternal services. However, the degree of technical expertise and distribution of human resources differs at each level. The national level constitutes the most specialized biomedical services. The country’s two teaching hospitals, Korle-Bu

⁵ Following African theologians such as Kofi Asare Opoku (1978) and John Mbiti (1969) and historians such as Clarke (1986) I use the term ‘traditional religion’ to encompass the variety of ways in which Ghanaians have historically constructed a notion of and communed with ‘a supreme being’. As theorists argue, terms such as ‘animism’, ‘paganism’, ‘fetishism’, ‘ancestor worship’, or ‘polytheism’ adopted by Western theologians and anthropologists, to impose “evolutionary theories of religious development” (Clarke, 1986:222), “confuse rather than clarify the picture” (Opoku, 1978:8) of a fundamental similarity between traditional African religion and other world religions. Opoku notes that while ‘every religion is a blend of universal principles and local setting’, traditional African religion, like all religions deal with “the holy and springs from man’s eternal quest to comprehend the universe and the come to terms with the forces that control his inner being”(p.8).

Teaching hospital in the capital Accra and Komfo Anokye Teaching hospital in the second largest city Kumasi, operate at this level, providing a mix of specialized clinical care as well as academic and practical training and research in medicine and allied fields. These hospitals are affiliated to the country's two medical schools, University of Ghana Medical School (UGMS) and the Kwame Nkrumah University of Science and Technology Medical School (KNUST), respectively. A less specialised network of hospitals, clinics, health centres and maternity homes, serves regions, districts, sub-districts, and communities. Generally, the ratio of biomedical professionals to prospective patients is low. It is estimated that the ratio of doctors to number of potential patients is 1 in 12,000 (Tsey, 1997). This is compounded by the gravitation of professionals to urban settings, leaving rural facilities without adequate human resources. Two important points must be noted. First concerns unequal gender distribution of professionals: women are under-represented in the specialized clinical and medical technological professions, and over-represented in the nursing and community oriented professions (see Table 1.1). The second point to situate further discussion on psychosocial interventions, is the low numbers of professionals with training in psychology, counselling and social work: there are lower than 50 psychologists working in Ghana, for example, and the majority like doctors are based in the southern regions.

Table 1.1 Distribution of Human Resources for Biomedical Services in Ghana

Category	Male	Female	Total
Physicians	890	186	1076
Pharmacists	143	49	192
Professional Nurses & Midwives	726	5003	5729
Community Health Nurses	2	2289	2291
Laboratory Technicians/Assistants	134	11	145

(Source: Government of Ghana (MOH), 1996)

Adjunct to the services provided by the formal sector are the services provided by mission and non-governmental organisations (NGO) and the private sector. No formal statistical data exists on the levels and distribution of human resources within these two sectors, although their broad contributions to health delivery are well documented. Mission institutions, run by the Christian

community (with a dominant Catholic presence) and the Muslim community, and NGO organisations work in close collaboration with the government. They provide essential public health services such as family planning, as well as curative services, particularly in underserved areas such as the rural North (Government of Ghana (MOH), 2001). The private sector, which consists of doctors, nurses, pharmacists, midwives and licensed chemical sellers (general traders licensed to sell over-the-counter drugs and herbal medicines in their general goods stores and kiosks) has undergone considerable growth in recent years and is estimated to account for 35% of healthcare delivery nationwide. The majority of private services are concentrated in urban areas and their key focus is the provision of curative services. There is limited collaboration between the public and private sector.

1.2.2. The informal healthcare system

Ghana's informal health care arena constitutes the ethnomedical and alternative health systems. The ethnomedical system can be divided into two main categories of practitioners based on treatment methods. One group treats illness solely with herbal preparations (herbalists), another employs a mix of herbal and traditional religious treatment (traditional religious healers). Herbalists range from small scale travelling salesmen who sell their wares on public transport, in markets and even hospital grounds, to organised groups of trained herbalists who run 'clinics' and incorporate biotechnological methods into their treatment repertoire. Indigenous midwives working mainly within rural biomedical centres can be subsumed within this category. This group has been retrained as Traditional Birth Attendants (TBAs), like several across the region (DeJong, 1991). Traditional religious healers usually referred to as 'fetish priests' or 'juju men' (see Appendix A) employ a mixture of herbal treatment, divination, possession and the calling of deities in their healing repertoire.

During the research process two further distinctions were identified within the ethnomedical field. The first distinction was based on disease causal theories informing professional practice. Here I distinguished between 'bio-tech herbalists/practitioners' and 'holistic herbalists/practitioners'. 'Bio-tech herbalists' placed greater emphasis on biological

causal theories, demarcating this as area of particular or sole expertise and incorporated biomedical ideas and techniques to practice. 'Holistic herbalists' placed equal emphasis on biological and spiritual causal theories of disease, demarcated both aspects as areas of treatment expertise and placed equal importance on both scientific and traditional values and beliefs. The second distinction was based on the extent to which professional practices were explicitly politicised. Non-politicised practitioners embraced biomedical knowledge and practices uncritically as a means of legitimising their status as 'modern' 'bio-tech' literate herbalists. They, like a growing group of herbalists identified across the continent answered to the title 'doctor' and organised their services in the manner of private GP practices (DeJong,1991). Simultaneously they explicitly drew on Christian identities to distinguish and distance themselves from traditional religious practices. Politicised practitioners were open to biomedical knowledge systems, but critical of it. They expressed concern about appropriation of ethnomedical intellectual property by national and international health systems. They also embraced religious pluralism, placing traditional religious values on par with Christian values. For this group, the value of ethno-pharmaceutical knowledge was perceived as equally important and valid as biomedical and global pharmaceutical knowledge; and taking on Christian identities did not preclude use of traditional religious systems. These distinct professional identities had a discernible impact on in-group and out-group professional relations in the medical pluralistic sphere, with particular implications on chronic illness and diabetes care, as discussions in Part Two will highlight.

Within the alternative healing sphere, two main categories can be identified. The first group constitutes both Ghanaian and non-Ghanaian healers who draw from non-African traditional medical sources such as Ayurvedic and Chinese medicine. The second category constituted faith healers belonging to evangelical Christian churches or independent African churches. Their method of treatment is usually through prayer and fasting or 'deliverance', which is carried out in prayer camps affiliated to the majority of the churches spread throughout the country.

Like missions, NGOs and private sectors, there is lack of information on actual distribution patterns and spread within the informal health sector, and the little that is known centres on ethnomedical practitioners. For example it is estimated that the ratio of indigenous healer to number of potential patients is 1 in 400 (Tsey, 1997) and that “traditional and herbal remedies constitute the first line and commonly only source of treatment for most Ghanaians” (Government of Ghana(MOH),2001:33). An important observation made in the preliminary stages of this study was the over-representation of male practitioners in bio-tech ethnomedicine, as well as faith healing systems. In contrast, women made up the entire subcategory of indigenous midwifery (traditional birth attendants). However, with the more traditional form of ethnomedical practice where healers originate from the community in which they practice, male and female practitioners are more equally distributed.

1.2.3 Medical pluralism and chronic illness care

Contemporary healthcare in Ghana mirrors that of many African countries. Both urban and rural populations live within a mix of the ethnomedical, biomedical and alternative healing systems described above and use all simultaneously or sequentially (Nukunya, 1992; Twumasi, 1988;Danquah, 1982).

While both ethnomedical and alternative healing systems provide legitimate informal services, ethnomedical systems have received greater official attention, as highlighted earlier. Research studies indicate that services provided by ethnomedical systems incorporates both primary and long-term care; people frequently combine biomedical treatment with traditional forms of treatments for both minor and major ailments, and in cases where illness is chronic and requires long term, life long treatment and management, are often likely to turn to traditional healing systems (Twumasi, 1988; Pobee, 1993; Pobee et al, 1975).

Health policy responses to the informal health sector have also been targeted mainly at the ethnomedical group. Following the Alma-Ata declaration in 1978, the late 1970s to 1980s saw the first wave of collaborative initiatives aimed at harnessing traditional medical knowledge

and practices in primary healthcare (Twumasi, 1979; Warren et al, 1982). Some of the initiatives, such as the Dorma primary health project in the Brong Ahafo region (A. Anum, personal communication, 2001), and the use of indigenous midwives (retrained as traditional birth attendants) in rural antenatal care, continue to operate providing an invaluable source of support in healthcare delivery particularly in areas underserved by biomedical professionals. The Centre for Scientific Research into Plant Medicine (hereafter the Mampong Centre), a unique biomedical research and clinical centre (and one of two in the continent), was set up in the late 1970s to conduct collaborative pharmacological research with herbalists into plant medicine. The centre continues to produce a broad range of ethno-pharmaceuticals and prescribes these alongside global pharmaceuticals. Chronic conditions such as hypertension, diabetes and arthritis, are a specialist focus. Furthermore, in the last ten years, greater concerted effort has been directed at the legalisation and regulation of ethnomedical practices within an overarching collaborative health model. The Ghana National Association of Traditional Healers (GNATH) has been created to regulate the practices of the two formally recognised groups of ethnomedical practitioners – herbalists and traditional religious healers. The Mampong Centre and the national Food and Drugs Board have both acquired the new role of conducting clinical trials and standardising ethnomedical drugs. The Traditional Practice Act (Act 575) passed in 2000, confers legality to registered ethnomedical professionals (Government of Ghana (MOH), 2001; K. Edusei, personal communication, 2001). The overall objective of these activities is to open up and regulate ethnomedical practices and to create an enabling environment for both biomedical and ethnomedical systems to engage in mutual generation and sharing of knowledge and expertise.

Despite these important developments, there has been a problematic neglect of the role of ethnomedicine in other areas of healthcare delivery, such as long-term clinical and palliative care. There is strong indication that the ethnomedical systems constitute critical resources for individuals in constant eclectic search for cures for chronic conditions (Pelletier, 1989). Of equal concern to this thesis, is the absence of policy discussions on the role played by the

alternative health system in informal healthcare delivery. The growing importance of alternative health practitioners who draw from non-African traditional medical sources and non-African religious sources was noted earlier. The increased uptake of faith healing services provided by a growing network of evangelical Christian churches has also been noted. It is within this pluralistic medical context that discussions of diabetes care have to be situated.

1.3. DIABETES CARE

1.3.1. Local research and policy perspectives on diabetes

Ghana's health system operates with insufficient resources to address the country's double burden of disease. This drives chronic illnesses further down the list of priorities. Diabetes is particularly under-funded and under-researched despite the fact that it has been high on the list of priority of health interventions outlined by the Ministry of Health since the mid-nineties (MOH, 1996, 2001). A recent research paper reporting on a national epidemiological and KABP study conducted in collaboration with the two teaching hospitals, the drug company Eli Lilly and the (North American) University of Virginia – termed informally and referred hereinafter as the Ghana Diabetes Project - summarises the current state of diabetes care succinctly. It is worth presenting the summary in full:

“Ghana has no diabetes advisory board and no guidelines for diabetes care for the various healthcare levels. Diabetic medications are not tax-exempt. Diabetes registers are available for only the two teaching hospitals. No data are available on diabetes mortality, morbidity and disability. A general deficiency in facilities and resources for diabetes care exists in health facilities and there is an erratic supply of essential diabetes products at health institutions. Diabetes care in Ghana has hitherto been largely uncoordinated with no formal national policy on diabetes. Major hindrances to care include lack of trained diabetes health care personnel and lack of the team approach to diabetes care.” (Amoah et al, 2000; 150)

A review of the 'grey literature' and official Ministry of Health documents as well as interviews with expert informants, yielded some information on prevalence rates, mortality rates, disability issues and the broader structural as well as socio-economic aspects of diabetes experiences. On prevalence, the Ministry of Health estimates a 4% rate for Ghanaians aged between 15 to 70 years (Government of Ghana(MOH), 2001). However, given the well-documented difficulties impinging on regional epidemiological work (Cooper et al, 1998a,1998b), epidemiological work on chronic illness in Ghana has had a patchy unreliable history, and experts speculate that current rates might be higher (F, Ofei, personal communication, 2000). A prevalence study carried out in the country's capital as part of the Ghana Diabetes Project, for example, found a 6.3% crude prevalence rate, a figure, which prompted speculation that national rates could be higher than currently documented (Amoah et al, 2002). I should note also that the majority of diabetes work (including public health education) has been focused in the southern urban sector, even though there is recorded prevalence of diabetes in the northern urban and rural sector.

There is no reliable empirical information on national morbidity and mortality rates, although the most recent clinical research, conducted in the country's capital, showed a doubling of hospital admissions over a ten-year period. Within the hospital groups studied, researchers recorded high incidences of acute metabolic complications and mortality rates which they linked to poor medical management and 'harmful self-care practices' (Adubofour et. al., 1993). A critical issue raised within MOH reports is the rising levels of disability among people with diabetes: diabetes is a major cause of blindness, and the second major cause of amputations, next to traffic accidents. A draft report of the Non-communicable Disease Control Programme (NCD Control Programme, 2001) highlights that 37% of all diabetes cases have a prognosis for the development of renal failure. Recent small-scale exploratory studies have strongly implicated poor self-care practices, delayed biomedical consultations and healer shopping in high rates of complications and disabilities (Ofei et al, 1996; Amoah et al, 2002).

These discussions resonate with regional literature, which problematically attributes healer-shopping, dual-use and general non-compliance to the heightened (and perceived negative) role

of ethnomedical systems in chronic illness care (see Chapter Two). However research studies and policy discussions acknowledge a link between poor self-care and inadequate biomedical care. Firstly, researchers note that the increase in number of people with diabetes accessing poorly financed and staffed health services – particularly in rural areas - has led to increased responsibility on individuals for prolonged out-patient management (Ofei et al, 1996). Secondly, attention has been drawn to the impact of high biomedical cost on poor compliance and self-care (NCD Control Program, 2001; J. Teprey, personal communication, 2000). At the time of research, it cost between ₵1,200,000 (£120) and ₵2,800,000 (£280) to control one case of a non-complicated diabetes mellitus per year, a substantial sum when contrasted with a minimum daily wage of ₵5,000 (50p). The argument made is that individuals may not access biomedical care, or will drop out of treatment because of the high cost and that such individuals are more likely to access cheaper ethnomedical and alternative healthcare, which sets up a vicious cycle of increased complications which carry significant financial burden for people with chronic illness as the healthcare system. The NCD Control Programme (2001) quoted £40,000 for a renal transplant and ₵60,000,000 (£6,000) per person per year for dialysis in 2001. These are costs the health system and the majority of individuals can ill-afford.

There is growing recognition within African health policy discussions that given the absence of adequate formal health services particularly in the arena of chronic illness care ‘healthcare is self-care’ (Msiska et al, 1997: 250). The constellation of issues outlined here suggests this to be the case for diabetes care in Ghana. This implies that research that seeks to improve overall quality and continuity of care has to address not only the structural barriers to quality care, but to pay equal attention to the social context of self-care. To date, this area has received little empirical attention. To make a final case for the empirical questions guiding the thesis, I turn to a brief discussion of some key findings within mainstream and critical health psychology work on diabetes in order to highlight the intersection of psychological, and socio-cultural dimensions of living with diabetes – and its particular implications for self-care. These diabetes specific

discussions are embedded within broader critical health psychology discussions on chronic illness experiences, which are dealt with in greater depth in Chapter Two.

1.3.2. Mainstream and critical health psychology perspectives on diabetes

The World Health Organisation (WHO) (2002) defines diabetes mellitus as “a chronic disease caused by inherited and/or acquired deficiency in production of insulin by the pancreas, or by the ineffectiveness of the insulin produced”. Two principal forms are distinguished: Type 1 (also known as insulin-dependent) in which the pancreas fails to produce insulin and occurs most frequently in children and adolescents; Type 2 (also known as non-insulin-dependent) which results from irregular physiological responses to insulin production. Insulin deficiencies and irregularities result in increased concentrations of blood glucose, which can damage many bodily systems, but most crucially blood vessels and nerves. Left untreated, raised blood-glucose levels can lead to a range of medical complications; some of the more serious threats posed by uncontrolled diabetes are vision impairment and blindness, loss and damage to limbs, heart disease, and renal damage leading to kidney failure.

While research suggests a complex, non-linear relationship between daily control of blood-glucose levels and prevention of long-term complications (Posner, 1977; Shillitoe and Miles, 1989) clinicians generally place emphasis on daily management as key to good prognosis. Effective biomedical management of diabetes requires a rigid regimen involving four elements: monitoring of glucose levels, medication with injectable insulin and/or oral medicine, diet and exercise. Individuals on biomedical treatment, attempt to control their blood sugar level by creating a balance between amount of insulin injected or taken orally, food input and energy output. Regular monitoring of blood-sugar levels is important. Such structured everyday activities are aimed at preventing complications and improving prognosis in the long term.

The diabetic regime, as Shillitoe and Miles (1989:208, in Sissons Joshi, 1996) observe is “intrusive, pervasive and requires life-long self-regulation of behaviour”. Studies show that although people living with diabetes are concerned about prognosis, they find the required

regimes oppressive and compliance and self-care rates are low (Wing et al, 1986; Samanta et al. 1987; Shillitoe and Miles, 1989; Sissons Joshi, 1996). Studies attribute low compliance and poor self-care to the fact that the relationship between adherence and/or self-care behaviour, and the control of diabetes is complex. Some studies attribute this complexity to psychosocial factors; African-based medical psychological studies for example attribute poor compliance and poor self-care to the emotional burden of living with diabetes with inadequate economic resources (Akanji, 1996; Famuyiwa et al,1985). Cultural practices have also been implicated: work carried out in India (Sissons Joshi, 1996), with British-Bangladeshis (Greenhalgh et al, 1998; Chowdhury et al, 2000), and native Canadians (Garro, 1995; Gittelsohn et al, 1996), suggest that cultural food practices can undermine the success of the biomedical diet regime drawn largely from Western food groups and diets. African work also suggests that cultural concepts of exercise and rest can facilitate or undermine the success of conducting regular exercise as part of diabetes management (Gill et al, 1997). Crucially, while the majority of these culture-centred studies suggest that culture shapes attitudes to and approaches to diet restrictions and exercise, some present evidence suggesting that individuals can and do move beyond culture in negotiating daily self-care (Anderson et al, 1996).

A final point must be made on doctor-patient relationships. The terms ‘social logic’ and ‘medical logic’ were coined within the critical health psychology field to distinguish between the knowledge drawn on by people with illness and their caregivers to manage the condition and that drawn on by their healthcare providers (Herzlich & Pierret, 1987; Nettleton, 1995). ‘Medical logic’ is drawn from the disease centred approach to illness and focuses on a restricted repertoire of practical routines aimed at addressing the physiological dimension of the illness. ‘Social logic’ draws from intersubjective experiences of the individual with illness and focuses on a broader repertoire of practical routines aimed at addressing the physiological as well as social dimensions of living with illness. Research suggests that people with diabetes are more likely to draw on social logic, rather than medical logic in their daily management of diabetes (Krause and Cornego, 1997; Drummond and Mason, 1990). Researchers argue that the everyday

knowledge and skill drawn from 'social logic' confers a particular expertise to people with diabetes and their caregivers that encapsulates and transcends the expertise of their healthcare providers - this expertise has to be brought to the fore (and legitimised) in examinations of medical and self-care (Nettleton, 1995; Bury, 1997).

The empirical questions I outline next were informed both by the particular socio-economic and structural context of diabetes care in Ghana, as well as the diabetes-specific health psychology findings outlined. These findings suggest four intersecting areas for critical examinations of self-care:

1. The physical dimension of diabetes has to come to the fore. This is an area that has so far been ignored within diabetes work in Ghana, despite evidence of the disabling effects of living with diabetes and possible impact on work, identity and social relationships.
2. The socio-economic dimension of diabetes care requires systematic examination. In low-income settings such as Ghana, economic status shapes the extent to which individuals engage in successful everyday drug and diet management. As current informal Ghanaian debates on diabetes and the broader African work (to be discussed) suggest, poverty has a dual impact on access to good healthcare and psychological and emotional responses to daily experiences or people living with long-term illness and those in their life-worlds.
3. The link between socio-cultural practices and successful diabetes management requires examination. So far research on the cultural dimensions of diabetes, has focused on cultural concepts of disease categories and the impact of these on negotiating professional care within pluralistic medical systems. Diabetes demands life-long lifestyle changes – it is important therefore to move beyond the role of culture in the use of pluralistic medical services to examine everyday socio-cultural practices - such as food practices and concepts of exercise - that facilitate or undermine diabetes lifestyle management within life-worlds.

4. The life-world of caregivers, family and friends is likely to play a critical role in everyday negotiation of self-care, given the particular structural and economic context of healthcare in Ghana. In the current context of expensive diabetes treatment and the absence of a welfare system, it is likely that the burden of care will fall on both people with diabetes and significant others in their lifeworld. The impact of diabetes on the internal dynamics of the life-world, such as quality of support and care-giving, will require empirical examination.

1.4. THE RESEARCH QUESTIONS

The empirical objective of the thesis was to map out the psychological, socio-cultural and structural context of diabetes experiences and illness action. From above discussions, this would necessitate a systematic exploration of shared socio-cultural knowledge on diabetes, chronic illness and health and healing, as well as intersubjective experiences and social practices from three social spheres: the 'lifeworld' of individuals with diabetes (in which I include family members and close associates), the (public) sphere of lay healthy individuals, and the pluralistic medical sphere.

The central empirical task with respect to life-worlds of people with diabetes, was to examine the types and sources of knowledge held about diabetes, how diabetes shaped everyday experiences and how knowledge and experience shaped illness action. Four questions were explored with people with diabetes and their significant others:

1. How did people with diabetes (and significant others) make sense of health and illness and of pluralistic medical systems? How did lay knowledge and practices mediate engagement with pluralistic medical systems?
2. How did people with diabetes (and significant others) make sense of diabetes? What were the sources and content of their knowledge?

3. What was the nature of ‘biographical disruption’ caused by diabetes and what meanings were ascribed?
4. What constituted illness action, what were the goals of illness action and what modalities of social knowledge and dimensions of inter-subjective experience facilitated and/or undermined the strategies and styles adopted towards these goals? A critical focus here was to map participants’ illness action goals to that of their health professionals.

Chronically ill individuals, as Radley (1994:136) notes live “with illness in the world of health” and make sense of and respond to their illness in relation to society around them. The second empirical task therefore related to the public sphere and aimed to examine how the wider Ghanaian society made sense of diabetes and the ways in which this social knowledge, as well as social relations shaped by this knowledge, mediated illness experiences and action. Three questions were explored with lay healthy groups:

1. How did lay healthy individuals make sense of health and illness and pluralistic medical systems? How did social knowledge mediate engagement with pluralistic medical systems during general illness episodes?
2. How did lay healthy individuals make sense of diabetes?
3. In what ways did lay perceptions of diabetes, diabetes experiences and lay interactions with people with diabetes impact on illness experience and illness action?

Taking the emphasised view within critical health psychology perspectives that medical knowledge systems and practices and lay health beliefs and practices intersect and mutually influence each other, the third empirical task aimed to examine the knowledge systems and practices of health professionals within Ghana’s biomedical, ethnomedical and alternative healing spheres. Because of the emphasis made on Ghanaian spiritual causal theories of chronic illness, and the particular emphasis placed on the social, economic and health service role of evangelical Christianity to contemporary Ghanaian society, faith healers were selected as

research participants in my examination of knowledge and practices in the alternative health sphere. There were two objectives to examining professional representations. First, to identify the ways in which professional knowledge and interactions with people with diabetes, and treatment practices, impacted on diabetes experiences and illness action. The second objective was to examine how the relative strengths of each system could be harnessed within the current collaborative model of health delivery for long-term diabetes care. Four questions were posed to health professional groups:

1. How did health professionals conceptualise health, illness and pluralistic medical practices?
2. How did health professionals make sense of diabetes and people with diabetes?
3. How did professional groups perceive and assess general and diabetes-specific in-group knowledge and practices?
4. How did professional groups perceive and assess out-group general and diabetes-specific knowledge base and practices? In particular what influenced dominant perceptions of the other and to what extent did these perceptions facilitate or militate against professional collaboration?

OVERVIEW OF CHAPTER TWO

This three-part chapter provides a critical review of current African-based chronic illness research, as well as Western-based critical health psychology approaches. In Part One I outline the dominant and alternative cultural approaches to chronic illness research. Part Two outlines the KABP and psychosocial approaches. I draw out key intersections between the psychosocial studies, the alternative cultural approaches and the Western-based critical health work to make a case for amalgamating critical health and social psychological approaches for diabetes work in Ghana. Part Three elaborates on key ideas and studies within critical health psychology that draw on the concepts of biographical disruption and illness action. Then, attention is turned to the social psychology of participation. The usefulness of this approach to diabetes intervention in Ghana is discussed.

CHAPTER TWO

CHRONIC ILLNESS RESEARCH: A CRITICAL REVIEW OF AFRICAN-BASED WORK AND WESTERN-BASED ALTERNATIVES

Cultural perspectives on chronic illness – and to some extent psychological perspectives - draw from a long tradition of empirical research on African lay health beliefs, with beginnings in colonial anthropological research on rural indigenous medicine and health beliefs, running through to contemporary sociological and anthropological work on the impact of medical pluralism and social change on health practices. It is crucial therefore to situate discussions within the broader context of such work. For this purpose I carried out a critical review of empirical anthropological, sociological and medical psychology work, the results of which frame key discussions of the strengths and limitations of the regional work. The review covered 62 studies (26 anthropological; 23 sociological; 13 medical psychological) from 21 countries: Botswana, Cameroon, Egypt, Ethiopia, Ghana, Ivory Coast, Kenya, Liberia, Malawi, Mali, Nigeria, Rwanda, Sierra Leone, South Africa, Sudan, Swaziland, Tanzania, Uganda, Zaire, Zambia, and Zimbabwe. To keep the review contemporarily relevant studies reviewed were published after 1970.

Three points require emphasis to contextualise the discussions that follow. First, this review is not intended to lump all these countries under one homogenous cultural category. Sections of the discussion will highlight that there are as many inter- and intra-cultural similarities as there are differences in lay health beliefs and treatment practices. The aim of the review was to outline the regional context of health research and healthcare in order to place Ghana within its appropriate research-policy context.

Secondly, by collapsing anthropological and sociological work, there is a risk of downplaying the distinct theoretical and conceptual frameworks that characterise both disciplines. However a number of broad generalisations can be made about the conceptual frameworks underpinning both areas of work, as well as their empirical goals in particular

relation to the African context. Firstly, the majority of sociological studies were rooted within the medical sociological paradigm, while anthropological studies drew mainly from a medical anthropological paradigm. Secondly, within this broad range of studies, the empirical focus has been on general health and illness concepts, or on health and illness behaviour with particular respect to acute illnesses. Thus while this body of work has provided useful – though not always adequate or appropriate as will be highlighted later - insight into African systems of thought with respect to disease classification, notions of causality and health-seeking practices, very little information is available on the ways in which people conceptualise and manage specific chronic illnesses. Much of the critical synthesis provided on chronic illness is derived from selected lay health belief studies that in the process of examining general lay knowledge and practices, touch upon the subject of chronic illness. Finally the broad aim of the majority of studies is to identify ways in which biomedical services can be improved in order to increase access and successful use of services.

Finally, the regional medical psychology field has a shorter history compared to the sociological and anthropological fields. The volume of (officially published) work is therefore considerably less than the cultural work reviewed. The approach has been applied in fewer countries and in the majority of cases lacks the conceptual rigor of the more established cultural studies.

This chapter begins first with a summary of lay concepts of health, illness and chronic illness, followed by specific discussions of cultural, medical psychological and critical health psychology approaches to chronic illness.

2.1. AFRICAN HEALTH AND ILLNESS CONCEPTS

2.1.1. Lay health concepts

For the majority of studies reviewed, health in most African societies is conceptualised in terms of internal (physical, mental) and external (social, metaphysical) balance (eg. Swantz, 1979; Brautigam & Osei, 1979; Davis-Roberts, 1981; Caprara et al., 1993; Nkwi, 1994). Good health

is judged in terms of normal body temperature and absence of pain. Health is also interpreted in terms of the relationships an individual maintains with his or her community, the natural environment and the spirit world. Within these contexts illness is seen to arise from internal (eg an abnormal or prolonged rise in body temperature) or external imbalance (eg family or social conflict, offending the gods).

2.1.2. Lay illness concepts

Illnesses in most regions are conceptualised within a tripartite categorisation system: as naturally caused, socially caused, and spiritually/supernaturally caused (Amuyunzu, 1998; Green, 1985; Kloos et al, 1987; Opala & Boillot, 1996). Natural causal theories refer broadly to causes mediated through the natural world, such as climatic conditions (heat, cold, dampness etc), injuries and environmental pollutants. Certain diseases like malaria, fevers, respiratory problems and general aches and pains are accepted as natural in the sense that they form part of the accepted natural/physical order. Social causal theories refer to illnesses caused through 'conscious or unconscious interpersonal malevolence' (Helman, 2000: 93) and have been sub-classified in this region under witchcraft and sorcery theories. The former refers to malevolent action caused by 'witches' – people possessing mystical powers used to harmful ends; the latter refers to malevolent action caused by ordinary individuals through knowledge and use of spells or rituals. Supernatural theories refer to illnesses caused through the direct action of supernatural beings such as gods and ancestral spirits. Social and supernatural theories are referred to interchangeably as 'magico-religious beliefs'. Rare or unnatural events such as the death of a child or young adult, or chronic illnesses or illnesses which cause sudden death in otherwise healthy adults are attributed to social or supernatural forces. While the origins of these conditions are perceived to be serious and mysterious, some are ultimately curable. Cultural studies have focused on how each classification evokes distinct illness behaviour and practices.

It is important to note that although the majority of studies place great emphasis on the centrality of magico-religious beliefs on health and illness, it is in this area that qualitative differences between societies can be observed. While some societies attribute serious illness to spiritual/supernatural agents (God, witchcraft, ancestors, spirits or curses) in a direct way, others do so in an indirect way. Nyamwaya (1987) notes for example – in his anthropological study of treatment practices in Kenya - that Pokot society see these agents as secondary causes of illnesses. They are only referred to when an illness becomes protracted and/or critical. The Botoku (an Ewe ethnic group) of Ghana also conceptualize spiritual causes of illness in a multi-level way notes Tsey (1997) in his sociological study of ethnomedical practices. For this group, belief in spiritual causation of illness does not imply that the individual or the community is a puppet in the hands of the gods. There are two levels of responsibility for every human misfortune – the ‘spiritual’ over which the individual has no control and the ‘human’. Thus spirits cause illness only when individuals or communities create the necessary conditions for such activity.

A direct link is generally made within the majority of studies, between illness causal theories and health seeking practices, much in the same way as KABP studies. Health seeking practices have been documented mainly in terms of the engagement of ethnic groups and societies with indigenous ethnomedical systems or the biomedical system. Despite empirical information gathered on the centrality of family, community, society and the environment in lay health beliefs, the interrelationships between these social dynamics and the bi-directional relationships between these and individuals living with illness have not been examined.

2.1.3. Concepts of chronic illness

Both dominant and alternative cultural studies highlight two consensual themes. Firstly most studies place causal theories of chronic illness within the social and ‘supernatural’ realms. Secondly, writers note that individuals living with chronic conditions which biomedicine cannot cure invariably turn to the phenomena of healer shopping or dual use. Both practices are

perceived negatively in the broad sense that they undermine biomedical goals (bearing in mind that the practical objectives of the majority of studies is oriented towards improving the use of biomedical services and of compliance). However each group adopts a different interpretive framework in outlining the socio-cultural dynamics of illness practices. Central ideas expressed within the dominant cultural approach, are reviewed first. Attention is then turned to the alternative approach, which illuminates the limitations not only of the dominant cultural approach, but also the dominant KABP work within the medical psychology field.

2.2 CULTURAL APPROACHES TO CHRONIC ILLNESS RESEARCH: DOMINANT AND ALTERNATIVE STUDIES.

2.2.1. Dominant cultural studies

The conceptual approach to chronic illness within the dominant framework is underpinned by two assumptions. First, theorists place emphasis on a shared value system between lay people and health professionals, as a necessary prerequisite for treatment choices and practices. Two interrelated explanations are provided. It is argued that people seek treatment outside of the biomedical sphere, or abandon biomedical treatment, because biomedicine lacks the conceptual framework and clinical expertise to treat the spiritual dimensions of chronic illness (Green, 1992a; Kirby, 1993). Simultaneously, there is the notion that both lay society and ethnomedical systems subscribe to spiritual causal theories of chronic illness; this 'shared value or belief system' constitutes the dominant motivation that drives ethnomedical treatment choices. Writers emphasise that on the one hand, there is the tendency for people across the region to consult biomedical health services for acute or infectious diseases such as fevers, malaria and respiratory problems, which are seen as natural and for which biomedicine has been shown to be highly effective (Green, 1992b; Jackson, 1985). On the other hand, traditional medical systems are the first and often only point of call ^{for} diseases attributed to social and supernatural causes, such as chronic conditions, childhood diseases, diseases which respond slowly to biomedical treatment (eg. Tuberculosis) (Nkwi, 1994). This notion of a shared belief system places biomedicine in one camp and lay individuals and ethnomedical practitioners in another, the former modern, the latter traditional. Consequently, treatment choices and practices are conceptualised in terms of activities driven by traditional beliefs.

The second assumption centers on the remit of biomedical and ethnomedical professional expertise. Biomedicine is accorded a pre-eminent position, by virtue of its status as a modern scientific discipline, and contrasted with indigenous medical systems collectively labeled traditional and non-scientific. Scientific biomedical systems demarcate the physical dimensions of disease as areas of expertise. While traditional ethnomedical systems also deal with the physical, expertise in this area is limited to indigenous conditions with simple

physiological profiles (Swantz, 1979; Mburu et al.,1978; Barker, 1973). For the majority of writers, ethnomedical expertise lies in the social and supernatural context of disease; practitioners are seen to treat individuals within the context of their family and social groups, pay considerable attention to patient satisfaction and provide adequate interpretations of the social and supernatural significance of illness (Green, 1992b). This 'holistic' expertise is viewed positively, particularly for indigenous conditions historically attributed to social or spiritual/supernatural aetiologies. However for complex physiological conditions such as chronic illnesses biomedical knowledge and expertise is deemed more sophisticated and better placed, than ethnomedicine, for successful treatment.

Binding both assumptions is a conceptualisation of medical systems as a hierarchy of alternatives, with scientific biologically-focused biomedicine at the top, and traditional socially/spiritually-centred ethnomedicine at the bottom. There is a sense that biomedicine can act as a powerful force for conceptual and practical change in the health arena. As lay people and ethnomedical practitioners become educated and more aligned with biomedical principles, 'faulty' magico-religious beliefs will give way to scientific causal theories and treatment choices will shift from ethnomedicine to biomedicine.

Implications of the dominant cultural approach for chronic illness care

Since chronic illness beliefs are viewed as constrained by culture, and further reinforced and legitimized by ethnomedical practice, this is an area where a clash between tradition and modernity is purported to occur. An explicit argument is made that 'modern' biomedical goals are undermined by traditional/cultural beliefs and practices of both lay individuals and ethnomedical practitioners. For example a recurrent theme in this area of work points out that traditional structures of illness management block biomedical therapy exactly when innovations would be effective, and encourages the inappropriate use of biomedical drugs and therapy at other times (Kirby, 1997).

The implications of this tradition-modernity dichotomy for chronic illness care are two fold. First, there is the tendency for the dominant biomedical system to assume exclusive expertise

and exclude indigenous healing systems. Implicit within this is the taken-for-granted superiority of the biotechnological approach. Secondly, in the area of clinical care and public health education, lay health beliefs are either ignored when dominant disease-centred models are applied or held in subordination to biomedical beliefs and practices when they are addressed in health policy discussions. Recommendations focus on addressing 'faulty cultural beliefs and practices' through 'culturally sensitive' education, as a means of improving public awareness and understandings of biomedical constructions of chronic conditions, as well as compliance and self-care. There are a number of problems inherent with this level of analysis that become evident when attention is turned to the alternative cultural approaches.

2.2.2. Alternative cultural studies

The alternative more fluid approach to the tradition-modernity distinction focuses on social change through intra-cultural and cross-cultural processes. Within this framework, western cultural products constitute only one of a broad range of agents of socio-cultural change. Drawing from this, studies have challenged the three core assumptions of the dominant studies.

Challenging the overemphasis on shared value system between lay people and health professionals

Some studies have focused on how meanings individuals ascribe to illness experience influence treatment practices. Writers note that an individual with an illness will ask *how* the illness came about and *why* the illness came to them (Nyamwara, 1987; Mavi, Owen and Gelfand, 1983). The 'how' dimension refers to the meaning ascribed to the natural and physical causes of illnesses. Here common-sense explanations such as old age, 'bad air', moisture, and organisms are applied. The 'why' dimension refers to the symbolic implications of contracting a particular condition. People refer to social and spiritual relationships, or ascribe blame to God, witchcraft, ancestral spirits and other supernatural agents. Researchers note that this quest for meaning at both levels underpins treatment practices. Individuals will consult practitioners who they believe can answer simultaneously how an illness came about and why it came to them

(Mavi, Owen and Gelfand, 1983). For example, in the realm of acute illness both ethnomedical and biomedical systems have empirical driven responses to cause and cure. Therefore, a doctor or a traditional healer might be used for exclusive treatment of an illness throughout its duration. Choices will be mediated by cost, proximity and so on. However, in the realm of chronic illness, neither system has clear answers to cause and cure, thus generating great uncertainty. Treatment in this case might be sought from both simultaneously throughout the duration of the illness. This interpretation is supported by empirical work which highlights that individuals access biomedical services for both physical conditions, as well as conditions deemed to be caused by supernatural agents (Etten, 1976). Thus the suggestion that natural diseases are the domain of biomedicine and are therefore best treated in hospitals and dispensaries and that social and spiritual illnesses are the domain of the traditional healer 'simplifies and misinterprets the empirical reality' of the two health care systems (Morris, 1986: 368). Crucially, researchers argue that this emerging fact that a 'shared world view' is not prerequisite for efficacious healing allows an examination of *how social groups move beyond their belief systems, and open up to the belief systems of other cultures* within the realm of health and illness.

Challenging the dichotomy between ethnomedical and biomedical epistemologies

The notion that only two systems of healthcare exist in Africa, one traditional, pre-scientific and ethnic, the other modern scientific and Western, is misleading and poses problems for any form of cooperation between the two systems in contemporary healthcare (Yoder, 1982; Nyamwaya, 1987). Morris (1986) argues that while both medical systems have obvious differences some commonalities run through them. They each, for example, depend to a large degree on the close observation of symptoms and on dispensing medications. They are similar too in the sense that the rituals of biomedicine have pronounced therapeutic effects just as traditional ritual curing is reported to have positive therapeutic effects. The critical difference, Morris argues, is that ethnomedicine has no developed theory of natural causation, while biomedicine treats social and psychological problems only as secondary therapeutic problems. More recent studies indicate

that there is an explicit move towards bio-technological expertise within regional ethnomedical practice (DeJong, 1991). The flexibility and adaptability of ethnomedicine to biotechnology has historical roots in ethnomedical openness and willingness to integrate foreign medical elements into professional repertoires (Rekdal, 1999). Considerable evidence has been gathered within anthropological work on cross-cultural healing to demonstrate the ways ethnomedical practitioners constantly 'invent tradition' (Rekdal, 1999; Ingstad, 1989; Landy, 1977; Obbo, 1996) to strengthen professional legitimacy in the pluralistic medical landscape. This evidence challenges the notion of ethnomedicine as culturally conservative and bound by ancient indigenous knowledge. Rekdal (1999), drawing on his Tanzanian work on Iraqw healers notes:

“A common characteristic of many of the practices of African traditional healers is that they are not traditional at all. They may well be transmitters of ancient and powerful knowledge, but they are also, and sometimes solely, inventors of medical tradition, agents facilitating the incorporation of new ways of thinking and acting.”(p. 472)

The changing face of contemporary ethnomedicine is further described by researchers who argue against the emphasis on indigenous healing practices as holistic, and against the assertion that shared socio-cultural networks between healers and patients are actively used in the healing process (eg Rekdal, 1999; Swartz 1997). Their studies demonstrate that in reality the contemporary urban healer originates from a different ethnic group, and a different part of the country, (or even outside the country) compared to their clients (Rekdal, 1999; Swartz 1997). Furthermore, for the contemporary often urban-based herbalist who increasingly adopts a bio-technological approach, the biophysical dimensions of disease are prioritised over the social and spiritual context. This suggests that a demarcation between biomedicine and ethnomedicine based on the implicit assumption that ethnomedical practitioners lack the ability to adopt new areas of biotechnological competence is wrong.

Finally, researchers argue that the taken-for-granted superiority of a bio-technological approach to the management of chronic illness remains unproven. Chronic illness, it is argued, constitutes one key area for which all medical systems lack conclusive answers regarding cause and cure (Huertin-Roberts and Becker, 1993). The uncertainties chronic illnesses raise for

biomedical practice have been more clearly identified and discussed within critical health psychology and will be taken up shortly.

Broadly it has been argued that the relationship between African traditional medicine and biomedicine “can be competitive, complementary or supplementary” (Nyamwaya, 1987, p.1.). Researchers note that a significant number of societies conceptualise healthcare systems in terms of a co-existence of alternatives, within which the biomedical system is perceived as one in a wide repertoire of pluralistic medical systems generating more options for health intervention. Within Kenyan Pokot society, for example, Nyamwaya (1987) notes biomedicine is not regarded as superior or inferior to traditional medicine. According to them, the introduction of biomedicine has generated more options for intervention at the causal level of illness. Within the Tabwa society in Zaire, each system is seen to have its strengths and weaknesses, but more to the point, both are regarded as '*subordinate* in the same way to the broader epistemologic concerns that give Tabwa medical system as a whole its meaning and vitality.' (Davis-Roberts, 1981, p.316). Other studies discuss similar findings (cf. Bledsoe & Goubaud, 1985; de Zoysa et al, 1984; Hielscher & Sommerfield, 1985; Lasker, 1981; Ryan, 1998). Thus, in contrast to the displacement thesis offered within the dominant field, the acceptance and public legitimation of biomedicine within a variety of societies, has not lead to a rejection of ethnomedicine: ethnomedicine and biomedicine co-exist and are drawn on interchangeably.

Implications of alternative cultural approach for chronic illness treatment

The alternative cultural studies implicitly highlight, in direct contrast to the dominant cultural studies, that the selection of treatment options is not so much about a split between traditional and modern ways of thinking. It is more about how a new experience changes an one's social reality, and sets one on a course to understand or even overcome the new experience within the extensive repertoire of existing lay health knowledge and medical options available. The socio-psychological dimensions of this process are implicit but remain to be systematically theorized.

The elucidation of the interplay between individual, social and structural dimensions of illness experience within this sub-field highlights not only the shortcomings of an exclusively cultural approach, but also of the individualistic approach adopted by the dominant KABP work within the medical psychology sub-field.

2.3. PSYCHOLOGICAL APPROACHES TO CHRONIC ILLNESS RESEARCH: KABP AND PSYCHOSOCIAL STUDIES

The regional medical psychology field consists of two sub-groups – the KABP and psychosocial studies. Both draw on mainstream psychological models on health behaviour, the development of which, traditionally, has been guided by the notion of individuals as active self-reflecting and self-regulatory processors of information (Bandura, 1977). Three different strategies have been applied to mainstream work on health behaviour. The first strategy applies formal psychological theory to the health domain. Theories linking attitudes and behaviour (such as Subjective Expected Utility Theory, the Theory of Reasoned Action and the Theory of Planned Behaviour) have been adapted to examine beliefs about health and resulting behaviours. The second strategy has been to develop health-specific conceptual frameworks or grounded theories to explain health-relevant outcomes. Grounded theories include the Health Belief model, Protection Motivation Theory and various stage models of health-relevant behaviour change. Finally, some research has focused on specific social and personality processes relevant to health behaviours such as optimism, self-awareness and the relationship between various emotional experiences and illness (Salovey, Rothman & Rodin, 1998). The KABP work draws from the second body of mainstream work, while the psychosocial work draws predominantly from the third.

2.3.1. The KABP studies

All regional KABP studies have followed a similar empirical approach. They aim to examine the level of biomedical knowledge individuals with chronic illnesses have about their particular conditions and the impact of this on 'management-related behaviours'. Each study begins with a strong hypothesis linking poor management-related behaviour to poor biomedical knowledge and sets out to reveal this link. Empirical work and interpretation of results are framed by these conceptual parameters. Some studies have focused on (biomedical-oriented) accounts from individuals with chronic illness, such as knowledge of the physical aspects of their conditions, and key aspects of drug, diet and lifestyle management (Kamel et al, 2000a, 2000b; Nyazema, 1984). Other studies have conducted clinical assessments alongside gathering subjective accounts on knowledge and self-perceived health (Erasmus et al, 1999; Elagbir et al, 1999; Wikblad, 1997). The majority of studies have been conducted in urban settings and drawn from hospital populations.

In most studies the social dimensions are excluded from empirical examination, as are alternative (ie non-biomedical) causal theories of illness. The majority of studies have reported high levels of poor knowledge - for example about complications associated with diabetes (Egypt based study by Kamel and colleagues, 2000a; 2000b) or drug use behaviour in hypertension (Zimbabwe based study by Nyazema, 1984) – among respondents engaged in poor self-care or living with the most complications. All recommendations focus on the development of health education programmes for people with chronic illness, and better training of biomedical personnel to communicate these programmes more effectively.

Within this sub-field then, the primary focus is compliance and good self-care, both practices are abstracted from the social context of the individual and construed in terms of a simple application of expert biomedical knowledge to the control of physical symptoms. Interestingly, some studies show that poor compliance among their respondents occurs irrespective of duration of illness, educational status and quality of biomedical advice given during clinical encounters (eg Kamel et al, 2000b; Erasmus et al, 1999). The implications of such findings –

that non-compliance could be attributable to other factors apart from the communication and application of biomedical knowledge – have not been explored. The psychosocial studies shed some light on these unexplained KABP findings.

2.3.2. The psychosocial studies

Using modified psychosocial and general health questionnaires, the psychosocial studies aim to examine the psychological and emotional impact of chronic illness experiences and factors mediating such disruption. Studies also examine the links between psycho-emotional disruption and illness practices.

Studies show that prolonged physical disruption from chronic illness undermines individuals' ability to work, which undermines ability to earn and exacerbates economic deprivation (Famuyiwa et al, 1985; Ohaeri et al, 1998). Loss of income and increasing dependence of family and significant others can in turn cause disruptions within the lifeworld (Ohaeri et al, 1995). Researchers note that these socio-economic stresses underpin a variety of emotional, psychological and spiritual responses. Studies on experiences of cancer, sickle-cell anaemia, asthma and diabetes have uncovered depression and fear of death as dominant emotional responses (Green et al, 2001; Ohaeri et al, 1995, 1998). Other studies note that the prolonged stress of living with a chronic illness can lead to 'psychiatric disturbance' (Ebigbo and Oli, 1985), or to 'suicidal ideation' during times of acute physical crises (Ohaeri et al, 1995). 'Chronic unhappiness' (Ellis, 1996) and spiritual distress (Ohaeri et al, 1995) caused by the uncertainties of living with long-term illness (in terms of one's physical identity, social identity and life trajectory) have also been identified. Chronic unhappiness can undermine social and medical relationships (Ellis, 1996), while spiritual distress evokes religious forms of coping such as frequent prayer (Ohaeri et al, 1995). These disruptions can occur even within the context of strong family support.

While emotional, psychological and spiritual disruptions undermine the ability of individuals to engage in successful self-care, poor self-care is at root shaped by broader structural factors. Studies strongly implicate the high cost of chronic illness care and poverty in

poor management practices (e.g. Akanji, 1996; Famuyiwa et al, 1985). The economically deprived have restricted access to formal healthcare and may seek cheaper options (Famuyiwa et al, 1985). Others link poor illness practices, such as healer shopping within ethnomedical systems, to inadequate biomedical care: evidence suggests that individuals consult ethnomedical practitioners partly due to poor dissemination of biomedical knowledge and the uncertainty this evokes within individuals, in terms of what their condition implies, and the best way to cope (Nyazema, 1984).

Some researchers recommend a range of interventions centred on biomedical mediation of 'emotional management': health education and community support to improve knowledge of conditions and coping strategies, empathic communicative practices and counselling within biomedical consultations (Green et al, 2001; Nyazema, 1984). Others emphasise the improvement of structural dimensions of chronic illness care, in particular the improvement of social welfare systems (to provide socio-economic support for low-income individuals) and addressing availability and affordability of biomedical treatment (Famuyiwa, 1985; Akanji, 1996). None provide clear guidelines through which these recommendations can be carried out.

By highlighting the social and material context of self-care, the psychosocial studies support the alternative cultural view that healer-shopping is mediated as much by psychological and socio-economic needs as they are by cultural mores. The evidence gathered on the use of biomedical systems by the chronically ill, suggests pluralistic health systems are viewed in terms of a coexistence of alternatives, rather than hierarchy of expertise. Studies also suggest that the use of ethnomedical systems may be driven by inadequate practical medical knowledge on the prognosis of illness for individuals, the uncertainties this lack of knowledge evokes, and the high cost of biomedical care. This undermines the dominant view that a shared traditional value system drives healer-shopping within ethnomedical systems.

The psychosocial studies also uncover the mutual inter-relationship between physical, emotional and socio-economic dimensions of chronic illness. They agree with critical health

psychology findings and critiques levelled against mainstream psychology overemphasis on rationality and health, and the problems this poses for understanding the complex social psychological processes underpinning compliance and self-care for the chronically ill.

These findings push the regional research agenda towards a more integrative approach to the cultural, social and psychological dimensions of chronic illness experiences and negotiation of professional care. To operationalise such an approach three under-researched empirical areas require critical examination. The first concerns the complex process of coping. Chronic illness disrupts the lives of the chronically ill at a variety of levels, but there is scant information on the ways in which the chronically ill deal with and/or overcome the burden of illness within the low-income context. The second concerns the lifeworld of the chronically ill. The internal dynamics and reciprocal relationships within life-worlds, in particular the responses of family, friends and caregivers to individuals with chronic illness, have been under-examined. The final area is the challenge of developing and implementing feasible, practical interventions to improve the quality and continuity of care. The psychosocial work recommends a variety of psychosocial, economic and structural interventions. However there is little discussion on how these interventions can be developed, implemented and maintained within the context of limited economic, technical and structural resources.

The methods employed to examine these under-researched areas are discussed next. Critical health work on biographical disruption and illness action is drawn on to conduct a critical examination of the role of the subjective, lifeworld, and medical contexts in self-care. Applied social psychological approaches to participation in low-income country settings inform the development of feasible practical interventions.

2.4. CRITICAL HEALTH PSYCHOLOGICAL APPROACHES TO CHRONIC ILLNESS: BIOGRAPHICAL DISRUPTION AND ILLNESS ACTION

This section presents a summary of ideas and findings, about biographical disruption and illness action, which have implications for empirical work on diabetes in Ghana. Two interconnected dimensions are addressed. First the intersubjective impact of chronic illness for people with chronic illness and those they associate with in their life-worlds, their broader communities and the medical context. Second the ways in which individuals cope with and overcome biographical disruption, alone, or within supportive social relationships.

2.4.1. Biographical disruption: negotiating symptoms and society

Chronic illness causes bodily and reshapes the sufferer's life circumstances and social relationships. It has two important consequences. On the one hand individuals have to deal with physical symptoms and *impairments* ("loss or abnormality of physiological or anatomical function" Radley,1994: 141) and/or *disabilities* ("restrictions in the ability to carry out or to fulfil a role in a normal way" Radley,1994:141). On the other hand, individuals have to negotiate and fulfil social roles and responsibilities. Bury's (1982) concept of biographical disruption - described as the disruption chronic illness causes to both the physical body and life trajectory of the sufferer - was coined to capture this intersection of physical and social demands and responses evoked. Bury (1997) has noted that defining chronic illness as a disruptive event "allows for its meaning to be situated in a temporal and life-course context"(p.124). Two types of meaning are distinguished. 'Meaning as consequence' refers to meanings and interpretations ascribed to everyday practices of negotiating treatment and support within one's lifeworld, community and the medical sphere. 'Meaning as significance' constitutes, as Conrad (1990) notes the "more metaphysical understandings in terms of an individual's personal meanings of life, death and the unknown' (p. 126). Empirical work suggests that practical and 'metaphysical' meanings are interlinked and mutually influential.

Herzlich's (1973) classic work demonstrates the ways in which the physical dimension of chronic illness highlights the relationship of self to illness and the extent to which the illness is 'incorporated' into the identity and way of life of the individual. Radley and Green (1985, 1987), elaborate on Herzlich's notion of 'incorporation', arguing that the relationship between self and illness can be one of opposition or of complementarity. Opposition is characterised by the fight to overcome and/or defeat the illness. This response is likely to be successful when the individual has the necessary resources and the ability to use these to counter the effects of disease. Complementarity has two strands. First, it refers to the process whereby "self encloses the illness": the individual accommodates the illness, negotiating ways in which social life can be retained despite the limitations imposed by illness. Second, complementarity can signify a process whereby 'illness encloses the self': illness limits the life of the individual and there is gradual withdrawal from social life. This latter process does not necessarily have to be negative. Drawing on Herzlich's (1973) concept of 'illness as liberator', the theorists argue, that positive qualities, or 'secondary gain' can be derived from withdrawing from social life and seeking other fulfilments that lie outside work and its rewards. Opposition and complementarity co-exist during the course of illness and are drawn on depending on the nature of the illness, absence or presence of physical symptoms, the nature and severity of symptoms when they appear and the resources one has to attend to such symptoms.

The dominant empirical focus of critical health psychology has been on the lifeworld of the chronically ill. However health systems are increasingly recognised within the field as key resources on which the chronically ill draw to deal with the burden of physical symptoms (Bury, 1997; Krause, 2003). The complex and unpredictable nature of the biophysical aspects of chronic illness and the need for frequent or intermittent professional consultation highlight the important role played by health professionals in the lives of the chronically ill. Theorists note that health professionals, by offering diagnoses and information about treatment regimens and medical interventions, offer a degree of control and reassurance to counter the apprehension and anxiety evoked by the threat and disruption of illness (Bury, 1997). However, this role has

significant drawbacks. Research evidence suggests that while biomedicine may help reduce uncertainty for sufferers by offering technical and practical advice on the biophysical nature of chronic conditions, it simultaneously reveals a considerable lack of technical knowledge on the nature and prognosis of a variety of conditions (Bury, 1997; Crossley, 2000; Mayer, 1994; Krause, 2003). Thus a distinguishing characteristic of chronic illness experiences, theorists contend, is the pervasive uncertainty generated for sufferers and those involved – both formally and informally – in sufferers’ care.

While the relationship of self to illness is a crucial dimension of the chronic illness experience, the chronically ill “live with illness in a world of health” (Radley, 1994:136). This highlights the intricate relationship between self and society. Individuals do not just respond to the biophysical event of illness, but draw on shared ideas circulating within society about the body, health, illness, life and death (Kleinman, 1988; Bury, 1997). The impairments and disabilities that chronic illness brings, are not matters solely for sufferers – they become focal points around which societal perceptions, responses and relationships revolve and are reshaped. The changes can have a profound impact on shared experiences, role expectations, values and identities. As Crossley (2000:82) notes “shattered assumptions regarding the future and one’s body means that the person living with illness feels profoundly alienated from the world of other people”.

The chronically ill face potential ‘handicap’, defined as the (mainly negative) “assumptions that others make about the sick and their reactions to them” (Radley, 1994:148). These assumptions are underpinned to a considerable extent by emotional conflict and contradiction. Radley identifies the “double implication of compassion and abhorrence”, which leads to simultaneous endorsement of and resistance to the chronically ill within society. Handicap, therefore, in Radley’s (1994:158) view captures the disadvantage that people face from the world of health:

“...good adjustment does not spring ready-made from the individual sufferer. The dilemmas that the chronically ill often experience are grounded in the contradictory expectations of the healthy.”

Radley (1994) argues that emotional conflict deepens with decreasing social links, exacerbating handicap in the public sphere, and lessens with stronger social links – thus significant others in the life-world are better placed to respond with greater compassion than abhorrence to the chronically ill. While, theorists support Radley's thesis regarding the emotional tensions mediating relationships between the healthy and the ill, there is a broader view, which suggests that emotional contradictions and handicap are as acute in proximal relationships as they are in distant relationships. Charmaz's (1983, 1991) work, discussed shortly highlights this clearly, as does Crossley's (2000) discussion of the psychodynamic conflict underpinning doctor-patient relationships. Both theorists stress that emotional conflict is often bi-directional and underpinned by the uncertainty chronic illness evokes for sufferers and carers.

Handicap has to be viewed therefore as both cause and product of psychological and socio-cultural processes. This integrative interpretation illuminates the usefulness of 'legitimation', another key concept drawn on within the critical health field. Described within classical sociological discourse as 'the process through which (political) authority is made credible' (Bury 1997:456), legitimation can be viewed from the perspective of society as espoused in Friedson's (1970, in Nettleton, 1995) typology of lay legitimation, or from the perspective of the chronically ill, as discussed by Bury (1997).

Initially developed within the context of the sick role, Friedson's typology is relevant to discussions of chronic illness, because as Nettleton (1995:71) notes it "draws attention to the extent to which experience of illness is bound up with the wider social context, and...makes clear that the meanings imputed to illness can impact upon the experience and identity of the sufferer." Friedson (1970) distinguishes three types of lay legitimation. Firstly, 'conditional legitimation', which refers to temporary rights and privileges offered to individuals experiencing temporary periods of acute ill-health. The criterion for this type of legitimation is the tacit expectation that individuals will get well with treatment and is therefore likely to apply to chronically ill individuals experiencing acute phases of their illness. Secondly, 'unconditional legitimation', refers to the process or act of granting unlimited rights and

privileges to individuals living with long-term serious/severe illnesses or disabilities, who cannot act to get well. Finally, an individual's condition and identity may be deemed illegitimate – this can occur in cases where the illness is stigmatised by society and the rights and privileges that come with being ill are revoked. Given the long-term nature of chronic illnesses, their acute and latent phases, and the range of impairments and disabilities experienced by sufferers, it is fair to assert that all three types of lay legitimation may be applied along the course of one's illness.

Bury (1997) discusses self-legitimation in terms of the way the chronically ill negotiate the public and private dimensions of illness experience in order to minimise biographical disruption. He notes:

“...legitimation refers to the attempts by people to establish the place of a disabling illness within an altered daily life and within the web of social relationships in which the person's life may be enmeshed. Effort, at this level is aimed at sustaining claims to ‘cultural competence’ and personal authority in the face of threat.”(pp.125-6)

A focus on self-legitimation allows researchers to examine not only the impact of society on the chronically ill, but the ways individuals reconstruct and manage altered identities within the context of close and intimate relationships, as well as the more distant public sphere. Examined from both perspectives, the legitimation process illuminates the individual-social context of biographical disruption and of ‘meaning as significance’.

Charmaz's (1983, 1991) prominent study of the social psychology of disability, adds empirical weight to key notions of biographical disruption and legitimation and presents particular food for thought for work in the Ghanaian context. Charmaz's work is framed by attention to the American system of healthcare, designed for the disease-centred approach to acute illness, which leaves the chronically ill to be cared for by family and caregivers in social isolation, a situation that resonates with Ghanaian formal healthcare delivery. Charmaz (1983, 1991) identifies four social psychological conditions that mediate - in interconnecting ways - the relationship between self and illness and of self and society, for individuals living with chronic

illness and disability in isolated life-worlds. First there is the impact of living a restricted life, which comes to focus particularly in cases where illness brings about disability and the lack of mobility causes an individual to be homebound. Secondly, there is a sense of social isolation. Fears and anxieties may arise from feeling, or being made to feel by others, that one is diminished in social worth. Thirdly, individuals experience 'discrediting definitions of self'. Such negative self-sentiments are strongly linked to the difficulties of handicap. They occur when others react negatively to the individual's condition, especially when the condition reshapes one's physical identity or when the condition is stigmatised. Discrediting definitions of self can also occur within the lifeworld, when individuals can no longer carry out taken-for-granted tasks and activities with significant others. Fourthly, there is the fear of becoming a burden on family, friends and caregivers. When illness becomes debilitating, individuals may find themselves unable to fulfill their formerly ascribed social roles and obligations and can no longer "claim with authority the identities that are based on doing these things" (Radley,1994:148). This engenders a feeling of uselessness both to self and to others, which may in turn have a negative impact on the capabilities of caregivers. The burden placed on significant others within the lifeworld can strain family relationships: marriages, for example, are at greater risk following the onset of disability (Nettleton,1995, Blaxter, 1976; Topliss, 1979). This fourth dimension also highlights the impact of cultural values on social relations and practices (Nettleton, 1995). Nettleton (1995) notes: "in a society where 'doing' is privileged over 'being', those who cannot perform conventional tasks tend to lose the very means needed to sustain a meaningful social life"(p.87).

2.4.2. Illness action: responding to biographical disruption

Illness action, a notion coined within a phenomenological sociological framework, refers to "the outcome of continuing efforts on the part of the sick person, and those with whom he [sic] associates, to make sense of what is going on in the light of the knowledge, resources and motivations available to them" (Dingwall, 1976:121). This notion, which captures the evolving nature of inter-subjective meanings and practices engendered by long-term, unpredictable

chronic illness experiences, is one that has gained increasing currency within the critical health field. Theorists note that it facilitates an explicit conceptual departure from the notion of illness behaviour, which focuses exclusively on “the biophysical event of disease” (Nettleton, 1995: 78) and excludes the social context of illness.

Adopting illness action as an analytical framework facilitates examination of the ways in which individuals live with and respond to chronic illness. Within the literature, illness action has been described implicitly in terms of ‘coping’, ‘strategies’ or ‘styles’. There is considerable overlap between these key terms and they are often used interchangeably; however, it is worth defining each briefly to set the context for concepts adopted in the broader discussion of illness action.

Radley (1994) has distinguished between ‘problem-based coping’ and ‘emotional-based coping’: the former refers to daily strategies the chronically ill adopt to address biographical disruption, the latter refers to “the ways in which people maintain or recover a sense of self-worth”(Bury,1997:130). Bury (1997) argues that emotional-based coping is a better definition as it emphasises the ways people ‘put up’ with illness and disability and brings into focus cognitive as well as emotional dimensions of illness action. Problem-based coping, which mediates daily strategies, moves beyond this, to bring into sharper focus “ the ‘rules and resources’ of social hierarchies” Bury (1997:131): it draws attention to the cognitive-emotional resources individuals draw on in adaptation, as well as the importance of social and material support. The focus on social support and networks is particularly important. Studies highlight the ways illness leads to loss of wider social contact and increasing dependence on partners and family members; more crucially socio-economic disadvantage has been shown to exacerbate handicap. ‘Style’ refers to a particular mode of long-term coping arrived at through negotiation of self and social identity in response to the dual burden of symptoms and society. Bury (1997) notes that style suggests planning, rehearsal, evaluation of everyday actions with concurrent ‘refashioning of the self’ in the face of long-term illness and disability. Drawing on socio-cultural theories of emotion (see Chapter Three) I take the view that, while the terms emotion-based coping (or coping in the general sense), problem-based coping (‘strategies’) and styles

offer clear guidelines for examining particular aspects of illness action, it is conceptually limiting to draw strict distinctions between them. It is more useful to see problem-based and emotion-based coping as intricately linked processes, which, examined over time, highlight the personal styles adopted in response to illness.

Studies exploring illness action demonstrate that chronically ill individuals cannot be characterised solely in terms of passive or emotionally conflicted individuals whose identities, agency and communicative power are undermined and marginalized by the dual burden of symptoms and society. Charmaz's work, for example, demonstrates that loss of self and loss of participation in social life does not constitute a permanent feature of the chronic illness experience. Individuals actively participate in the recreation of their lives and identities (Charmaz,1987) and in so doing move beyond a state constrained by the dual burden of physical and social disruption. Herzlich's (1973) classic work highlighted the ways in which illness could constitute a catalyst for restructuring one's life positively. Theorists argue that individuals live with a "raised consciousness" (Radley,1994) or "a politicisation of self" (Nettleton, 1995) born of recognition of the social implications of their changed selves and they adopt daily strategies that 'mobilise resources and maximise favourable outcomes' (Bury,1997) within their life-worlds and broader social relationships. There is increasing evidence to suggest that patients "are not just recipients, but expert providers of their healthcare" (Nettleton,1995:96). Studies document the ways in which people living with multiple sclerosis, arthritis, inflammatory bowel disease and diabetes, gather technical information about their condition and its management, to offset biomedical uncertainties (Bury,1997; Flick,1998b; Krause,2003). Within these contexts patients' knowledge often exceeds their healthcare providers, and doctor-patient relationships focus less on the affective component and more on the negotiation of technical information regarding prognosis, as well as the costs and benefits of treatment regimes. Individuals may adopt 'careful pattern of experimentation' between health providers and choices of treatment (Bury,1997:127) and draw more confidently and flexibly on social logic in the negotiation of everyday self-care (Krause, 2003).

The development and use of self-help groups is another key area in which the chronically ill become active providers of their own healthcare (Crossley, 2000; Nettleton, 1995). Often set up in the face of institutional and social neglect, self-help groups are driven by social support, educational and/or socio-political agendas (Nettleton, 1995; Bury, 1997; Krause, 2003). Studies suggest that the social support provided by self-help groups can transcend the support received through primary social networks (Greenhalgh & Collard, 2001; Krause, 2003). The increasing expertise, autonomy and socio-political power wielded by individual patients and self help groups, has led to the view, that “‘pooling expertise’ of patient and practitioner is a more useful way forward than the medical preoccupation with ‘patient compliance’” (Bury, 1997:127).

Ultimately the strategies and styles individuals adopt to address the dual burden of symptoms and society are not reducible to de-socialised individual qualities or attributes exclusively or to a constraining impact of society on the individual. Illness action constitutes a co-construction and mutual renegotiation of self, identity and agency between the chronically ill, their significant others and people they associate with in the social and medical domains. This intersubjective activity evolves over time, in response to the various stages of illness progression and is framed, as studies indicate, by the material and structural context of care.

2.5. SOCIAL PSYCHOLOGY OF PARTICIPATION: A TEMPLATE FOR DIABETES INTERVENTION IN GHANA

A ‘three-pronged approach’ has recently been proposed for the chronic illness research agenda by a multi-national expert team of health researchers (Unwin et al, 2001). The proposal calls for equal attention to epidemiological surveillance, health promotion and prevention for wider societies and the improvement of quality and continuity of care of people living with chronic illness. The authors stress that given the current lack of economic resources with regional healthcare systems, the challenge lies in the development and implementation of robust

interventions that allow the effective and efficient use of existing economic and human resources.

Within the broader context of health intervention in Africa, participatory projects have been driven by long-term, resource-sensitive agendas. Participatory projects have achieved some level of success in the prevention and control of communicable diseases, as well as the improvement in sexual health through educational change, community mobilisation and community financing activities (Atim, 1999; Valente et al, 1997). I adopt the view that some approaches, for example rural community financing, and the use of self-help groups with common socio-psychological and socio-economic projects, are particularly applicable to the development of interventions in chronic illness care in the region and to diabetes care in Ghana.

However current participatory approaches do not provide an adequate practical context for chronic illness work. There are fundamental differences between acute communicable disease and chronic non-communicable disease in the African setting, which have to be factored into development strategies for chronic illness intervention. Acute communicable diseases in the majority of African countries constitute perceived and real recurrent threats to wide sections of society. This collective problem makes participatory work, to some extent, a shared ideal between local and international health professionals and policy makers and for communities and groups at risk of contracting or having to treat disease. Chronic conditions on the other hand, have a complex and divisive profile. They are marginalised within policy circles, fuel professional antagonism between biomedicine and ethnomedicine, undermine professional and client relationships, place considerable long-term burden on relationships in the lifeworld and disrupt social identities and wider social relationships. This suggests that participation in the classical sense of mobilising entire communities with collective vested interests, will require some conceptual reworking. Empirical work will have to closely examine and identify key actors and sites through which this process is best mobilised, communicated and conducted. It will be important to examine the nature of the problem, the groups it directly affects, and groups who will benefit from intervention. Also essential is the identification of groups who can participate, the capabilities they possess, and to what extent and for how long can they

participate. These activities necessitate close attention not only to negotiating and maintaining long-term success but also to the development of a socially-sensitive conceptual approach that legitimises the positions and capabilities of all participants.

2.5.1. Participation: Utilitarian (top-down) and empowerment (bottom-up) models

While 'participation' has engendered different meanings and applied methods in different Primary Health Care contexts during the history of its use, two approaches are distinguished (Rifkin, 1996; Morgan, 2001). First, the 'utilitarian' or 'top-down' approach draws on modernisation theory or models and conceptualises participation as technocratic use of groups and communities for legitimating projects. While groups may be instrumentally involved in such projects, they are excluded from decision making and sharing political and economic power. The majority of African projects can be subsumed under this category. Second, the empowerment model or 'bottom-up' approach, draws from the dependency model and views participation as a means of empowering marginalized people to make their own health choices and critically foregrounds as its broader objective socio-political change.

Critics note that neither approach in isolation has yielded successful sustainable results. It has been argued that both draw on a Western scientific paradigm, approaching the development of interventions as though the outcomes were predictable and controllable (Rifkin, 1996). Furthermore they both have the underlying assumption that 'developed' societies are the 'model' to be emulated, that 'development' is a process of 'catching up' and thus fail to recognise 'local resources and problems involved in the cultural and material differences between contexts' (Campbell and Jovchelovitch, 2000:258). This has resulted in a body of work that construes 'participation' in terms of health planners' preconceived notions of progress and development rather than 'as an outcome of a dynamic interaction among all those involved in developing a specific health programme in which the outcome is neither controlled nor predictable' (Rifkin, 1996:87).

Drawing lessons from these failures researchers argue for multi-level health interventions that combine the strengths of both approaches to healthcare and management. These must be

underpinned by two explicit considerations. First the importance of ‘understanding each context in its own right’, which means prioritising the ‘local context’ perspective and experience in development programmes (Campbell and Jovchelovitch, 2000). Second, taking into account the complex inter-relationship between heterogeneous knowledge systems, identities and power dynamics mediating lay health practices as well as practices of health providers and policy makers (Campbell and Jovchelovitch, 2000; Woelk, 1992; Kelly and Van Vlaenderen, 1996; Campbell, 2004). Theorists note that by taking into account that understandings are ‘shaped by the differences in social reality of the different levels of social organization’ (Woelk, 1992: 420) different types of evaluations can be developed which reflect and legitimise the social realities framing these multiple views and experiences.

2.5.2. Social psychology of participation: a multi-level approach

The social psychology of participation approach is strongly aligned with the multi-level approach and provides a useful framework to address conceptual and practical gaps. It has two significant advantages over existing approaches in the region. It blends the concerns of applied critical health and social psychology to inform theory and policy driven participatory interventions in community health. Practically, it has informed Latin-American projects, some of which have been consistently awarded the ‘best practice’ label for implementing and maintaining successful long-term community health projects (World Bank, 1996; UNESCO, 2003). Key ideas from these projects have been applied to general health intervention in Africa (Onyango-Ouma et al, 2001).

Two key studies are adopted as key guides: Guareschi and Jovchelovitch’s (2004) psychosocial approach, which offers general principles for designing community health interventions in impoverished settings, and Krause’s (2002, 2003) approach which offers a model for chronic illness intervention.

The framework developed by Guareschi and Jovchelovitch (2004) involves three interlinked foci, which operate both conceptually and empirically: diagnosis, (psychosocial) intervention

and critical reflexivity. Diagnosis aims “to understand, engage with and map out the local systems of knowledge of the community, the ways in which it conceives of itself and its mode of relation both inside and outside its boundaries” (p.316). Intervention aims to produce what the theorists refer to as ‘productive alliances’ between different social actors with divergent knowledge, experiences, expertise and status. These productive alliances then mediate exchange and transformation of knowledge and experience between the social actors: they “learn from each other and are put into a position of changing in relation to both themselves and others” (p.317). Finally critical reflexivity provides the overarching principle of psychosocial intervention. It draws on the basic assumption of critical theory, which views reality as “a field of open possibilities”. The task of critical reflexivity, Guareschi and Jovchelovitch note, is to engage with this field and identify alternative possibilities that can transform reality. Critical reflexivity is an evolving conceptual, empirical, and analytical process that underpins the research process and the interrelationships within the research community as well as between the research community and the researcher. It facilitates the mapping out of complex social realities and modes of transformation of social realities.

Krause’s (2002, 2003) action research work on diabetes, hypertension and inflammatory bowel disease uses a similar typology to Guareschi and Jovchelovitch (2004). Employing knowledge dissemination within participant groups and wider society, development and mediation of social support structures, and continuous reflexive engagement with the field, Krause shows how productive alliances between expert patients, self-help groups and their health professionals transform social representations of debilitating illness over time. The profile of the health settings and socio-economic positioning of the participants bears close similarity to the Ghanaian diabetes context. Furthermore, Krause’s explicit incorporation and examination of the biophysical aspects of the chronic illness experience within the socio-political context is in line with the central focus of this thesis. Both studies offer particular strengths to the theoretical and methodological development of social representations theory.

OVERVIEW OF CHAPTER THREE

This chapter outlines the theoretical framework of this thesis. First, I introduce the theory of social representations and draw out three key ideas proposed by Moscovici: (1) the centrality of the 'unfamiliar' to the development of social representations; (2) the role of emotions in the representational process; and (3) the constructive power of social representations. In the second part, I discuss the strengths and limitations to these key ideas in relation to cross-cultural and critical health work, drawing on social psychological critiques, anthropological perspectives on socio-cultural knowledge production and socio-cultural theories of emotion. Finally, I make a case for re-conceptualising Moscovici's hypothesis of cognitive polyphasia as cognitive-emotional polyphasia. I discuss the application of cognitive-emotional polyphasia as a conceptual-analytical framework for social representations work in Ghana.

CHAPTER THREE

THE THEORY OF SOCIAL REPRESENTATIONS: A FRAMEWORK FOR CROSS-CULTURAL AND CRITICAL HEALTH WORK

The theory of social representations was developed by Serge Moscovici in the 1960s as part of a broader intellectual goal for a social psychology of knowledge. Borrowing from and integrating the conceptual work of an eclectic group of seminal thinkers, including the sociology of Durkheim and Levy-Bruhl, the social psychology of Bartlett, the developmental psychology of Piaget and (much later) Vygotsky's socio-cultural approach, Moscovici had two primary aims for a social psychology of knowledge. First he sought to rehabilitate common sense, "grounded in our ordinary experience, everyday language and daily practices" (Moscovici, 2000:228) from the inferior status accorded it within post-war scientific discourse, and place this at the centre of social psychological enquiry (Moscovici,1998, 2000; Purkhardt, 1993). Second, he aimed to resocialize key theoretical terms in the dominant American tradition of social psychology of the time (Moscovici & Hewstone, 1983; Farr, 1993; Moscovici, 2000).

Key to this vision of a social psychology of knowledge was 'the primacy of representations', a notion Moscovici emphasised was associated with "the relationship between communication and knowledge, and the transformation of the content of knowledge" (2000: 233). The 'social' in social representations served an explicit theoretical purpose. It aimed to bridge the artificial gap between Durkheim's ([1898]1974). ; ([1912]1995) concepts of 'collective representations' and 'individual representations'. By "giving up the word 'collective'" (Moscovici, 1988: 219) for 'social' Moscovici aimed, firstly, to highlight the plurality and diversity of representations within groups. Secondly he aimed to demonstrate the creative power of representations. While Durkheim had focused on the coercive power of collective representations, Moscovici was interested in "representations that were always in the making, in the context of inter-relations and actions that were themselves in the making" (1988: 219). The creative process generated

through group and individual interaction was explicitly tied to “important phenomena in the modern world” (1988:219).

Communication played a key role in the dynamic creative process: it facilitated the convergence of individual thoughts and feelings and allowed ‘something individual to become something social’ (Moscovici, 1988:219). In Moscovici’s view, the social exchange and interaction process afforded by communication was as theoretically significant as individual and group contributions to the representational process.

These broad conceptual themes informed his earliest work, which focused on how the technical vocabulary of psychoanalysis became a part of popular 1960s French culture (Moscovici ([1961]1976); Farr, 1990). Moscovici examined the changes in content of common-sense thinking as psychoanalytic concepts diffused from professional psychiatry into the public sphere via two sections of the popular media: the Communist Press and the Catholic Press. He also examined how changing discourses framed by social representations of psychoanalyses changed social practices. Moscovici proposed a number of key, often conflicting, themes that underpin the theory of social representations.

3.1. KEY CONCEPTS WITHIN SOCIAL REPRESENTATIONS THEORY

Moscovici (1984, 1988, 2000) emphasised the genesis of social representations as a process concerned with rendering the unfamiliar familiar. In its broadest sense the unfamiliar referred to ‘any empirical other’ (Jovchelovitch, 2001:173) that emerged outside or within boundaries of culture, society and self (Moscovici, 1987; 2001). In its narrow sense, the unfamiliar was explicitly tied to products of modernity: the rapid changes and transformations generated by scientific and technological advances constituted the unfamiliar confronting contemporary (Western) societies (Moscovici,2000;2001). The process of familiarising the unfamiliar was dependent on two key “mechanisms of a *thought* process” (Moscovici, 1984:29, italics mine): anchoring and objectification.

Anchoring was a mechanism that strove “to *anchor* strange ideas, to reduce them to ordinary categories and images, to set them in a familiar context’ (p.29,emphasis in original). Anchoring constituted classifying and naming something new or strange. Moscovici viewed responses to the unfamiliar as largely emotional. He made two concurrent proposals. First, Moscovici (1984) argued that the unfamiliar “attracts and intrigues individuals and communities, while at the same time, it alarms them”(p.25). In this formulation responses were underpinned by emotional ambiguity or tension; a simultaneous process of drawing to and recoiling from the unfamiliar, of drawing “something foreign and disturbing that intrigues us into our particular system of categories” (p.29).

Second, Moscovici asserted that the unfamiliar evoked fear. Moscovici noted that things which are ‘unclassified and unnamed are alien, non-existent and at the same time threatening’ (1984:30). The inability to evaluate something or describe it to ourselves and to others sets up a resistance, which we seek to overcome by categorising or labelling with a familiar name. Anchoring, by facilitating classification and naming reduces the threat of the unfamiliar. In 1960s France psychoanalysis - a ‘medical treatment without medicine’ (1984:26) - seemed strange and paradoxical. However, people compared elements of the psychoanalytic process such as free association to the process and rules of Catholic confession. Moscovici (1984:26) argued that once the method of free association had been detached from its psychoanalytic theoretical origins and transposed to the religious context of “priests and penitents, of father confessors and contrite sinners”, it ceased to be “offensive and paradoxical” and assumed an ordinary, normal character.

Anchoring was mediated by cultural systems of thought and action: “any system of categories presupposes a theory which defines and specifies it and specifies its use”(Moscovici,1988:30-31). Furthermore, anchoring effected an emotional outcome by generating “a shifting of values and feelings”(p.26).

Objectification, like anchoring, served to familiarize or domesticate the unfamiliar. It was the process through which unfamiliar phenomena, or abstract ideas and concepts, were condensed

into what Moscovici(1984:38) referred to as a 'figurative nucleus' – "a complex of images that visibly reproduces a complex of ideas". Objectification reproduced the unfamiliar 'among the things we can see and touch and thus control' (Moscovici, 1984:29) or as Jovchelovitch (2001:172) succinctly describes, gave "novelty a concrete, almost "natural" face". Once abstract ideas or unfamiliar phenomena were linked to a figurative nucleus, this then joined other images circulating in the symbolic social environment and became a subject of communication, and a constituent of social practices. Objectification was strongly implicated in the construction of reality. Moscovici has argued that: "when an image linked to a word or idea becomes detached and is let loose in a society it is accepted as a reality" (Moscovici, 1984:39).

Objectification was mediated by cultural systems of thought, emotion and action: society conferred "figurative powers, according to its beliefs and to the pre-existing stock of images" (Moscovici, 1984: 39). Again findings from his seminal study, in Moscovici's view, lent validity to these ideas. He noted that central elements of psychoanalytic theory, such as Freud's emphasis on sexuality and libido, which were 'heavily charged with imagery', remained surprisingly abstract within French societal thought and practice. Moscovici argued that these elements evoked taboo subjects in 1960s French society and were thus excluded from the collective objectification of psychoanalysis, in order to maintain socio-psychological integrity (Moscovici, 1988; Gervais et al, 1999). Thus, figurative power was conferred to new ideas in two culturally mediated ways. First, if new ideas could be linked to pre-existing stock of images in the symbolic world and second, if they did not contravene threatening cultural taboos.

In summary, both anchoring and objectification were central to the genesis of social representations. Both were culturally mediated *thought* processes, which served to domesticate the unfamiliar. They constituted what Markova (1996) has referred to as 'cognitive globalising' processes: anchoring made "the world simpler and more manageable" by grouping complex events and objects into similar or equivalent categories, while objectification re-constructed a complex or abstract event "into something less differentiated, similar to something we already know, and into something conventional" (p187). Simultaneously, Moscovici conferred on both

processes a dynamic, evolving and creative power: both socio-cognitive processes lay at the core of the constructive power of social representations. He notes: “the representations we fabricate – of a scientific theory, a nation, an artefact, etc – are always the result of a constant effort to make usual and actual something which is unfamiliar or which gives us a feeling of unfamiliarity. And through them we overcome it and integrate it into our mental and physical world, which is thus enriched and transformed.” (1984:27).

I should note here, to set the context for later theoretical development, that the socio-cognitive processes of anchoring and objectification, have acknowledged theoretical roots in Bartlett’s (1932) notions of conventionalisation and reconstructive imagination, respectively (Moscovici, 1988; 2001). In Bartlett’s original formulation, both transcend cognition: they are explicitly embedded in the “setting of interest, excitement and emotion” which shape societal and individual biases to the unfamiliar emerging from outside and within socio-cultural boundaries (Bartlett, 1932: 255).

Alongside anchoring and objectification, Moscovici ([1961]1976) proposed a third concept - cognitive polyphasia. Cognitive polyphasia captured the dynamic nature of social communication and thought when groups and individuals were faced with the unfamiliar. Moscovici (in Moscovici and Duveen,2000) noted that, in constructing representations of psychoanalysis, people used different and even contradictory modes of thinking, in terms of the relationship and relevance of psychoanalysis to their practical, professional or ideological lives. He notes:

“Psychoanalysis was not just taken out of books and made public. There was a cultural fight, the Communists fighting against it, the Catholic Church subtly and consistently resisting it and constructing a rather different innocuous representation. [...] It was in the context of the study of communication that I started thinking about cultural fights – what Germans call Kulturkampf – something like ‘a battle of ideas’, and these take place in the field of communication in the formation of social representations.”(p.275)

These ‘cultural fights’ engendered by media propaganda against psychoanalysis set up “intellectual polemics and opposition between different modes of thinking”(p.229), which co-existed between and within social groups, as well as in individual minds. People used different modes of thinking depending on group membership, the social contexts and interactions in which they were engaged and so on. Moscovici described ‘cognitive polyphasia’ as a state engendered by “dynamic co-existence of distinct modalities of knowledge, corresponding to defined relationships between human beings and their surroundings” (1971/1976:186, translated by Gervais, 1997:53). He hypothesised that the concept would facilitate a way of analysing “the transformation – equilibrium and evolution – of these modalities of thought, of the relationships which are established between them, and of their adaptation” for productive life (Moscovici, 1961/1976:187; translated by Gervais, 1997:53).

Moscovici has asserted in his discussions of the conceptual importance of the hypothesis that: “cognitive polyphasia, the diversity of forms of thought, is the rule, not the exception”(2000:242). The hypothesis resonates with classical and contemporary social psychological perspectives on the dynamic, heterogeneous and often contradictory nature of socio-cultural knowledge production. It offers a more coherent framework for examining the constructive power of social representations, and the functions of anchoring and objectification within such a process. This is drawn on, in conjunction with Bartlett’s (1932) and Billig’s (1988; 1993) robust perspectives on socio-cultural knowledge production, for theoretical development later in the chapter.

In sum, three core themes underpin the phenomena of social representations, all or some of which guide theoretical and empirical work in the field.

1. Social representations constitute a particular kind of social knowledge produced by interacting, communicating groups and individuals, through anchoring and objectification, when novelty (the unfamiliar) meets the familiar.
2. The genesis of social representations is emotionally mediated. This process is interpreted broadly as one of ambiguity or tension towards the unfamiliar or narrowly as

one of collectivised fear of the unfamiliar. The emotional goal is to domesticate or tame the unfamiliar.

3. Social representations both constitute and construct social reality. Anchoring and objectification lie at the heart of the constructive process.

All three themes have ambiguous or contradictory elements at the levels of conceptual or methodological development that require critical reworking. In the next section, I work through each in turn, highlighting problematic areas and the way theorists have sought (successfully and unsuccessfully) to resolve them. The aim is to draw attention to the implications of the limitations outlined to cross-cultural and critical health work and to incorporate external theoretical perspectives where appropriate to strengthen the theory.

3.2 ADDRESSING LINES OF AMBIGUITY WITHIN SOCIAL REPRESENTATIONS THEORY

3.2.1. Making sense of the unfamiliar: the universalistic thesis versus the particularistic thesis

Two coexisting, conflicting lines of thought run through Moscovici's conceptualization of the phenomena of social representations; both stem from Moscovici's eclectic choices of theoretical ancestors.

On the one hand he has defined social representations in terms of practical socio-cultural knowledge, developed and transformed through dynamic social interactions and communicative practices. He draws on universal themes of language, communication and the relationships between individuals and society. These direct Moscovici's attention towards the more general aim of developing what he has referred to interchangeably as a 'social psychology of knowledge' or a 'psychosocial theory of thought and action'. Culture or traditional knowledge

features explicitly, as a substrate on which interacting groups and individuals draw social knowledge. Common sense is conceptualised in the universal sense as “folk knowledge...something that links society or individuals to their culture, their language, their familiar world”(Moscovici and Duveen, 2000:237). Moscovici notes:

“we have so many folk sciences, folk psychology, folk physics, folk medicine, folk magic and so on, all of which offer wonderful materials for a rich exploration of our culture, our ways of thinking and speaking, our modes of relating and behaving in groups. Nothing but the study of this kind of material can be the source of more general and complex theories which could explain the structure and genesis of our knowing and acting in common.”
(p.237)

A social psychology of knowledge, Moscovici argues, attempts to make sense of the way societies draw on a rich tapestry of heterogeneous folk knowledge in “constantly producing new representations to motivate action and make sense of human interactions that spring from people’s everyday problems”(Moscovici,1988:217). Within this context, social representations theory has a dual purpose: “first, it is a theory conceived to respond to specific questions concerning beliefs and social bonds, and to discover new phenomena. Secondly, it is also the basis of a social psychology of knowledge.”(Moscovici, 1998, p.280). The theoretical distinctiveness of social representations lies in this inter-relationship between language, common-sense thinking and communication and the construction of new meanings and ways of being by social actors. There is general agreement (Moscovici, 1988, 2000; Markova, 2000; Duveen, 1998; Jovchelovitch, 2002) that this line of thought is framed by Moscovici’s alignment with the theoretical ideas of Levy-Bruhl and Vygotsky, both of whom proposed what Markova (2000) has referred to as a ‘discontinuous approach’ to socio-cultural development. Less is made of similar intersections with Bartlett’s (1932) social psychology which provided the theoretical context for the notions of anchoring and objectification. Fundamentally, the discontinuous approach views culture and the individual mind as dynamic and interdependent; both are open to qualitative transformations and co-construct these transformations.

On the other hand, Moscovici has described social representations as historically specific modern phenomena, developed in a consensual world of lay people, through reciprocal, though unequal interactions with a reified world of scientists and other technical experts who shape (Western) modernity. A historically specific task is set for social psychological enquiry. Moscovici (2000;2001) juxtaposes the task of anthropology with that of social psychology, stressing that while anthropology is concerned with progression of common sense to scientific or abstract thought - a problematic misrepresentation of the discipline as prominent theorists such as (Horton, 1993) would argue - social psychology *has to be* concerned with the opposite process, the progression of abstract scientific ideas into common sense thinking. He notes:

“What remains is our version of the problem, which few people have tried to tackle and which seems to me to be specific to social psychology. It consists of knowing how science, by spreading throughout society, turns into common knowledge or lay knowledge: in short, how science manages to become part of our cultural heritage, of our thinking, of our language, and daily practices”(2000:10)

Within this context, social representations are a form of “collective ideation in conditions of modernity”(in Duveen,1998:467): “the equivalent, in our [modern] society, of myths and belief systems in traditional societies...the contemporary version of common sense’ (Moscovici, 1981:181, in Wagner et al, 2000:303). The theoretical distinctiveness of social representations lies in their inextricable association with conditions and products of (Western) modernity. Moscovici asserts we are living in an ‘era of social representations’ (1982). This implies, as Duveen (1998) notes that “under other conditions of social life the form of collective ideation may also be different”(p.467). Markova (2000) notes that this line of thought draws on the theoretical ideas of Durkheim and Piaget who propose a “continuous approach” to socio-cultural development. This “static pre-dialectical” approach fails to capture the interdependence and co-construction of culture and psyche (Markova, 2000): psychological and cultural development are conceptualised in terms of hierarchical displacement.

Following Billig (1988; 1993), who has noted this problematic conflict within Moscovici’s writings and its explicit and implicit impact on theoretical development in the field, I term the

discontinuous line of argument the universalistic thesis to reflect its prioritization of social representations as phenomena “presumed to be found in all forms of society and in all historical epochs” (Billig, 1993:48) and the continuous argument the particularistic thesis to reflect its prioritization of the phenomena as “particular to some social arrangements but not all” (Billig, 1993:48).

At the heart of these conflicting lines of thought lie two theoretical dilemmas. First, the nature and source of the unfamiliar around which social representations emerge. Second, the extent to which the production of heterogeneous socio-cultural knowledge is a modern phenomenon.

The source(s) of the unfamiliar

There is general consensus within the field that social representations emerge through the familiarization of the unfamiliar. As Jodelet (1984:367) notes anchoring and objectification “illuminate an important property of knowledge: the integration of novelty, which appears as a basic function of social representations.” Within the universalistic thesis, the unfamiliar referred to ‘any empirical other’ (Jovchelovitch, 2001), that emerged from outside and within the boundaries of culture, society and self. Moscovici (1987) notes:

“What I have in mind with the “non-familiar” is not something that is unknown or invisible, something completely cut off from the world, social relations, or even language. Something is unfamiliar to me just because it is part of my world, my relations, and my language, but at the same time has some feature about it that escapes me. A paradoxical way of expressing it would be that I am visualising something because I cannot yet visualise it clearly, either because it has not yet materialised or because I have had no direct contact with it.” (p.519)

Responses to the unfamiliar were culturally mediated, and thus open to cultural specificities. Echoing Bartlett (1932), Moscovici (1984:26) maintained that “the images, ideas and language shared by a given group always seem to dictate the initial direction and expedient by which the group comes to terms with the unfamiliar”. Furthermore, Moscovici (2000) underscored the creative agency of social groups and individuals in producing the unfamiliar. In his view, new

ideas and 'philosophies' could be introduced into society by any variety of minority groups (constituting reified worlds) and through 'persuasive' communicative practices change old ways of thinking and social practices within broader lay society.

Within the particularistic thesis a narrower definition of the unfamiliar is offered, which limits the unfamiliar to the novelty of products of Western modernity and in particular science. Moscovici (1988:215) notes: "most knowledge and ideas circulating in the mass media and by word of mouth are actually of more or less scientific origin". Simultaneously, the source of the unfamiliar becomes exclusively external: science constitutes the lone 'reified' world which produces unfamiliar concepts. Moscovici separates the world of science and scientific production from the consensual lay world and lay productivity. Common sense knowledge, which he sought to restore to the centre of socio-cultural knowledge production, is given a peripheral role. Moscovici notes, "in societies like ours, there are no longer myths, nor even common sense in the correct meaning of these terms" (1984, p.953). Common sense is 'science made common' (1984:29), its very nature transformed by scientific and technical terms seeping into lay discourse via the mass media and to a lesser extent inter-individual communication (Moscovici, 1984). When common sense is granted a central role in social interaction, communication and productivity, it appears intricately and exclusively linked to familiarising unfamiliar scientific ideas. Moscovici coins the notion of 'folk postsciences' for example to highlight the way common sense "enlarge science by transforming it into a new common sense" (2001:12).

The conflict surrounding the source(s) and nature of the unfamiliar has received some critical attention within and outside the field. Critics argue that while Moscovici's seminal work was concerned with transformation of psychoanalysis into common sense versions within the French public sphere the theoretical distinctiveness of the theory cannot lie exclusively in this meeting of science and common sense.

Gervais (1997) notes that while the theory in its particularistic formulation provides a useful way of examining the relationships between structural societal changes and psychological functioning, the over-emphasis placed on one particular dimension of modernity (science) denies an examination of other dimensions of modernity which play a role in the constructions and transformation of contemporary consciousness.

Billig (1988,1993), Purkhardt (1993) and von Cranach (1998) move beyond this, centering their argument on the problematic overemphasis on science and other products of modernity, as well as the neglect of the roles of tradition and culture in contemporary social knowledge production. As Purkhardt (1993) notes: "Within the theory it is science that produces unfamiliar concepts which provide the impetus for transformations in social representations. However discoveries and innovations are not peculiar to the universe of science"(p.40). Purkhardt (1993) draws attention to social representations work on madness (Jodelet,1991; De Rosa, 1987), and on health and illness (Herzlich and Pierret, 1987), which reveal "the persistence and re-emergence of beliefs that are embedded in the history of our culture"(p.40).

Ultimately, critics assert that the unfamiliar has to be explicitly theorised as a phenomenon that emerges from within as well as outside socio-cultural boundaries. Cranach (1998) argues that the familiar co-exists with the unfamiliar, processing between familiar and unfamiliar is bi-directional, and 'the familiar' as he notes "can become suddenly alien" (p.38). He argues that instead of rejecting the importance of familiar knowledge (ie traditional common sense) in contemporary knowledge production for an exclusive focus on unfamiliar knowledge (ie originating from scientific discourse), theorists should be concerned with how 'a dynamic, pluralistic, multilevel society' (p.38) simultaneously utilises the familiar and unfamiliar.

This multi-level approach is endorsed within Billig's (1988,1993) rhetorical psychology approach. Billig (1993) draws on Bartlett's (1932) empirically informed assertion that socio-cultural groups possess the socio-psychological ability of 'turning their schemas round' to make sense of the familiar and unfamiliar. At the heart of this process, Billig (1993:46) notes, is "the argumentative aspects of communication". Thinking societies and

individuals, Billig argues, accept and reject, criticise and justify, their social worlds when faced with the unfamiliar. The unfamiliar is not ‘painlessly anchored’ into familiar categories of thought; ‘ideological dilemmas’ often ensue on how the unfamiliar can be anchored. Public and individual internal “debate about the meanings of the categories into which the unfamiliar will be categorised” (1993:50) highlights the way the process of anchoring or categorization is intrinsically bound to the process of particularisation: “the very faculty which enables us to categorize, also enables us to criticize categorisations by suggesting particularisations or alternative categorizations” (1993:50). The crucial link between Billig’s notions of ‘argumentation’ and ‘ideological dilemmas’, Bartlett’s notion of ‘turning schemas around’, and Cranach’s argument, is that through the dialectic relationship between “particularisation and categorization and between justification and criticism” the unfamiliar inherent in mundane, everyday individual thinking and action can be evoked. Moscovici’s elaborations on the hypothesis of cognitive polyphasia strongly resonate with these key ideas. While they address the contemporary Western context, they are applicable to – and central to understanding – socio-cultural knowledge production in the contemporary African context, as will be demonstrated shortly.

The production of heterogeneous socio-cultural knowledge

The ‘social’ in social representations has been conceptualised in two ways within Moscovici’s work. First, as a social psychological bridge constructing: “a viable integration of the psychological with cultural” (Purkhardt, 1993:23). The emphasis here is on the way individuals and social groups make sense of and transform their social worlds; ‘social’ captures the dynamic interface between “the power of society and the agency of individuals” (Gervais et al, 1999: 422). Second, the ‘social’ is used to capture structural societal changes. The processes through which social representations emerge are, as highlighted earlier, inextricably linked to “important phenomena in the modern world.” (Moscovici, 1988:219). While both interpretations co-exist in Moscovici’s writings, the latter has often taken precedence in theoretical development.

Moscovici has suggested that social representations are the form of collective ideation in conditions of modernity. He asserts that Durkheim's concept of a collective representation was appropriate in understanding the thinking of people in pre-modern societies. For Durkheim, society appeared to be a system of relations generating collectively shared beliefs, norms, languages and rituals; these collective representations were common to all members of a social group, transmitted from generation to generation (thus pre-existing them and surviving them), and imposed on and constrained individual agency (Horton, 1993). Moscovici (1984) argues that in most modern societies, however, the nature of knowledge has changed. Myth and belief, which constrained social groups, have given way to new forms of knowledge emerging from the worlds of science, technology and mass communication. These render representations and the groups producing them, less bound by cultural mores, more dynamic and continually changing. These distinct changes warranted the shift from collective (denoting static and homogenous cultural states) to social (denoting fluid and heterogeneous cultural states).

The extent to which theorists endorse Moscovici's view of social representations as distinctly tied to (Western) modernity varies. For the sake of simplicity I discuss the dominant views under two categories: 'weak' and 'strong' endorsement. Elaborations made by Duveen (1998) and Jovchelovitch (2001) typify the range of views expressed under weak and strong category, respectively, and are drawn on in illustration.

Duveen (1998) argues that Moscovici's particularistic formulation is concerned fundamentally with 'legitimation of knowledge'. He warns that while it would be mistaken to describe pre-modern – or traditional – societies as homogenous, the legitimation of knowledge and beliefs within such (European) societies was regulated by centralized institutions of church and state, which stood at "the apex of the hierarchy of power" (p.468). In modern societies however, these centralised institutions have given way to "more diverse centres of power, which claim authority and legitimacy" (p.468), thus the legitimation of knowledge and beliefs 'is no longer guaranteed by divine intervention, but becomes, rather, part of a more complex and contested social dynamic in which representations of different groups in society seek to establish a

hegemony' (p. 468). Duveen interprets Moscovici's particularistic formulation in terms of the way collective life in contemporary societies adapts to the decentering of the legitimation of heterogeneous knowledge and beliefs.

Jovchelovitch (2001), in contrast to Duveen (1998), proposes a clear demarcation between the traditionalised and 'de-traditionalised' public spheres. Jovchelovitch argues that the principles of traditionalized public spheres stand in clear opposition to those of de-traditionalised societies at three key levels: in terms of the nature of social relationships, of socio-cultural knowledge, and of collective response to the unfamiliar. Social relationships in the traditional public sphere, Jovchelovitch argues, rely on the authority of a few people. This group "define(s) the legitimacy of worldviews", protect the sacred within culture through imposed secrecy and deepen social inequalities by giving voice to some members of society and silencing others. The dominant social knowledge produced within the traditional public sphere, in Jovchelovitch's view, constitutes collective representations. Drawing heavily on Durkheim's tripartite concept of collective representations, Jovchelovitch notes that traditional public spheres draw on everyday knowledge that binds all members and confers solidarity, is ritualistic and thus "resistant to experience, argumentation, and logical proof", and has minimal possibilities for change. Finally, Jovchelovitch notes that the very nature of collective representations - with its emotionally powerful social bond that "reproduces and perpetuates traditional ways of life" - is designed to resist "novelty and the transformations it may entail" (p.169). Jovchelovitch contrasts these key dynamics of the traditional public sphere with the de-traditionalised public sphere within which "both strong elements of tradition and strong challenge to tradition exist side by side. These diverse tendencies meet, clash and are constantly negotiated in the public sphere" (p.170). The dynamic critique and negotiation of social knowledge and identities characterising social relationships in this sphere, opens it up to the novel. For Jovchelovitch these key distinctions: "binds the theory of social representations to a theory of modernity, insofar as the distinctive phenomenon it theorizes - social representations - are bound to a modern, detraditionalized, public sphere." (p.174).

Jovchelovitch's ideas are buttressed within an emerging group of studies, which draw on Moscovici's hypothesis of cognitive polyphasia for analytic work. In these studies cognitive polyphasia take on a distinctly modern character. Gervais (1997) in her theoretical discussion notes that cognitive polyphasic processes occur when "people living in modern societies... having to face and to resolve ever more complex social and natural problems... would not only have to learn new 'languages' but also develop varied mental apparatuses"(p.54). For Wagner and colleagues (1999a) cognitive polyphasic processes arise from the constant 'flux and transformations' of 'the culture of contemporary society': "the transition from the traditional to the modern is also a transition from collective representations to social representations, from a relatively static order of unquestioned beliefs, to complex forms of different, even competing beliefs" (p.4). Wagner and colleagues (1999a,2000) apply this conceptual framework to a study of social representations of madness in India.

There are two issues at stake for both theoretical camps. The first relates to the core question underpinning the development of the theory, which Jovchelovitch (2001:174) identifies: "what happens with knowledge – any form of knowledge – as it moves context and permeates the lives of different social groups and is reworked by a variety of modes of communication and interaction"? On this issue both camps are in agreement: social representations emerge through 'argumentation' or cognitive polyphasia; a process of challenge and critique of socio-cultural knowledge between heterogeneous social groups. The second issue concerns the extent to which this socio-cultural process can be labelled as distinctly modern. In the weak endorsement offered by Duveen social representations may be tied to complex contemporary social relationships, but are not conferred an exclusively modern character. There is room for the possibility that social representations, as processes and products of social legitimation, embody universal socio-psychological phenomena. Rhetorical thought and action, as Billig (1993) argues, and anthropological work demonstrates (Apffel-Marglin, 1996; Rekdal, 1999) is not restricted solely to contemporary social arrangements. In the more popular strong endorsement offered by Jovchelovitch and others, no such possibility exists.

In contrast to heated debates on the conflict surrounding the nature of the unfamiliar, the implications of tying social representations theory to a theory of modernity has received little attention. At present, the ideas proposed by Jovchelovitch and others, appear to dominate conceptual development. More crucially they are applied to work in contemporary non-western contexts (Wagner et al, 1999, 2000). This framework, which draws on a tradition-modernity dichotomy, has problematic implications for social representations work in contemporary non-western settings. I revisit alternative cultural work, introduced in Chapter Two, to outline the key problems.

In Chapter Two I drew attention to discussions on cultural resistance and cultural openness to biomedicine offered by the dominant and alternative cultural fields, respectively. Within the alternative cultural field, a large number of studies attribute medical pluralism to cultural 'openness' to alien cultural health practices and professional systems. This phenomenon has been observed in Islamic health practices (Twumasi,1981; Bierlich, 1995, 2000) and mental health discourses (Jahoda, 1961) in Ghana; exchange and adaptation of medical concepts and practices among the Pokot of Kenya (Nyamwaya, 1987); continental migration and traditional health practice among Iraqw of northern Tanzania (Rekdal, 1999) and social practices of the Lele, a Central African ethnic group (Douglas, 1975). It is particularly prominent in sociological, anthropological and theological discussions on the nature and functions of religious pluralism in Africa (Nukunya, 1992; Clarke, 1986; Opoku, 1978; Mbiti, 1969; Horton,1993). The roots of cultural openness, many argue, precede western contact.

Rekdal (1999) presents a useful discussion on the role of cultural openness in the production of heterogeneous lay health knowledge and practices. Drawing on his anthropological work with the Iraqw of Tanzania, Rekdal (1999) asserts that two socio-cultural processes facilitated the acceptance of biomedical health services by Iraqw society.

First, Iraqw socio-cultural emphasis on the healing power of the culturally distant; an attribution which implied Iraqw "*openness to the unfamiliar, the alien, the unknown*" (p458,

italics mine). This openness to the unknown was inextricably linked to intra-cultural tensions. On the one hand there was a tendency for local healers to challenge local political authority in their quest to expand professional expertise. On the other hand everyday social relationships were underpinned by emotional tensions and conflicted alliances based on a reflexive awareness that “the intimacy so highly valued between neighbours renders them vulnerable to each other”(p.468).

The second facilitating process was the flexibility and adaptability of Iraqw healers towards alien forms of healing – a process underpinned by their historical ability and power to ‘invent tradition’ in order to move with changing times and socio-cultural demands. Rekdal challenges the dominant views of colonial officials, first, that biomedicine was readily accepted by Iraqw society because of its superior clinical achievements and, second, that biomedical acceptance would lead to abandonment of indigenous medical systems. He notes: “Biomedicine as a way of understanding and approaching illness was certainly new to the Iraqw; *what was not new was the incorporation of an alien way of looking at and acting on illness*”(p.472, italics mine). Rekdal speculates that for the Iraqw and communities elsewhere on the continent, where biomedicine and ethnomedicine co-exist and are drawn on interchangeably as legitimate healthcare resources, people may accept biomedicine because they “believe, in and “cling to” their “native medicine”, with its emphasis on the healing power of the culturally distant” (p.473).

The work of Rekdal and others challenge the key assumptions underpinning Jovchelovitch’s (2001) strong endorsement of social representations as products of modernity. First, social relationships are characterised by co-existence with, as well as dissent towards authority. Second, cultural knowledge is not static or constraining. Finally culture is open to novelty: this openness is underpinned by intra-cultural emotional tensions. Put differently, the characteristics outlined as core to the de-traditional sphere emerge as core characteristics for the ‘traditional’ societies studied by Rekdal and others. It is important, therefore, that social representations

work carried out in the contemporary African context, takes an explicit position against the alignment of social representations theory with a theory of modernity.

Fundamentally the particularistic thesis, which proposes that social representations operate solely within the confines of a 'post-scientific common sense' or a 'de-traditionalised public sphere' poses conceptual and empirical problems for work in societies like Ghana, which are labelled 'traditional' in the Durkheimian sense. At worst, the thesis seems to suggest that such societies, which often exist without the key dimensions of (Western) modernity (science, technology, mass media, literacy etc) deemed central to pluralism and social legitimation, will lack the ability to construct social representations. At best, it confers a socio-cognitive evolutionary framework for methodological work. Since the impetus for change within the particularistic thesis is imposed by the unfamiliar other, and the unfamiliar other is limited to science, technology and other products of Western modernity, the genesis of social representations in these social contexts will constitute the anchoring and objectification of products of western modernity into traditional thought systems and social practices. This approach will inevitably ignore or misread the complex ways individual and groups within such societies produce and transform socio-cultural knowledge independent of – though not excluding – confrontation with novel ideas and practices of other cultures. The universalistic thesis, on the other hand, with its general principles for human thought, feeling and productivity, offers a more appropriate framework for conceptual and analytic work.

3.2.2. Emotions and social representations: moving beyond the 'fear of the unfamiliar' hypothesis

The role of emotions in the social representational process has received some attention and conceptual treatment within the field. Anchoring and objectification, as described earlier were cognitive globalising processes mediated by 'fear of the unfamiliar'. Broadly, Moscovici (1987,1988,2000) has made frequent references to the emotional character of social representations. A number of theorists have argued that the exclusion of emotions from the

theoretical framework undermines full understanding of knowledge production and use (Flick, 1998; Joffe, 1991; Markova & Wilkie, 1987). In their work on AIDS, Joffe (1993;1995;1999) and Markova and Wilkie (1987) have highlighted the emotional underpinnings of discourses and inter-group attitudes, as has Jodelet's (1991) classic work on rural French discursive practices around madness. Duveen (2001) has discussed the importance of the emotions in identity construction. These discussions are important because they resonate with broader social psychological perspectives, which demonstrate the centrality of emotions to psychological and socio-cultural life. More crucially, they open up the social representations framework to critical examination of chronic illness experiences.

In Chapter Two, I presented empirical discussions on the ways emotions underpinned biographical disruption and illness action, as well as relationships in the life-worlds and social worlds of people with chronic illness (Crossley, 2000; Krause, 2003; Ohaeri et al, 1995,1998; Bury, 1997; Radley, 1994; Charmaz, 1983, 1991; Nettleton, 1995). A study of diabetes experiences and illness action would therefore be theoretically inadequate without a systematic examination of the role of emotions.

Despite proposals for incorporating the role of emotions in social representations framework, this is an area that remains considerably underdeveloped. This, in my view, is fundamentally attributable to two interacting problems. First, there is a recurrent taken-for-granted assertion within major theoretical texts that social representations emerge from a 'fear of the unfamiliar' and function to 'domesticate' or 'tame' the unfamiliar' (cf.Wagner et al,1999b). This view is implicitly - and problematically - universalised. Secondly, social representations work has generally focused on collective level phenomena. Thus with few exceptions - e.g Jodelet, 1991; Joffe, 1993,1999, who focus on the role of emotions at group level - discussions on the role of emotions in the social representations process has remained at a macro-social level. The role of emotions at the subjective and inter-subjective level is ignored.

The 'fear of the unfamiliar' hypothesis has faced external criticism. Jahoda (1988) has argued that no relevant evidence has been offered by theorists to substantiate the claim that the unfamiliar is threatening and has to be tamed. He offers that curiosity motivation or attraction to novelty could just as easily form the basis for the development of social representations. A recent critical review of Moscovici's seminal work, supports Jahoda's critique. Gervais and colleagues (1999), draw attention to 'theoretical absences' in Moscovici's seminal work, which led to unnecessary overemphasis on fear as a motivation underpinning objectification of psychoanalytic concepts. In the study, they note, Moscovici gave undue importance to Freud's peripheral concept of libido, centering his reading of psychoanalysis around this concept, rather than the more pertinent notion of "defensive conflict". The non-objectification of 'libido' within French society was due simply to the fact that it was a peripheral notion within psychoanalytic theory and thus less widely accessed. Gervais and colleagues note that a different theoretical outcome may have arisen had Moscovici examined lay contents of psychoanalysis in juxtaposition with a broader more critical reading of psychoanalytic theory. They note:

"The explanation for the apparent gap between Freud's own ideas and the lay theories that derived from them would lose some of its power...since the gap itself would disappear. There would be little justification for Moscovici to assert that the libido was absent from the social representations uncovered because of some deep psychic resistance to psychoanalysis or because of the cultural taboo it breaks."(pp431-432)

This central flaw in the development of the hypothesis casts serious doubts on its theoretical and ecological validity as a prerequisite for the social representational process.

A body of African-based anthropological work simultaneously challenge the fear of the unfamiliar hypothesis and underscore the need for critical engagement in the role of emotions at different levels of social organisation. Rekdal's (1999) work, again, presents important insights. Rekdal gives an account of inter-ethnic relations between Iraqw and Maanda Uwa: on the one hand the Maanda Uwa are held in disdain by the Iraqw because of their 'unclean' customs. On the other hand the Maanda Uwa are among the most widely respected and widely used healers,

because the Maanda Uwa provided the 'apical ancestor' of the clan possessing the greatest ritual expertise and power among the Iraqw. Rekdal notes: "contempt and respect thus seem to go hand in hand in Iraqw stereotypes of the Maanda Uwa" (p.469).

Rekdal discusses two ways in which emotional responses towards the culturally distant have been conceptualised within anthropological discourse as a framework for making sense of the emotionally ambivalent relationship between the two ethnic groups. He notes that the first view often called on to explain why Europeans looked down on Africans in the early centuries of contact, revolved round ethnocentrism, distance and antagonism. The second view has conceptualised cross-cultural relations as processes framed by the supernatural and mythical power of distance and the 'sacred' and 'magico-religious' attributes of the stranger.

Rekdal argues that these divergent perspectives are not necessarily contradictory; they are mutually influential. Cultural distance between the Iraqw and Maanda Uwa may generate "ethnic contrast, conflict, and contempt", but "the power inherent in the ambiguity of the culturally distant" is simultaneously drawn on to expand and strengthen local healing and ritual expertise (p.470). Thus, despite Iraqw "expressions of disdain...the perceived cultural distance to the Maanda Uwa means that they are associated with the "supernatural, mythical and powerful"" (p. 470). This culturally mediated process of drawing on a co-existence (and often) opposing emotions in dealing with the unfamiliar does not only apply to cross-cultural relations, but also to intra-cultural relations. As discussed earlier, daily social relations and practices among the Iraqw are underpinned by a fundamental emotional paradox of intense loyalty and mistrust.

The key findings from Rekdal's work have been uncovered in other anthropological work. Masquelier's (1994) Niger-based study shows how Bori healers and mediums appropriate and rework the spiritual powers of their oppressors and adversaries to their professional advantage. Boyer's (1986) cognitive anthropological study of the Fang ethnic group of Cameroon and Gabon, highlights the way discourses on external supernatural forces and traditional religious healers – and social mediators and interpreters of the supernatural - draw simultaneously on fear

and reverence. From anthropological studies and theological discussions on religion, crucial evidence merges on the unpredictability of cultural outcomes generated by familiarisation of the unfamiliar (Mbiti, 1969; Clarke, 1986; Horton, 1993). For some societies, the incorporation of the unfamiliar into the familiar facilitates transformation or reinvention of cultural and groups identities and agency. For others, the very process of opening up the familiar is aimed at reaffirming and fortifying cultural and group boundaries.

Put together these findings point to three conclusions. First, the unfamiliar does not necessarily have to constitute a threat: it can for some cultures be desirable and be actively courted, as Jahoda (1988) suggests. Secondly, the outcome cannot be fixed: openness to the unfamiliar can be underpinned by a variety of pre-meditated socio-cultural goals or lead to a variety of post-hoc goals. Finally, and crucially, the familiarisation process seems to be underpinned by emotional tension or ambiguities: this suggests a co-existence of a variety of emotions drawn on interchangeably or in conflicting ways in cultural life. Significantly, this underscores the theoretical importance of Moscovici's initial emphasis on 'emotional tension' as a mediating dynamic in the anchoring process.

These findings are important, because they link to 'mild functionalist' perspectives on emotions which conceptualise the role of culture in emotional life as dynamic and open (Keltner & Haidt, 2000).. These perspectives simultaneously describe the ways in which culture shapes emotional life and legitimise social and individual agency and thus move beyond the traditional functionalist assumption that culture as conservative or constraining force. However, these perspectives are fundamentally limited to a cultural level of analysis: they alert theorists to the possibilities of complex intra-cultural processes, but do not provide an analytical framework to examine these processes. Diabetes experiences are shaped by complex subjective and intersubjective processes, which are embedded in but transcend the structural and cultural context, as Chapters One and Two highlighted.

Socio-cultural theories of emotion: exploring the role of emotions in psychological and social life

Three approaches within current socio-cultural perspectives on emotions provide an appropriate integrative framework for examining the role of emotions at a multi-dimensional level: post-structuralist, phenomenological and psychodynamic.

Poststructuralist perspectives are concerned with the discursive dimensions of emotional experiences. The central focus is the constructive role of language in the production, negotiation and transformation of subjectivity. Discourses are not merely reflections or descriptions of subjective and social phenomena: they actively construct these phenomena (Harre,1986; Abu-Lughod & Lutz,1990; Jackson,1993).

The discursive approaches are aligned with phenomenological perspectives, which focus on *lived* experiences. Within the phenomenological approach, lived experiences are viewed as historically-situated and socially-mediated (Crossley,1998). However there is a tendency to overemphasise the 'true' or 'authentic' self (see also Chapter Four, section 4.1.1). Post-structuralist perspectives adopt the strengths of the phenomenological approach, but reject the notion of 'true' or 'false' selves that exist independently of society and culture (Lupton,1998). Instead, they examine the ways lived experiences are transformed through discourse and socio-cultural practices. However, the discursive approach also has noted shortcomings. Studies have been accused of 'discourse determinism'. It is argued that while studies acknowledge the physical underpinnings of emotions, they are treated as incidental to the linguistic practices used to define and display emotional states (Lupton, 1998). The upshot is a dominant view of the social actor as overly rational, drawing consciously and purposefully on emotions to motivate action and highly dependent on language to articulate and justify feelings to self and others.

Psychodynamic perspectives provide a theoretical bridge between poststructuralist and phenomenological perspectives to facilitate a fuller examination of emotional life. Theorists acknowledge that as individuals experience their worlds through interactions with others,

emotional experiences and subjectivity are inextricably linked to discursive practices. However, the traditional emphasis within psychodynamic theory on 'unconscious processes' 'inner conflict' and emotional ambivalence moves psychodynamic theory beyond an overly rational and discourse deterministic treatment of emotional life. By granting legitimacy to unconscious processes, theorists highlight the ways in which emotions often escape conscious identification even as they shape human action; and how the need to express emotions or feelings to others can be undermined by the inadequacies of language and discourse even as meaning is enhanced through physical gestures (Hollway, 1984). The focus on inner conflict and emotional tensions demonstrate the contradictory dimensions of subjectivity: individuals actively and simultaneously give in to and resist personal and social objectives. Henriques et al (in Lupton, 1998) assert: "psychoanalysis gives space to our fundamental irrationality: the extent to which will or agency is constantly subverted to desire, and the extent to which we behave and experience ourselves in ways which are often contradictory" (1984:205).

Critical health theorists have drawn on psychodynamic ideas, such as 'projection', to understand the ways in which the chronically ill undermine their own health, as well as social and medical relationships (Crossley, 2000; Mayer, 1994). Psychodynamic theories have been useful to broader social psychological theorisation of individual and group resistance to social norms and expectations (Hepburn, 2003; Joffe, 1999). These are important conceptual guides. However, the psychodynamic overemphasis on 'irrationality' has fundamental flaws, in my view. On the one hand it pathologises everyday lived experiences and social relationships to too great an extent. The empirically evasive 'unconscious', within which the inherent irrationality of subjectivity is embedded, is viewed as potentially disruptive to psychological life. On the other hand, psychoanalytic theory neglects the role of cultural norms in shaping what constitutes rationality and irrationality. Anthropological work discussed earlier suggest, that not only do some societies, groups and individuals live with, accept and negotiate emotional tensions, but also that emotional tensions and ambiguities may play a critical role in the rational organisation of their everyday life. It is perhaps more important to adopt the broader view that while lived

experiences are underpinned by emotional conflicts and ambiguities, these do not always produce destructive irrational outcomes.

3.2.3. The (re) constructive power of social representations

Theorists assert that social representations are not interpretations or reflections of social reality, but are constitutive of reality: social representations 'create reality' (Gervais, 1997:47). Social representations theory adopts a constructivist position, rather like that adopted within contemporary cultural psychology, which is based on the premise that culture informs and complements psychological processes which in turn generate and transform culture (Shweder, 1991).

The nature and scope of social construction has received considerable theoretical attention within the field. Duveen (1997) notes that construction within the theory refers, not only to the process through which meanings are produced through active engagement but also - and more crucially - to the process through 'which new forms of understanding are generated' (p.466). The theory of social representations therefore distinguishes representations constructed as part of a stable and 'fixed' pattern of meaning, from representations constructed as a process through which new meanings are created and projected into the social world. They are to paraphrase Moscovici: "representations that [are] always in the making, in the context of inter-relations and actions that [are] themselves in the making" (1988, p.219).

Gervais (1997) distinguishes between a 'weak' form of construction and a 'strong' form of construction. She notes that to take a purely epistemological stance to the theory would be to take a 'weak' constructionist position, which is concerned only with the 'cognitive productions of historically situated people' (p.48). This would be erroneous as Moscovici's theoretical focus was concerned not only with epistemological processes but also with ontological realities.

The adoption of a 'strong' version of social constructionism, Gervais argues, prevents the theory from:

“lapsing into a non-dialectical conception of the relationship between what social actors do and what they think; between the world in which they live and the world which they represent and change. It ... allows us to understand why a social group converts its representations into reality” (p.48).

The ‘strong’ version of construction is endorsed by Purkhardt (1993), who draws on the ideas of Mead and Vygotsky. Purkhardt argues that the ‘social reality’ that provides the basis for, and is in turn reconstructed through, social representations has to be explicitly conceptualised as a dynamic ‘organism-environment-cultural system’. This system constitutes ‘a social being that is part of a physical and cultural context’, in interaction with other social beings, the physical environment and the culture that ‘exists in the emerging relationship between people and their environment’. Purkhardt foregrounds two important considerations. First, the interdependence between social reality and social individuals, underscores the theoretical significance of identity. The dynamics of social representations, in Purkhardt’s view, cannot be adequately captured without a systematic examination of the “the role of people’s identities in the social construction of reality” (p.75). Secondly, drawing on Billig’s rhetorical psychology, Purkhardt notes that the organism-environment-cultural system is inherently inconsistent, contradictory and antagonistic. Crucially it is the system’s inherent contradictions that give rise to the construction and reconstruction of identities and social realities. She notes: “discrepancies within an individual’s own social representations or identities will give rise to mutually antagonistic reactions. Alternatively, differences between individuals or groups will give rise to creative thought, novel actions, and the reconstruction of an object’s or person’s symbolic significance...through communication and interaction, a new social reality is established, transforming people’s social representations and reconstructing their identities.”

Despite these critical and prominent discussions, key absences in empirical work undermine full realization of the constructive dimensions of social representations. In a recent critique of social representations theory, the discursive psychologists Potter and Edwards (1999) capture the crux

of the problem. They note that by overemphasizing the 'perceptual-cognitive processes' of anchoring and objectification, social representations theorists adopt an overly socio-cognitive perspective, which undermines their social psychological project. For Potter and Edwards (1999) a key consequence of adopting socio-cognitive perspective has been the failure of theorists to explicitly theorize the action dimensions of social representations, even as theorists assert the centrality of action within the theory. They argue, rightly, that while social representations theorists draw on a wide array of social science methods including interviews, surveys and ethnographies which facilitate the analyses of discursive practice, theorists fail to "conceptualize the activities that are being done, and oriented to, when participants develop representations in their talk or texts" (p.450). Echoing Moscovici's emphasis on practical social knowledge, Potter and Edwards stress, that action – "the enormous range of practical, technical and interpersonal tasks that people perform, while living their relationships, doing their jobs, and engaging in varied cultural domains" (1998:448) – is central to everyday life and is therefore central to understanding everyday life.

Fundamentally, the neglect of action dimensions of social representations is empirical and not conceptual. Furthermore theorists admit to this shortcoming and its implications for applied theory (cf. Markova & Wilkie, 1987; Purkhardt, 1993, Wagner, 1998). What is required is explicit re-alignment of theoretical ideas with methodological and analytical work. Purkhardt's (1993) approach is particularly useful, since it ties together key strands of the theory in its universalistic characterisation. It focuses on the mutual interaction between individuals, their socio-cultural systems and physical environment and underscores emotionally mediated argumentation or cognitive polyphasia as a route through which new meanings and constructions emerge. The approach also legitimises the creative role of individuals and groups. Purkhardt's ideas are revisited shortly.

Summary

It is fair to conclude, from preceding discussion, that the three core themes underpinning social representations require conceptual expansion.

First, the focus on social representations as a particular kind of practical social knowledge produced when novelty (the unfamiliar) meets the familiar, is important. However, the conflict between the particular and universal nature of social representations needs to be resolved. Anthropological work presented here, suggest that the basis on which social representations is accorded a modern character, is flawed. It is more useful to view social representations as universal socio-psychological phenomena produced when individuals, society and culture are faced with the unfamiliar emerging from within and outside boundaries of self, society and culture.

Secondly, evidence suggest that theorists must move beyond the current emphasis on fear of the unfamiliar to examine a broader range of emotions and motivations underpinning socio-cultural and psychological life. This shift in focus will require explicit attention to the way social representations operates at different levels of social organization.

Finally, while social representations, as socio-psychological phenomena constitute and construct reality, it is problematic to view anchoring and objectification as sole mediators of this process. The practical and embodied dimensions of social representations require explicit empirical attention, in order to fully realize the socio-psychological functions of the phenomena.

Next I make a case for adopting cognitive polyphasia as a mediating concept to facilitate synthesis of these expanded themes in order to examine social representations of diabetes in Ghana.

3.3. COGNITIVE POLYPHASIA

In contrast to the concepts of anchoring and objectification, the hypothesis of cognitive polyphasia has received little attention in terms of systematic theorising within the field. To date discussions on the theoretical and analytical usefulness of the hypothesis have appeared in only six texts (Jodelet (1984), Gervais (1996), Gervais and Jovchelovitch (1998), Jovchelovitch (2000), Markova (2000) and Wagner et al (1999, 2000). Dominant interpretations as previous discussions highlighted have had their shortcomings. Other theorists have stressed the heterogeneity and contested nature of social knowledge broadly without explicit reference to cognitive polyphasia (Rose et al, 1995; Flick,1998; Cranach, 1998; Duveen, 1998; Purkhardt, 1993). This absence is attributable in part to absences within Moscovici's thesis. Moscovici's first proposal of the hypothesis appeared in one paragraph (Gervais, personal communication, 2002) of the French publication – and as yet un-translated - *La Psychanalyse, son image et son public* (Moscovici [1961]/1976). With the notable exception of a recent interview with Ivana Markova (Moscovici and Markova, 2000), subsequent discussions have appeared in almost footnote fashion (cf. Moscovici, 1987, 1998).

3.3.1. Cognitive polyphasia: key dimensions of the hypothesis

Moscovici's discussions on cognitive polyphasia have three key strands. The first concerns the socio-psychological nature of the phenomenon. Moscovici's earliest definition characterised cognitive polyphasia as a “dynamic co-existence of distinct modalities of knowledge, corresponding to defined relationships between human beings and their surroundings” (1971/1976:186; translated by Gervais, 1997:53). Moscovici asserts that cognitive polyphasia constitutes the (universal) norm for everyday social and individual thinking:

“the hypothesis of cognitive polyphasia assumes that our tendency to employ diverse and even opposite ways of thinking – such as scientific and religious, metaphorical and logical, and so on – is a normal state of affairs in ordinary life and communication. Consequently, the logical or cognitive unity of our mental life, which is taken for

granted by most psychologists, is a desideratum, not a fact.” (Moscovici and Duveen, 1998:245)

The emphasis placed on *co-existence* of diverse and opposing forms of thought is theoretically significant: distinct forms of thought may exist and be identified within any given socio-cultural context, but “it would be a risky generalization...to grant an exclusive privilege” (Moscovici, 2000:242) to one form of thought over others. Thus cognitive polyphasia, Moscovici(2000) argues, facilitates examination and understanding of qualitative “transformations of the systems of knowledge, of the forms of thought or discourses within the social context”(p.242). Simultaneously, such an examination elucidates the dynamic nature of subjective thought: cognitive polyphasia allows us to “understand how it is possible that, *not only in different, but also within* the same individuals, there coexist incompatible ways of thinking and representations.”(p.242, italics mine). These discussions draw on Moscovici’s broader engagement in the progressive socio-cultural ideas of Vygotsky and Bartlett.

The second strand concerns the emotional dimensions of cognitive polyphasia. Cognitive polyphasic processes, as noted in introduction, became evident when Moscovici examined communicative practices shaping anchoring and objectification of psychoanalysis in 1960s France. A central aspect of this process was public conflict or what he referred to as ‘cultural struggles’, a notion which resonates strongly with Billig’s (1988; 1993) rhetorical notion of ‘argumentation’ and Purkhardt’s (1993) discussion of a contradictory organism-environment-culture system. Like both theorists, Moscovici (2000) touches upon the emotional dimensions of argumentation. He asserts that when knowledge is shared or diffused in communicative practices there is a “conflict between new and old, between esoteric and exoteric ideas, which each party wants to win by strategies of persuasion.”(p.261) Moscovici maintains, drawing from the theoretical ideas of Berkeley that: “the communicating of ideas marked by words is not the chief and only end of language, as is commonly supposed. There are other ends, as the raising of some passion, the exciting to, or deterring from an action, the putting in mind in some particular disposition.”(p.261). In Moscovici’s view, therefore, persuasive communicative

strategies are put forward, contested and negotiated emotionally. Elsewhere he has made glancing reference to the embodied dimensions of communication (Moscovici, 2000). Together these bring his ideas closer in line with socio-cultural perspectives on emotional life.

The final strand focuses on how the hypothesis may be applied to theoretical and methodological work. Moscovici proposes that norms, context and goals shape the ways groups and individuals draw eclectically and, sometimes, in contradictory ways on heterogeneous socio-cultural knowledge. Moscovici's view of norms resonate strongly with critical cultural perspectives on epistemology (cf. Ladson-Billings, 1999; Pigg, 1996; Berger and White, 1999); in his view attention to norms facilitate understanding of the way culture constructs the parameters for everyday life, including the legitimation of rationality and irrationality (Moscovici, 2000). Context refers to the source and nature of the unfamiliar, which set in motion the processes of anchoring and objectification. Finally, Moscovici asserts that individual and social goals shape the use of knowledge: "knowing takes on a different shape according to the specific aim it strives to achieve" (2000:246). Crucially, the social representations process moves beyond fear and domestication of the unfamiliar. It is geared towards a variety of socio-psychological ends - ideological, scientific, emotional or existential.

3.3.2. Cognitive-emotional polyphasia: an expanded conceptual framework

Moscovici's ideas provide the starting point to construct a conceptual framework that allows compatible theoretical links to be drawn, not only between the absences within the field, but links with external ideas that resonate with the theory of social representations.

Cognitive polyphasia, argumentation and emotions

The explicit emphasis on a dynamic co-existence of distinct modalities and contents of knowledge, suggests that the application of cognitive polyphasia, has to move beyond its current focus on the interplay between traditional and contemporary knowledge. Modalities of knowledge, such as myth, belief, ideology and science, which are often treated as discrete categories and examined as functions of particular epochs, societies and groups, can be viewed

as co-existing and interchangeably drawn on within cultural, social and psychological life. The emphasis on norms simultaneously offers an epistemologically sensitive framework. This open framework, coupled with Moscovici's recognition of the emotional and embodied dimensions of argumentation, facilitates the incorporation of emotions as both knowledge modality and embodied phenomenon. Drawing on Moscovici's references to social representations as emotional phenomena and the proposal by Markova and Wilkie (1987) to re-conceptualise social representations as cognitive-emotional processes, I re-conceptualise cognitive polyphasia as cognitive-emotional polyphasia. In line with socio-cultural theories on emotion, I take the view that cognition and emotion are inextricably linked and mutually influential (Barbalet, 1998; Crossley, 1998; Lupton, 1998). There is general agreement within this field that emotions are not diametrically opposed to rational processes, but that emotion and reason are "mutually constitutive" (Jagger, 1989: 157). As Crossley (1998:21) asserts: "we do not just account for or organize emotions, we account for and organize things emotionally".

Drawing from these discussions and evidence from African-centred anthropological work, the psychodynamic emphasis on the role of emotional tensions in everyday life is fore-grounded within this framework, but the overemphasis on irrational and disruptive outcomes is rejected. As previous discussions highlighted, opposing emotions may evoke cultural, social and psychological conflict with disruptive and irrational consequences within some contexts; yet within other contexts oppositional elements may constitute the fundamental basis for rational organisation and creative construction of everyday life. Ultimately, these contrasting functions cannot be taken for granted and have to be subjected to empirical analysis.

The dynamic organism-environment-culture system: social representations, identities and the construction of reality

Moscovici has consistently placed emphasis on the shifting nature of social representations at different levels of social organisation. He notes:

“There is a world of difference between representations envisaged at the person-to person level and at the level of the relations between individuals and group, or at the level of a society’s common consciousness. At each level, representations have a completely different meaning. The phenomena are related but different.” (1998: 228)

This multi-level view of social representations is taken up by other theorists (cf. Duveen & Lloyd, 1990; Purkardt, 1993). However, there has been a tendency within the field to focus on collective level phenomena with comparative neglect of the role of groups and individuals in the social representations process. The adoption of cognitive-emotional polyphasia as a framework addresses this critical empirical absence. In its original formulation cognitive polyphasia captures group and individuals thinking and action, and emphasises group and individual agency. This explicit focus on group and individual processes and its implicit consequences for examining the role of identity is incorporated into the expanded framework. Cognitive-emotional polyphasia, as simultaneously embodied and discursive processes, facilitate the heterogeneous nature of knowledge, as well as the complex groups and individuals who construct and transform knowledge. Purkhardt’s (1993) ideas are particularly useful here: she foregrounds the interrelationship between social representations and identities in the construction and transformation of the dynamic organism-environment-culture system. For Purkhardt the unfamiliar contexts within which social representations emerge are inextricably linked to the dynamic organism-environment-culture system: “all aspects of organism-environment-culture system are involved in social change” (p.74). Thus core to the development of social representations is the location of groups and individuals within society and their objectives in relation to social representations. Also important is the interrelationship between individuals and their physical/material environment. Finally, it is possible to apply Purkhardt’s approach to an examination of the ways inter-relationships between different organism-environment-culture systems produce another key context for the emergence of social representations: the unfamiliar emerging from outside socio-cultural boundaries.

Figure 3.1b below constitutes a schematic depiction of the cognitive-emotional framework, modified from an original diagram (Figure 3.1a) by Wagner, Duveen, Farr, Jovchelovitch, Lorenzi-Cioldi, Markova, and Rose (1999). Wagner and colleagues draw on the typology of identity development developed by Duveen and Lloyd (1990, also Lloyd and Duveen, 1993), which complements Purkhardt's discussions of the role of identity in social representations. The typology has three inter-related levels. Sociogenesis is defined as the process through which social representations about specific objects are constructed and transformed by social groups. The emphasis is on the collective level; it takes place in time. Ontogenesis concerns the process through which individuals reconstruct social representations and in so doing transform social identities: it is through social identities, Duveen and Lloyd (1990) argue that social representations become psychologically active for individuals. Microgenesis is concerned with how the social identities asserted in interpersonal communication or interaction evoke social representations. Wagner and colleagues focus on the sociogenesis of social representations through the socio-cognitive processes of anchoring and objectification and limit social interaction and productivity to discursive practice. The modified depiction focuses on sociogenesis, ontogenesis and microgenesis of social representations through cognitive-emotional processes. The terms sociogenesis, ontogenesis and microgenesis are not employed in this thesis. Their broader interconnection with the production of social representations at levels of self, society and culture - the key focus of this thesis - is more pertinent. Figure 3.1b expands the current focus on anchoring and objectification, as perceptual cognitive processes, to embodied and discursive practices which draw simultaneously on cognition, perception (or imagination) and emotions. Discourses and embodied action, occurs at levels of culture, society and self, in dynamic interaction with the natural (material) environment. The original diagram and the modification are both presented to highlight the sections that require re-theorisation for the theory generally and for examining social representations of diabetes in Ghana.

Figure 3.1.a. Schematic depiction of the sociogenesis of social representations (Wagner et al, 1999)

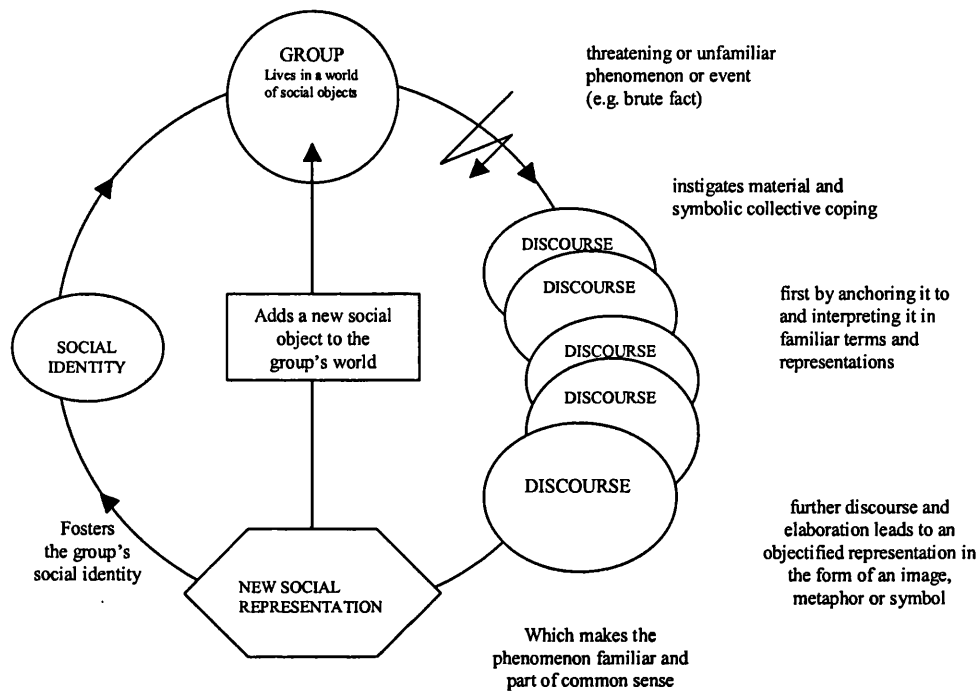
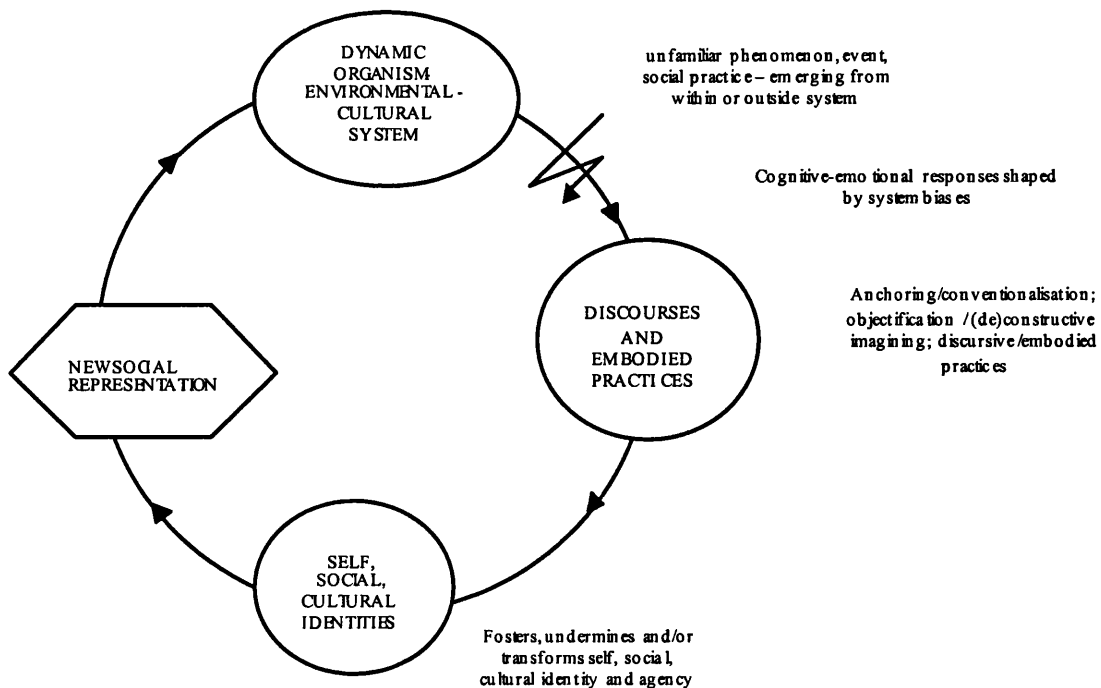


Figure 3.1b. Genesis of social representation at levels of self, society and culture: a schematic depiction (a modification of Wagner et al, 1999)



OVERVIEW OF CHAPTER FOUR

This chapter focuses on the development and implementation of the research design and is presented in three parts. In Part One I discuss the strengths of the three selected methods – individual and group interviews and ethnographies. In Part Two, I describe the selection of research settings and participants groups. Subsumed within this is a discussion of ethical aspects of field relations, in particular the way attention to issues of entry, field identity, reciprocity and confidentiality, informed reflexive engagement with the development and management of fieldwork. Part Three focuses on data collection and analysis. Data recording, transcribing and translation issues are discussed, as well as the development and application of the coding frame.

CHAPTER FOUR

METHODOLOGY: RESEARCH DESIGN, IMPLEMENTATION AND ANALYSIS

This thesis is aligned with qualitative researchers such as Silverman (2001) and Bauer and Gaskell (1999, 2000) who stress that the choice of methodology has to be influenced, to a large extent, by the research questions, and that credible research, whether quantitative or qualitative, is predicated to the extent to which appropriate methods are applied in a rigorous and critical manner. Within this framework attention has to be paid to issues of validity and reliability. In the development of my research design, issues of validity (both external and internal) and reliability were central to the choice of methods, the process of segmentation including attention to ethical aspects of field management, and the data gathering and analysis process. My description and discussion of these key strands of methodology will therefore incorporate introductory comments on the relevance of validity and reliability to particular processes and how these were realised in design and implementation.

4.1. METHODOLOGICAL TRIANGULATION: INCORPORATING EMPIRICAL AND THEORETICAL PERSPECTIVES

The first stage of research design involved choosing a method or group of methods that would allow exploration of the research questions in ways that did justice to my research goals. The primary concern was to select methods that had a 'good fit' (Silverman, 2001) with the overarching theoretical model and empirical questions. This issue of 'good fit' is a critical corollary to the attainment of internal validity (how the development of data tools merge into empirical and theoretical concerns) and reliability (how the data collection process feeds into empirical and theoretical concerns).

Fundamentally, the nature of the empirical and theoretical questions demanded methodological triangulation. Methodological triangulation involves the use of different methods to conduct comparative analysis of how multiple versions of reality are constructed within individuals or groups or cultures over time (Flick,1992; Gervais et al,1999). Some theorists stress the incorporation of theoretical perspectives within the comparative analysis process as a way of facilitating reflexivity in research (cf. Markova, 1996; Bauer & Gaskell, 1999). For example Markova (1996) argues that since human thought is multilayered and operates simultaneously at different levels of awareness (p.189), the choice of a combination of empirical methods have to be informed not only by their ability to examine a social phenomenon from different perspectives, but crucially by their ability to examine the social phenomenon “at different levels of an individual’s awareness” (p. 192). Both approaches to methodological triangulation informed the mix of methods I chose for empirical work.

Table 4.1 outlines the methods of data collection, the participant groups targeted with each and the empirical and theoretical objectives underpinning their choice. In the following section I describe the strengths of each method.

Table 4.1. Data collection methods and target social groups

Data source	Method	Objective of method
‘Lifeworld’ of people with diabetes including: Family members Close associates.	Group interviews	Gathering accounts of shared knowledge and experience of diabetes
	Individual interviews	Gathering subjective account of knowledge and experience of diabetes
	Modified ethnographic method (constitutes longitudinal individual interviews, participant observation)	Gathering subjective accounts of living with diabetes; living with, caring for or knowing a sufferer. Experience and knowledge of diabetes. Observing and documenting illness action.
Public sphere: Lay healthy individuals	Group interviews	Examining shared knowledge on diabetes and medical pluralistic practices.
Professional sphere: Expert informants, Biomedical Ethnomedical Faith healers	In-depth individual interviews	Mapping out the wider health policy and healthcare context and implications for diabetes sufferers through the accounts of medical knowledge systems and practices.

4.1.1 Individual interviews

The ability of individual interviews to tap into individual biographies (Kitzinger, 1995) has made it a standard data collection method for the study of social representations. The qualitative interview as Gaskell (2000:39) notes, “provides the basic data for the development of an understanding of the relations between social actors and their situation.”

The open-ended, flexible and respondent-centred approach of the method is aimed at facilitating detailed exploration of the ‘personal worldview’ (Gaskell,2000:46) of the respondent, with minimal imposition of the researcher's views, concepts and presuppositions on the subject under discussion (Gervais & Jovchelovitch, 1998; Farr, 1993). A successful in-depth interview, Gaskell notes, places the respondent ‘centre stage’, and allows the respondent time and space to engage in reflections and narrative construction of the past, as well as the meanings they attribute to the subject being explored.

Silverman (2001) notes that there are three versions of interview data corresponding to distinct conceptual frameworks: positivism, emotionalism and constructionism. Interviews conducted within the positivist mould are geared towards eliciting “facts about the world. The primary issue is to generate data which are valid and reliable independent of the research setting’ (p.86). Within this approach the random selection of interview samples and use of standardized closed-ended questions are aimed at eliciting objective facts. Interviewers drawing from emotionalist perspectives approach respondents as subjects who experience and actively construct their social worlds. The broad aim of interview data is to gain access and document authentic experiences of individuals. The primary methods through which such authentic accounts can be gained are through unstructured, open-ended interviews, usually based on prior, in-depth participant observation. The constructionist approach to interviewing is explicitly framed by the notion that ‘meaning’ is an ongoing process constructed between the interviewer and the interviewed. Silverman (2001) notes that for constructionist interviewers, interviews are not treated as standing in the way of accurate depictions of ‘objective facts’ and ‘authentic experiences’, but are used specifically to examine the ways in which meaning is mutually constructed. Bauer and Gaskell (1999) in discussing analytical frameworks for social

representations note that the interview situation constitutes a “dialogical triad: two persons (subject 1 and subject 2) who are concerned with an object (O) in relation to a project (P), along a time dimension” (p.45). The authors argue that this “triangle of mediation” constitutes the basic communication unit within which meaning is elaborated. Meaning, they note is “not an individual or private affair, but is always influenced by the other, concrete or imagined” (p.45).

My approach to the interviewing process applied a mix of emotionalist and constructionist perspectives. My central empirical question related to the link between knowledge, experience and social practice. Thus in a broad emotionalist sense I was concerned with accessing narratives of respondents as experiencing subjects and social actors. The incorporation of the ethnographic method was to examine the practical everyday aspects of the diabetes experience. However, I also take Silverman’s view that the search for ‘authenticity’ is as problematic as the search for ‘objective fact’. Both positivists and emotionalists outline and attend to organisational procedures, which might get in the way of eliciting the appropriate ‘facts’ or ‘emotions’ from respondents. In so doing both perspectives fail to realise that the ‘misunderstandings’ and ‘distortions’ that arise between the researcher and the researched, arise from “both parties’ employment of their everyday, common-sense knowledge of social structures to engage such business as recognizing a question and providing an answer which will be heard as ‘appropriate’ for a particular identity” (Silverman, 2001:94). It is this recognition that underlies constructionist approaches to interviewing. The overlap between these ideas and the core dimensions of cognitive-emotional polyphasia, informed the application of both perspectives. In using constructionist perspectives however, I make no claim to theorise the actual process of the co-construction of meaning within the interview setting.

4.1.2. Group interviews

Within the social representations field, an individual's thinking occurs against the backdrop of representations circulating the social environment. For this reason theorists place emphasis on examining wider social and institutional discourses from which the social representations draw

(Joffe, 1995). Methods that tap into communicative practices, such as focus group discussions and analysis of the mass media are prioritized in a significant number of social representations studies.

To examine social knowledge of diabetes in the Ghanaian public sphere, I opted for group discussions with both people with diabetes and lay healthy individuals. While the individual interview relies on the subjective account, the group interview examines the structure and process of social interaction.

The overarching aim of the group interview is to replicate, as far as a research design would allow, the social and cultural settings in which people live and the conditions under which they would normally interact (Morgan, 1988; Morgan & Krueger, 1993), or as Kitzinger (1995) asserts 'how knowledge, and more importantly, ideas, develop and operate within a given cultural context' (p.310). The focus group has been referred to as a 'more naturalistic and holistic setting' (Gaskell, p.47), in comparison to the individual interview, the 'thinking society in miniature' (Farr, 1995).

The explicit exploitation and exploration of group interaction with this method can be used to achieve a number of aims. Firstly, it encourages a wide variety of communication from members of a participant group, which then allows exploration into a wide range and form of understanding of the subjects under discussion. Secondly, it encourages participants to generate and explore their own questions and develop their own analysis of common experiences. Within this context it is possible to highlight participants attitudes, priorities, language and framework of understanding. Tapping into such interpersonal communication can also help to identify cultural values and group norms, as well as providing insight into the operation of group social processes in the articulation of knowledge.

Burgess and colleagues (1988, in Gervais, 1997) distinguish between 'once-only' groups and natural groups arguing that the perception of a focus group as a social group has to allow a distinction between groups that only meet once and for the first time and longitudinal small groups. With the former (once-only) group the discussion of the stimulus material takes precedence over the interaction between participants. In this sense once-only groups do not

constitute social groups in the strict social psychological sense. They are ad-hoc gatherings of individuals with no underlying patterns of stable relationships between group members, which provide the internal structures through which communication is mediated. With longitudinal groups however the structure of the group and the nature of the relations between the group members developed over time is the explicit frame through which the content of the discussion is interpreted. In a similar vein, Gaskell (1999) distinguishes between strong groups, who share a common socio-cultural project through awareness of the group's history, and weak groups who might share a common 'trajectory' but without the self-referential identity aspects characterising the former. The nature of and questions underpinning a qualitative research project, Gaskell argues, will determine the choice of groups targeted for empirical work.

I took these points into consideration particularly in the selection of people with diabetes for group discussions. Although all the groups with the exception of one⁶ met only once, each group consisted of participants who had a previous history as social units or groups through their frequent interaction at specialist diabetes centres or through self-help groups. In this sense these groups were natural groups in the way Burgess and colleagues describe or strong groups as described by Bauer and Gaskell.

4.1.3. The modified ethnographic approach

Silvermann (2001) highlights three central assumptions that frame the 'theoretical character of ethnography' (p.70). First, 'common sense is held to be complex and sophisticated rather than naïve and misguided' (p70). Second, social practices constitute the site through which common sense is perceived to operate. The empirical focus of ethnography is therefore on what people are doing, rather than what they are thinking. Thirdly the object of study is seen as locally produced 'through the activities of particular people in particular settings.' (p. 70). These assumptions all resonate with key aspects of social representations theory

⁶ One rural group discussion was conducted over three meetings, over three days, and lasted just under 6 hours.

Ethnography has been traditionally associated with the work of anthropologists, although its methodologies have been increasingly applied to sociological and social psychological studies. Within this latter context the primary focus on participant observation as the primary method of data collection has been expanded to include the use of interviews, as well as data from historical and contemporary textual sources (Duveen & Lloyd, 1993). Generally ethnographers construct an interpretation of everyday events through the use of a mixture of these methods. They also seek to test the adequacy of their methods through triangulation. Data and analysis, as well as the analyst's own understandings of these are made to play reflexively against each other. Within the ethnography framework as Silverman (2001:70) points out 'observational research, data collection, hypothesis construction and theory building are not separate things but are interwoven with one another'.

The ethnographic method was chosen as adjunct to individual and group interviews for a number of reasons. One of the critical concerns of this study is moving beyond an examination of the knowledge individuals and groups hold about diabetes, to an examination of social practices informed by both knowledge and experience of diabetes. To examine this adequately there had to be a level of observable description of the social processes characterising illness action. Both individual and group interviews are inadequate as methodological tools to examine the social interactions and activities that shape and reshape the world of the subject. Yet it is through these processes – the practical activities that underlie social interactions – that social knowledge is produced and transformed. Ethnography allows the study of practical activities, which in turn allows an examination of the social representations through which they are articulated (Duveen & Lloyd, 1993). It is important to note however, as Duveen and Lloyd suggest that a description of social representations using ethnography is only possible if the practical activities associated with the social representations are accessible to the ethnographer. Thus in cases where a social representation is not directly linked to an expression of social identity, ethnography will yield little descriptive information. And equally where the practical activities which frame social identities are inaccessible to the ethnographer, visual and verbal

methods of gathering data will be unsuitable approaches for examining the social representations held by the participants. These concerns shaped the methods chosen to examine and describe the life world of the diabetic individual.

My modified ethnographic method incorporated the use of multiple interviews, participant observation, conversations and informal discussions carried out over a period of six months. The aim was to provide a 'thick' description (Geertz, 1973), of the familial, social and pluralistic medical spheres within which people with diabetes negotiated and acted. To aid reflexive engagement with the data and the analysis of the data, a field journal was kept in which detailed field notes were made. Notes charted management and self-care practices and broader observations of relationships within the life-worlds. The field journal also contained notes about the fieldwork process such as community events that bore relevance to the research (such as ethnomedical advertising practices on rural market days for example, or the frequency of radio programmes on chronic illness or ethnomedicine, conversations with lay people about cultural practices and so on). Also central to the recording process was the importance of documenting my 'feelings' about the process and progression of the work. As qualitative researchers note, feelings enter into and colour the social relationships between the researcher and the researched, and inevitably influence one's choice of what is noteworthy, what is regarded as strange and problematic and what appears to be mundane and obvious (Hammersley and Atkinson 1995). Ultimately I used the field journal as a means of reviewing and revising the development of the research design, to pick up on and follow up the emergence of analytical themes and to systematize data collection.

4.1.4. A note on participant observation

While participant observation is not presented within this chapter as a separate method, it is important to note the very nature of the mix of methods applied to empirical and theoretical concerns necessitated an overarching social engagement with the settings studied. Qualitative researchers note that participant observation is more than just a method that describes a

particular way of carrying out traditional ethnographic research, but that it 'describes a basic resource of all social research' (Silverman,2001:45), framing the 'mode of being-in-the-world characteristic of researchers' (Hammersley and Atkinson 1995: 249).

Guidelines for participant observation emphasise foregrounding participants' perspectives, and describing unique as well as mundane details on the field. As described earlier the contents of the field journal contributed to a broad description of the research context and also guided the process of reflexive analysis during fieldwork.

4.2. SEGMENTATION AND ETHICS OF FIELDWORK MANAGEMENT

Mason (1996:6, in Silverman, 2001) notes: " I don't think qualitative researchers should be satisfied with producing explanations which are idiosyncratic or particular to the limited empirical parameters of their study...Qualitative research should [therefore] produce explanations which are generalizable in some way, or which have a wider resonance." Key to the development of qualitative work that has wider resonance (or external validity) is segmentation, defined by Gaskell (1999) as the process of identifying the intersection between interesting issues, groups and projects. Gaskell argues – in line with dominant views expressed by qualitative researchers - that, "the real purpose of qualitative research is not counting opinions or people but rather exploring a range of opinions, the different representations of the issue...whatever the criteria, the objective is to maximise the opportunity to understand the different positions taken by different members of the social milieu." (p. 41). The process of segmentation facilitates the systematic – as well as imaginative – process of selecting social groups, which 'offer possibilities for the comparative analysis' (p.175) of the different meanings and interpretations applied to the object of study. Central to this selection processes is the recognition of a distinction between strong and weak groups, discussed earlier, and the qualitative differences between such groups in terms of social positioning, knowledge production and use.

There are two main strands to the empirical objective of this thesis, which influenced the segmentation process. The broad strand was to map out representational fields from which people with people with diabetes drew on to make sense of and respond to the diabetes experience. This representational field as noted in Chapter One was likely to incorporate the lifeworld of the individual with diabetes, the wider lay context and the pluralistic medical context. The empirical aim therefore was to systematically explore knowledge, experience and action revolving round concepts of health, illness and diabetes from (a) people with diabetes (b) family members, caregivers and/or significant others (c) healthy lay individuals and (d) health professionals.

In earlier chapters I discussed the way the tradition-modernity dichotomy adopted by dominant cultural studies delegitimised lay and ethnomedical beliefs. To challenge this problematic dichotomy, conceptually and empirically, the research design incorporated two explicit approaches. First, a focus on the rural-urban divide in order to examine the ways making sense of diabetes diverged or converged between rural individuals (whose lifestyles are conceptualised in predominantly traditional terms) and urban individuals (perceived as modernised). With recruitment of research participants therefore, I systematically drew from rural and urban settings. Two Southern sector urban towns (Accra and Tema) and two Northern sector rural towns (Kintampo and Nkoranza) were chosen as research sites. Secondly, I focused on the biomedical-ethnomedical distinction to examine first, the extent to which differences in knowledge systems and practices were attributable to a tradition-modernity split and second to explore the ways in which the goals of both systems intersected with illness action. Here, I also included the much-neglected alternative healing system, which plays a significant role in contemporary healthcare in the Ghanaian context. With recruitment of health professionals I systematically included biomedical, ethnomedical and faith healer groups. Particular attention was paid to rural and urban representation in order to place narratives by people with diabetes and lay healthy groups within their local healthcare contexts.

4.2.1. Choosing the settings and formal health facilities

Prior to fieldwork my aim had been to select one urban setting (Accra) and one rural setting (Kintampo) as study sites. I chose Accra because it is the most urbanised city, with a dynamic mix of people from all four Ghanaian ethnic groups (due to steady rural-urban migration for better employment/standard of living), and from all educational, economic and religious backgrounds. As the capital it is the political, economic and the cultural nerve centre of the country and home to the majority of the nation's institutions. Within the health sector in particular, there is over-representation of both public and private biomedical facilities as well as ethnomedical health facilities, thus providing a rich source of professional diversity from which to recruit health practitioners. At a practical level, Accra also presented an advantage in terms of entry access to formal institutions and healthcare facilities since I had developed useful professional contacts through past work experience. The public health facilities selected were the diabetes centre at the Korle-Bu Teaching Hospital (one of two in the country) and the Mampong Centre. Tema, the second urban site, is an industrial town, which shares municipal boundary with Accra, as well as strong economic and social links. A key aspect of this relationship is the cross-use of health services. It became an adjunct research site by default, because some of the participants recruited in early stages of fieldwork from the diabetes centre at the Korle-Bu teaching hospital lived in Tema. Subsequently when I began selecting participants for individual interviews and group interviews, I actively sought to include more Tema residents. No Tema-based health facilities and health professionals were selected however.

Kintampo, a rural district town in the Brong Ahafo region, was chosen prior to fieldwork for three main reasons. First, it had a recorded prevalence of diabetes. Second, it had the broad range of health practitioners engaged in diabetes care. Third, it was within reasonable (6 hour) driving distance from Accra to permit a sequential process of data collection. Lastly and crucially for fieldwork, I managed to negotiate assistance with accommodation and field assistance in exchange for carrying out evaluative work for the Kintampo Health Research

Centre (KHRC). The KHRC, an organisation run in collaboration with the Ministry of Health and the London School of Hygiene and Tropical Medicine, conducts longitudinal epidemiological research in the Brong Ahafo Region, from an office base with excellent research facilities and more importantly constant electricity (via a stand-by generator) and telephone and internet access. Thus in addition to free accommodation and field assistance – albeit paid by intellectual work – I was able to carry out the more technical aspects of follow-up work (such as typing up field notes and changing interview guides on PC, making phone calls and sending emails) which may have been more difficult had I rented private accommodation in the town. Nkoranza, a neighbouring rural town, was selected a month into fieldwork, when I learned through a professional contact that the town had an active diabetes group run by and for its members. Thus even though I lived in Kintampo and commuted between the two towns, Nkoranza became the primary rural study site, with much of the rural work commencing in the town and both rural ethnographic studies being situated there.

There are a number of similarities between the profiles of the rural settings that are worth noting. Both Kintampo and Nkoranza are rural district towns, each made up of a nucleus (Kintampo town, Nkoranza town) and a satellite of villages. Each town has a rough population of 30,000, with the village populations of 3,000 and less. The majority of people living in the villages making up the districts are typically subsistence farmers, although some farmers engage in commercial agriculture with tobacco being the main crop. In the towns the minority of people tend to be traders, civil servants and artisans. Access to education is only at primary and secondary level and the literacy rate is reported to be low. Figures for female literacy Kintampo for example indicate only 23%.

At the primary and informal levels of healthcare both have a similar numbers of clinics and health posts and significant numbers of ethnomedical and alternative health services. However, the hospital in Kintampo is a government run facility with fewer staff and economic resources, compared to Nkoranza's wealthier, more adequately staffed Catholic mission facility. The latter is closely involved in two community level activities; a community health insurance

scheme which provides full cover for hospital care and the afore-mentioned diabetes self-help group.

While the majority of people in Nkoranza and Kintampo are Bono, part of the larger Akan ethnic group, Kintampo also has a minority population consisting of northern ethnic groups. With the exception of this latter group, who are practising Muslims, the majority of Kintampo and Nkoranza inhabitants are practicing Christians.

4.2.2. Negotiating entry

Negotiation of entry is a crucial first step to fieldwork, since it lays both the conceptual and methodological framework for the entire research process (Berg, 1989; Silverman, 2001). The development of roles that ease entry and facilitate receptivity of settings and participants is crucial to research design and implementation.

Entry to formal settings

Within the Ghanaian formal healthcare context, any research that involves recruiting formal health service users has to be approved by the ethics committee of the University of Ghana Medical School. Since the research necessitated recruitment of people with diabetes from formal healthcare facilities approval had to be sought from this body prior to the recruitment process. I submitted a successful formal application, which constituted an introductory letter and a research synopsis.

Having gained official permission, the second stage of the entry process involved negotiating access to expert informants, formal healthcare professionals and subsequently to people with diabetes accessing care within selected urban and rural health facilities. This process was facilitated in the urban setting by drawing on professional contacts, and in the rural setting by my official affiliation with KHRC. In both settings, the submission of an introductory letter and synopsis of my proposed research, followed by a telephone discussion or face-to-face meeting with the respective centre or departmental heads, secured acceptance to recruit both health professionals and people with diabetes.

The majority of people with diabetes recruited in Nkoranza were members of the self-help group. The process was mediated by the group's secretary, who also acted as the secretary of Nkoranza branch of the Ghana Diabetes Association. A different approach was adopted in Kintampo, because there was no organized social or medical support group. Permission was gained from the doctor in charge at Kintampo General Hospital to compile a contacts list from the hospital records of people who had attended the hospital for diabetes treatment in the last year. The list was used to carry out door-to-door recruitment of participants for interviews and group discussions.

Expert Informants

In order to map out the key issues regarding chronic illness and diabetes care, it was important to gather information from people who had critical knowledge and expertise in the field. Interviews with experts are useful for tapping into "the critical knowledge one possesses about oneself and one's community"(Gervais and Jovchelovitch, 1998:9) and provide a means of building information particularly in areas where documentation and records are scarce.

The majority of interviews with expert informants were held in the early stages of fieldwork. Expert informants were chosen from six key national and regional organisations involved in three key areas of formal and informal healthcare: national health care and health policy development, the collaborative health model, ethnomedicine and diabetes care. The organizations chosen for examination of the first area were the Ghana Health Service, the Brong Ahafo Regional Health Service and the Nkoranza Community Health Insurance Project. The Traditional and Alternative Medicine Directorate (TAMD) and the Centre for Scientific Research into Plant Medicine (CSRIPM) were chosen to explore the second area. To examine the profile of Ghanaian ethnomedicine, the national and Brong Ahafo regional branches of the Ghana National Association of Traditional Healers were selected. Finally the president of the Ghana Diabetes Association and the secretaries of the Greater Accra and Nkoranza branches of the association were recruited for interviews on national and regional information on diabetes care.

The interviews explored national health and policy issues and informed further development of research guides. The data gathered from this group is not included in the results, but constituted background information, which informed the overview of healthcare presented in Chapter One and is drawn on for discussions on interventions in Chapter Ten.

Entry to informal settings

Access to the private biomedical and the informal health sectors was less formal and negotiated largely through social contacts. Access to the faith healers and rural ethnomedical practitioners was relatively unproblematic and facilitated by social and professional contacts. Problems arose during the recruitment of urban ethnomedical professionals, particularly among those working in organised group practices. Difficulty of access revolved round ongoing issues of mistrust between these bio-tech herbalist groups and formal healthcare systems. I will discuss the process of entry into this domain, in the section on ethical aspects of field management, as issues of field identity came to the fore most clearly during this process.

Access to people with diabetes outside of the biomedical sector and to lay individuals was also negotiated through social contacts and through a snowball process.

4.2.3. Criteria for participant selection

People with Diabetes

The literature on diabetes suggests that while a group of people may be socially and medically 'united' by virtue of living with diabetes, there is a range of diagnostic types, which have varying socio-psychological impact. Furthermore the broader literature on chronic illness suggests that the length of time a person lives with illness impacts on the nature of responses to the experience. Attention was therefore paid to sampling accounts from individuals living with the broad range of diabetes types identified within the MOH literature, and for different lengths of time.

Gender and age constituted two additional selection criteria particularly for selecting participants for group interviews. Literature review and informal discussions with health

workers established that the majority of individuals living with type 2 diabetes (the most common form of diabetes) were in their middle age (mid-forties and above). It was also established that some side effects of diabetes treatment were gender specific and often gender-sensitive (for example penile dysfunction). It was important therefore that within the context of social interaction age and gender differences were taken into account.

Group interview participants

Participants were recruited opportunistically from three facilities - the Korle-Bu Diabetes Centre in Accra, the self-help group attached to the St Theresa's hospital in Nkoranza, and from the Kintampo hospital. Prior experience showed that participants in busy urban facilities rarely kept to appointments. Opportunistic sampling was the most appropriate way of collecting data from a predetermined mix and number of participants. Forty-four rural and urban participants (22 women; 22 men, age range 26-71) were recruited for 6 group interviews (group range: 5-9). Most participants had type 2 diabetes and lived with a broad range of complications. Some had been recently diagnosed, others had lived with the illness for over ten years. Full demographic details are presented in Appendix C.

Individual interview participants

Twenty individuals (10 urban, 10 rural; 9 women and 11 men) were recruited for interviews. Some were recruited from the afore-mentioned facilities and the Mampong centre, others through social contacts. Demographic details of the interviewees are presented in Appendix C.

Significant others of people with diabetes

Three people with diabetes were recruited for ethnographic study. For each person with diabetes, I selected family members, including caregivers and significant others, all of whom formed the focal point for interviewing, discussions and participant observation. The criteria influencing selection of family members was determined by family dynamics: life-world participants were essentially self-selecting. Within each life-world, the principle caregiver was actively recruited and two other close family members and/or significant others. These were 'formal participants' - those recruited and formally interviewed using standard interview guides for ethnographies. In the course of the six-month ethnography, data was gathered from

'informal participants' – members of the family or friends of the family who joined in informal conversations and discussions during home visits.

Eleven people participated formally in the ethnographies. The demographic characteristics of formal and informal participants are presented in Appendix C, and in Chapter Seven.

Lay individuals

The first criterion for recruiting lay healthy groups was absence of serious illness. The second criterion was accessing an age range reflecting that of participants with diabetes and also of groups at risk of getting diabetes. Groups were split into young and middle-aged categories.

In Nkoranza, a community leader facilitated selection of group participants. Both groups comprised of members who lived in a cluster of communities close to each other and had a history of social interaction. In Kintampo selection was carried out by KHRC fieldworkers who had comprehensive knowledge of the various communities and interacted socially with several community members. Again, emphasis was placed on selecting close to a natural group as the recruiting process would allow.

In the urban setting two groups - one young and one middle-aged – were recruited at the early stages of fieldwork. The urban young group, were recruited from the local university and constituted undergraduates and postgraduates from different disciplines and departments. Recruiting was facilitated by two contacts who worked for the Department of Psychology, and interacted socially with a wide range of students on campus. The middle-aged group was set up by a contact with active links with workers unions in Accra and Tema. My contact selected a mixed group from the two towns, some of whom had existing social links. However, I was unable to conduct group discussion with the middle-aged group, initially due to a time clash with rural work and towards the end of fieldwork due to illness. During a brief trip to Ghana six months after fieldwork, I recruited and conducted group discussion with a second young group. When discussing urban group views in Chapter Eight, it is made clear that the urban narratives have a young educated demographic bias.

Fifty-one participants took part in the six lay group interviews, 23 in the young groups (10 women, 13 men; age range: 20-35) and 28 in the middle-aged groups (12 women, 16 men, age range: 45-60). The number of group members ranged from 7 to 11. The demographic characteristics of the lay participants are presented in Appendix C.

Health professionals

Participant selection was based on two criteria. First, prospective health professionals had to be actively involved in providing diabetes care. Second, it was important to have representative views from the sub-groups of the three health professional systems. Attention was paid to sub-groupings as well as the structural and hierarchical arrangements within each professional group. For the biomedical group, doctors and nurses were recruited from a mix of public and private facilities operating at different levels of service delivery. In the urban setting two doctors (a consultant and houseman) and a nursing sister were recruited from the Korle-Bu Teaching Hospital, as well as the sole doctor at CSRIPM, and a General Practitioner running a private practice. In the rural setting a doctor and nurse working at the St Theresa's hospital in Nkoranza were recruited, as was the doctor in charge of Kintampo General Hospital.

Three identified ethnomedical sub-groups were targeted. In the urban setting, three bio-centred herbalists and one traditional religious healer were recruited. In the rural setting five practitioners were recruited. Of these three were bio-tech herbalists who ran a group practice, one was a mobile bio-tech herbalist, the final participant a traditional religious healer.

Two identified faith healer sub-groups were recruited, those who relied solely on spiritual healing as their treatment repertoire and those who had provided adjunct services as herbalists in the past or continued to do so at the time of the research. Two groups of faith healers from two prominent churches/prayer camps in Nkoranza and Kintampo were recruited. Due to time constraints, only one urban faith healer was interviewed.

With the exception of the urban and rural nurses, all participants were male. This gender bias in the recruitment profile is largely a reflection of the overrepresentation of male

practitioners in all three groups (see Chapter One) and within the specialist context of diabetes care.

Note: Diet management is a key component in diabetes management. Nutritionists therefore play a central role in diabetes care teams. My attempts to recruit nutritionists failed for two reasons. First, there was a general lack of expertise in the area. For example, there were no qualified nutritionists in the rural settings. The diabetes centre at Korle-Bu had a nutritionist. However, through a mix of frequent work absence and my urban-rural fieldwork schedule it became impossible to arrange an interview date. A generic booklet on diabetes care - "Living Well With Diabetes" - produced by local and international medical collaboration, provided some information on context specific nutritional advice.

4.2.4. Ethical field management

Qualitative methods, due to their exploratory nature, may be more intrusive and involve greater reactivity than surveys, tests and other quantitative methods (Patton, 1990). It is therefore important to anticipate and deal with the ethical dimensions of qualitative inquiry. This concluding section focuses on key ethical issues actively incorporated into the design and implementation of the fieldwork process.

Identity issues

Much has been written within ethnographic texts about the negotiation of field identities. Hammersley and Atkinson (1995) note that "although it would be wrong to think of the effects of these as absolutely determinate or fixed, such characteristics as gender, age, race, and ethnic identification may shape relationships with gatekeepers, sponsors, and people under study in important ways". Researchers note how gender bars female researchers from particular settings closed to women and how opposite dynamics can work against male researchers. Even in cases where the identity of the researcher is similar to that of the researched - say in terms of gender, ethnicity or religion - problems can arise on the field. Feminist researchers conducting work in

the Western context have highlighted how the interplay of class and race can affect the research dynamics between a white/black female researcher, researching black/white women (cf Phoenix, 1994; Mirza, 1998), and how cross-cultural differences can undermine field relations when minority ethnic researchers research minority ethnic populations (Egharevba, 2001).

Very little however has been written on how researchers with dual national/cultural identities negotiate fieldwork 'back home' within their countries of origin, although there has been some discussion on the ways class, coupled with Western affiliation, weakens emic knowledge and relationships (Ladson-Billings, 1999). The experiences of Whitehead (1986, in Hammersley and Atkinson 1995), a British-Jamaican researcher who conducted fieldwork in Jamaica lends weight to such concerns. Whitehead was described by the Jamaicans he studied, as the 'big brown pretty talking man'. Big referred to his status as an educated foreigner, and pretty talking to his use of Standard English and not patois. Brown referred to combination of light skin colour and desirable economic and social characteristics. Hammersley and Atkinson recount that when Whitehead tried to hold conversations with low-income men, they would avoid eye contact, refer him to someone 'bigger' and better placed than they were to answer his questions and generally answered his questions with deferential 'yes sirs' or 'no sirs'.

Elements of Whitehead's accounts resonate with my experiences of field research in Ghana, where a combination of my gender, age and British identity have either smoothed entry into some settings (for example formal health facilities run by male professionals) and restricted entry into others (high level female nursing professionals). In rural settings the responses have arisen from subtler differences. As a direct result or by-product of the priority given to 'Third World' rural community development within the development project, there is a high level of interaction between rural Ghanaians and white Western researchers. With the exception perhaps of African-Americans, there has been comparatively less interaction with black Western-based researchers. With past experiences of rural research work in Ghana, my identity as a young black woman from the UK has resulted in two dominant responses. First, curiosity as people I have met in the field attempt to reposition their ideas of black Westerners as based primarily in North America and/or as cultural tourists rather than researchers. Second, rapid

engagement as my Ghanaian credentials - and local language skills, in particular - become evident. I therefore approached fieldwork with full awareness of the varied impact others' perceptions of me would have on the fieldwork process.

I encountered few negative responses during the research process. However, during recruitment of the urban ethnomedical practitioners my 'foreignness' became an explicit issue and a negative dynamic to the fieldwork process. I encountered a number of failed recruitment attempts, where my request for interviews, even when facilitated by regular clients endorsing my 'genuine' intentions, was countered with suspicions about my research motives. Questions revolved round the purpose of my research, target of dissemination and the extent to which they had to divulge information regarding pharmacological properties of their drugs. During my interview with expert informants from GNATH for example, both threatened to pull out of the interview unless I paid a consulting fee of 100 US dollars. They argued, assuming I was African-American⁷, I would use the knowledge gained from them to 'advance my profession' and country, while they were 'left with nothing'. They recounted stories of numerous interviews they had granted foreign researchers who promised collaborative links and then disappeared without further contact. They resumed the interview, and waived the fee, after a lengthy discussion during which my Ghanaian parentage was verified.

Informed Consent

Informed consent has been defined as the knowing consent of individuals to participate as an exercise of their choice free from any element of fraud deceit, duress or similar unfair or manipulation (Berg, 1989). Obtaining informed consent is a crucial first step in giving participants control over their involvement in the research process. Because participants are in a position to give informed consent only when they are adequately informed in advance of all elements of the research process, this step also becomes the means by which open and honest interaction can be cultivated to ensure mutual respect and confidence between researcher and

⁷ My first name 'Ama' – a recognisable Ghanaian name - made no difference here, possibly due to increasing public awareness through the media as well as commercial and informal interactions with African-Americans tourists, that African-Americans adopt (or reclaim) African names, languages and cultures.

participants. During recruitment and at the beginning of data collection all participants were informed of the research aims and process, and the significance of their contribution. A mix of written and verbal consent was obtained. Names and contact details, including addresses - where possible - were gathered. My contact details were provided, in the case of individual interviews directly to participants, in the case of group discussions to the recruitment facilitator. The purpose of this exchange was to ensure that participants had access to exert their rights of participation, right to withdraw and/or withhold their data from analysis.

Confidentiality

This research focuses on personal and professional accounts, which are liable to be made public through supervisory, evaluation and dissemination processes. The potential harm of publicly disclosing personal information had to be minimised by guaranteeing a degree of confidentiality to participants. Confidentiality was honoured primarily through substituting participants' names with pseudonyms throughout the research process and when reporting data.

Data access and ownership

Some researchers – especially feminist and activist researchers – place emphasis on the importance of participants having access to data. This is seen as both ethically and methodologically appropriate. Comments from participants lead to exclusion of narrative areas they feel uncomfortable with or can lead to greater insight into new areas of enquiry, which then feed into the triangulation process. While participants did not have access to their interview transcripts, it was made clear that interviews would be edited at their request, if they had second thoughts about information or thoughts they had shared. For example two urban biomedical professionals, who made a series of critical remarks about the Ministry of Health and their organisations, asked that these comments not be included in the transcripts. In the presentation of results, this request has been honoured.

Reciprocity

Qualitative studies intrude into settings and people's lives. Participants give of themselves, by adjusting their priorities and routines to help the researcher. Building reciprocity into field management, allows researchers to minimise intrusion where possible, or compensate or show token appreciation for intrusion. Reciprocity was managed through remuneration of participants' travel costs, providing refreshments, as well as offering token sums of money for participation. Each participant was given 5,000 cedis (50p at the time), which was a little over the minimum daily wage. A number of urban participants declined the token amount saying they had gained useful knowledge through participation. In Kintampo two bars of household soap were given to each participant (which cost slightly less than token payment). It was advised that token payment reflect the norm established by the KHRC for participation in social science studies in the Kintampo district.

4.3. RELIABILITY AND PROCESS OF DATA COLLECTION AND ANALYSIS

Silverman (2001) argues that while overemphasis on systematized processes such as pre-testing of interview schedules and inter-rater reliability checks on the coding of answers to open-ended questions, can "deflect attention away from the theoretical assumptions underlying the meaning that we attach to interviewee's answers" (p.229), these conventional issues of reliability, cannot be ignored. Thus even if qualitative researchers are reflexively aware that interview accounts constitute more than just "simple 'reports' on reality", it is still useful to "pre-test an interview schedule and to compare how at least two researcher's analyse the same data". It is also important to satisfy the criterion of using low-inference descriptors. Low-inference descriptors involve recording and analysing data in concrete systematic ways that place participant narratives central to each process. The tape-recording of face-to-face interviews, transcribing of tapes according to the needs of reliable analysis, and presentation of long extracts of data in research reports (including the question that provoked any answer) all contribute to low-inference description (Silverman, 2001). I describe the ways in which attention to reliability

framed 'organisational procedures' (design and pre-testing of guides, training of field assistants), data collection and analysis.

4.3.1. Reliability and data collection

Organisational procedures

Fieldwork was carried out between November 2000 and June 2001. With the exception of expert informants who were interviewed at the start of fieldwork, and a second group of lay urban participants recruited and interviewed in December 2001, data collection with participants was carried out as groups were recruited opportunistically. The only structure imposed was to alternate between rural and urban study sites, spending three to four weeks at each site.

Interview guides were developed before fieldwork, informed by the research questions outlined in Chapter One, but further refined through two processes. First, interviews with expert informants provided useful background to the structural and social context of diabetes care. Elements of this background were incorporated into the guides. Second, translation of the guides into Twi, provided greater insight into language use and necessitated the rephrasing of questions. Key areas of the guides are presented in Figures 4.1 to 4.3. Detailed guides are presented in Appendix B.

Figure 4.1. Key interview areas for people with diabetes (and significant others)

- [1] Sources and content of social knowledge of health, illness and medical pluralism
- [2] Sources and contents of social knowledge of diabetes
- [3] Nature of 'biographical disruption' caused by diabetes and meanings ascribed
- [4] Nature of illness action, illness action goals and mediating factors.

Figure 4.2. Key interview areas for lay healthy individuals

- [1] Sources and content of social knowledge of health, illness and medical pluralism
- [2] Sources and contents of social knowledge of diabetes
- [3] Impact of lay knowledge and perceptions of diabetes, and lay interactions with people with diabetes on illness experience and illness action.

Figure 4.3. Key interview areas for health professionals

- [1] Sources and content of social knowledge of health, illness and medical pluralism
- [2] Sources and contents of social knowledge of diabetes
- [3] Assessment of in-group general and diabetes-specific knowledge and practices.
- [4] Assessment of out-group general and diabetes-specific knowledge and practices. Impact on professional collaboration.

I conducted all lay urban group interviews, individual interviews and modified ethnographic studies. A research assistant conducted urban group interviews with people with diabetes. With the exception of two interviews with people with diabetes which were conducted in the Akan dialects Fante and Twi, and group interviews with people with diabetes conducted in a mixture of English, Ga and Twi, the main language used in the urban setting was English. In the rural setting I conducted all interviews – in English - with formal health professionals. Three field assistants conducted remaining individual and group interviews and ethnographies. The primary language used in rural interviews and ethnographies was Bono – a variation of Twi, the Akan dialect.

The urban field assistant, Mr. Adote Anum, was a post-graduate psychologist, with considerable qualitative research experience and fluent Ga skills – the primary language used by both urban diabetes groups. All three rural field assistants – Mr. Danso Yeboah, Ms. Judith Parry and Mr. Osei - had post-secondary education, extensive field research experience in the Brong Ahafo region and spoke fluent Bono. Field research and language expertise were key factors in the recruitment of all field assistants. I understand, read and speak both Fante and Twi fairly well, and can follow simple Ga conversations. However, my vocabulary is not extensive enough to allow follow up and discussion of intricate ideas that could arise from a research interview or group discussion. In the rural setting, for example, where the ‘purest’ Bono is spoken, a hybridized, ‘broken’ Twi could interfere with the fluidity of conversation. My decision to use local field assistants for the majority of non-English individual and group interviews in both rural and urban settings arose from this concern. However, I was present during all the group

discussions (facilitating and taking notes), for 7 out of the 12 interviews, and for two-thirds of the ethnography home visits and interviews. In cases where a home visit was missed - usually due to the fact that I was engaged in urban fieldwork - I would make a follow up home visit. My presence ensured that gaps in meaning were addressed and tangential issues with bearing on research questions were followed up during interviews and discussions.

Two standardized procedures were implemented before field assistants begin work in the field. First, the rural interviews were translated into Bono in order to pick up changes in meaning and further refine questions posed to rural groups. This process was carried out with the principal assistant and had a dual function of facilitating familiarization with the research aims and categories for him and subsequently the other two assistants. Ultimately, all three rural field assistants opted to use the post-translation English guide for all interviews. Secondly, mock interviews followed by question and answer sessions were carried out with each assistant before the start of fieldwork. This process aimed to familiarize them with the individual and group interview process and help develop a repertoire of responses for chronic illness and diabetes-specific questions. Generally, communicative and cultural negotiation skills became more refined as more interviews were conducted. I was able to conduct urban interviews in Twi and Fanti without assistance, for example, because my vocabulary and mode of expression improved considerably through participating in rural group discussions.

The duration of group discussions ranged from an hour to 2 hours. One rural group discussion with people with diabetes lasted 6 hours and run over a three-day period. Individual interviews run between 40 minutes, to an hour and half. Permission was sought and granted to record all interviews and discussions.

Transcribing and Translating

Casual assistants transcribed two-thirds of the rural and urban tapes; I transcribed the remaining third. Initially non-English tapes were transcribed through two processes: first a literal transcription in Twi, then a translation of the Twi narrative into English. This turned out to be a

complex and time-consuming process, which required professional expertise. For a variety of logistical reasons - few experts in the field, exorbitant quotes for services - this process was abandoned for direct Twi-English translation. This involved the first translator transcribing tapes into English. The transcript then went through two reliability checks involving listening to the tapes while reading through – and correcting where necessary – the first transcript. A bilingual assistant carried out the first check. I carried out the second check at Stage One of analysis (see below).

The data set constituted 70 transcripts, with average word limit of 8000 for 54 individual interviews and 12,000 for 16 group interviews, yielding approximately 624,000 words of text. This large volume of textual data required a systematic analytic framework. Analysis was divided into two main stages. At Stage One, transcripts were subjected to a second reliability check, field notes were incorporated where appropriate and broad categories were identified. At Stage Two the data was subjected to systematic analysis using Atlas/ti.

4.3.2. Reliability and data analysis

Data analysis: Manual coding (Stage One)

The first stage of analysis involved reading and listening to each interview transcript (crude data) and carrying out manual coding of broad empirical categories. This was carried out in distinct phases; lifeworld, lay and health professional transcripts were read and corrected in block periods. This process allowed me to revisit the interview situation and regain a broader feel for participants' narratives. It also doubled up as a reliability check for Twi transcripts. During this stage I also revisited field journal notes in order to import analytic notes made in reference to interview dynamics, aspects of narratives that were not picked in recording, or general observations relating to communicative and social practices. Preliminary manual coding involved highlighting views expressed on the key research questions. For example, when examining narratives of people with diabetes, the range of views expressed in each individual or group interview transcripts on the key research questions were noted. Each section would be

highlighted with a different coloured marker to facilitate manual cross-references within and between transcripts. At this stage the aim was to identify the general trend of expressed views. Contents of themes as well as their sources and functions were identified. As set out in the analytical framework in Chapter Three, sources and functions were ascribed general open-ended categories. Sources were examined under three broad categories; external other (denoting cross-cultural contexts), internal other (denoting both (intra) cultural and social contexts) and self (denoting unique personal experiences or shared interpersonal experiences). Functions were viewed in terms of whether contents were called on in communication and memory in relation to self or other, or were constituent of identity, and everyday communicative and embodied practices.

A one-page summary of content, sources and functions of themes was developed for each transcript. For each segmented group, these individual summary sheets were further condensed to a one-page summary of interconnecting themes. The transcripts and summary sheets were revisited as I proceeded with Atlas-ti coding, in order to situate meanings of codes within the full context of individual and group narratives.

Data Analysis: Atlas-ti coding (Stage Two)

Atlas-ti facilitates two key activities: textual level work and conceptual level work. Textual level work involves the segmentation of 'primary documents' (each transcript) into 'codes' (short or long extracts of quotations), which can be labelled with succinct self-explanatory titles or with 'memos' (broader contextual information). Primary documents can also be annotated with memos; this allows important contextual information about particular interviewees or groups or their social and communicative settings to be appended to the end of the transcripts. Codes can further be grouped under 'families': codes with shared meanings that can be grouped under distinct empirical or conceptual subsets. All primary documents can be saved under one 'hermeneutic unit' (the entire data set), which facilitates cross-referencing and flexible manipulation of codes, families, and memos, across and within primary documents. These activities collectively provide the necessary background for conceptual level work, which is

facilitated technically by Atlas/ti's 'networking feature'. This feature allows meaningful semantic and conceptual relationships between selected passages, codes and memos to be linked visually, usually through graphical displays. Graphical displays can in turn highlight new relationships, which allow further textual and conceptual work to be carried out. The aforementioned functions were the only ones used for textual and conceptual work, because although the package offers a host of other functions, its key strength lies in the technical flexibility it affords the user and its ability to manage large data sets. The intricacies of conceptual work, ultimately lies outside its remit.

Manual coding set the organizational and overarching conceptual stage for Atlas/ti work. In terms of organisation, all primary documents including memos were imported into the hermeneutic unit. The conceptual framework, set out in Chapter Three had three key elements. At a broad level, I was interested in examining the links between 'social knowledge' 'experience' and 'action/practice' as the basic dynamic underpinning social representations. Sources and functions of knowledge were deemed central to this inter-relationship, as were the levels of social organisation at which knowledge, experience and action operated. Finally, it was important to identify elements of consensus, conflict and absence within and between these categories.

Two central coding processes were applied to the examination of these elements:

- (1) Identification of content, source, function, contextual features of (1) codes and (2) families
- (2) Identification of consensus, conflict/contradiction, absence within/between themes

These core processes were applied to three sequential activities. In Activity One, each individual and group interview transcript was coded as a unit of analysis. In Activity Two, segmented groups were analysed as units by examining intersections between 'families'. In Activity Three, interconnecting themes were mapped out across the entire data.

Coder reliability was established after Activity One. Bauer (1992) describes two types of coder reliability. Intra-coder reliability “measures the consistency of a single coder who is coding the same material twice with a time interval between the two codings ”(p.301). Inter-coder reliability “measures the simultaneous agreement of several coders on the same material”(p.301). Given the complex cultural and language dimensions of the research, I chose the former method. A month after the first set of coding, sample individual and group interview transcripts were selected from each social group. An index was calculated for the first set of coding, which constituted the number of consistent codings in relation to the total number of codings (Bauer, 1992, Krippendorff, 1980). The second set of coding yielded an index of 0.68, which exceeded the acceptable reliability level of 0.63 (Krippendorff, 1980). However the inconsistencies, which emerged in the second round, were analysed and the coding frame was improved. The use of two family labels – empirical and theoretical (see below) – was a result of the intra-coder reliability process. Bauer (1992) argues that: “reliability is a process to be optimised rather than maximized (p.300).” Bauer, like Silvermann (2001), views the reliability process not only as a process of establishing consistency, but also, crucially, as a process of describing the gradual improvements of one’s coding frame and making the coding process transparent.

I illustrate how the two coding processes are applied to Activities One and Two using interviews with people with diabetes. This is followed by a general discussion of Activity Three.

Activity One: Individual and group interview transcripts as a unit

Four empirical themes were explored within narratives of people with diabetes (see Figure 4.1): health and illness and medical pluralism; diabetes; biographical disruption and illness action. For each area some sub-themes were elicited through explicit prompts (see Figure 4.4 and Appendix C2).

Figure 4.4: Segment from Individual and Group Interview Guide (People with diabetes)

2. Diabetes

2.7. How has diabetes made an impact on your everyday life?

Prompts: Has the illness affected your diet?

Has the illness affected your social life?

Has diabetes affected your economic situation?

Have you had to make lifestyle changes?

Have you experienced any other problems as a result of your diabetes?

4. Medical Plurality

4.1. Which one of these treatment methods would you try if you were ill?

(1) advertising traditional healer with a cure for every illness

(2) a specialist traditional healer group practice using modern methods

(3) a fetish shrine

(4) a medical centre which uses scientifically tested herbal drugs

(5) a health post or clinic or hospital

(6) foreign versions of traditional medicine (Chinese herbal, acupuncture, chiropractic)

(7) religious/spiritual healing (prayer camp, regular church, private prayer)

(8) Home remedies (bitter leaf, bitters, other)

For example a question on medical pluralism, explored through prompts, ideas regarding biomedicine, ethnomedicine, faith healing and a variety of subgroups within these systems. For biographical disruption, prompts explored how diabetes affected a range of life circumstances, such as family life, work and social life. In addition to empirical themes, the interview guides sought to explore some theoretical themes, such as the nature of the unfamiliar, of emotions, and functions of socio-cultural knowledge. The empirical and conceptual themes were used as labels for two sets of 'Families'; 'primary families' determined by empirical questions and 'secondary families' determined by theoretical questions. Therefore each code had a prefix relating to the family to which it belonged: for example health concepts such as bodily strength and mobility would be assigned to the primary family 'health', while emotional categories such as fear, hope and trust would be assigned to the secondary family 'emotions'.

Identifying content, source, function, contextual features

The contents of codes constituted responses to general and prompted questions. These responses were viewed in terms of units of meaning – therefore codes were ascribed to both short and lengthy responses directed to questions or aspects of general discussions that bore relevance to the research categories. Sources were coded, in terms of external other, internal other and self-

derived categories. Functions were placed under two broad categories: 'called upon' from memory or through peripheral communicative practices or constituent of identity and everyday communicative and embodied practices. Usually sources and functions were explicit within codes. Sources and functions that were not so explicit were verified through examination of what I refer to as 'contextual features'. Contextual features situated codes within the broad meaning of full narratives, as well as social context of the interviews – features such as emotional stress, subtle and explicit interruptions, use of euphemisms and pointed silences.

Identifying consensus, conflict, absence

Definitions of consensus, conflict and absence changed depending on whether individual interviews or group interviews were being coded.

Consensus: Following from theoretical discussions, consensus was not viewed as homogenous, variations and different shades of meaning were expected and explicitly coded. The key goal was to document a core essence of meaning across consensual codes. At individual level consensus was coded in terms of 'consistency' or 'continuity' between interconnecting themes (for example between one's health concepts, health maintenance or illness action practices) or frequency with which particular themes emerged in response to interconnected interview questions.

Conflict /contradiction: The focus was on opposed forms of thinking, emotions, actions expressed in codes within group (interpersonal) and individual transcripts. Individual conflict was examined both within group discussion and individual interview contexts. Conflict at individual or group level was not viewed in terms of rationality or irrationality at this stage. Such inferences, where appropriate, were made during Activity Three when interconnections made within the data corpus facilitated a broad sweep of socio-cultural norms and values as well as the particularities of complex lifeworld and communities.

Absence: Following the typology of absence developed by Gervais et al (1999), absence was conceptualised and coded in three ways. First, in terms of an expressed lack of group or individual knowledge, experience and/or practice. Second, it referred to unexpected omissions

within a repertoire of discourses or practices (ie the absence of a theme that would follow naturally from an unfolding idea, argument or practice). Thirdly, absence was coded as products of inadequately posed or incomplete questions (poorly recorded segments of interviews which cut out sections of speech were subsumed into this category). A key source of research-led absence was the lack of professional nutritionists' perspective on diabetes care.

Activity Two: Segmented groups as units of analysis

At this point, much of the coding had been carried out. The two central coding processes focused on following through sources and functions of clustered themes in primary and secondary families, examining contextual features where necessary and identifying key areas of consensus, conflict and absence. For example I was interested in identifying the variety of ideas expressed by people with diabetes on biographical disruption and tracing the sources and functions of these ideas. Secondly, I was interested in the nature of consensus, conflicts and absences on the cluster of recurring themes at this group level. Intra-group dimensions were also examined. Patterns emerged during this process, clusters of dominant themes, or of conflicting ideas linked to groups or sub-groups. For example under primary family code 'biographical disruption (BD)', 'work' emerged as a dominant theme for rural farmers, or 'finances' for all rural and low-income urban people with diabetes. The clusters of dominant, marginal, consensual, conflicting, and silent themes, facilitated clearer identification of natural or strong groups (ie groups with common social realities and projects in Ghana). This set the context for mapping out inter-relationships within and between sub-groups, as a means of examining possibilities for in-group 'productive alliances' (Guareschi & Jovchelovitch, 2004).

Activity Three: The data corpus as a unit

Network features were applied to examine inter-relationships between discourses and practices across the segmented and emergent sub-groups. Intersections were worked out at family level, using the two central coding processes.

Three main forms of information were sought:

- (1) Shared/contested/absent thoughts, feelings, practices regarding health, illness and diabetes. This facilitated mapping out socio-cultural norms and values and modalities of socio-cultural knowledge, within which diabetes experiences and illness action could be understood.
- (2) The nature of biographical disruption as lived and/or discussed by different social groups. This allowed some insight into embodied experiences, the extent of handicap and the negotiation of lay and self-legitimation.
- (3) The nature of illness action: daily strategies, evolving styles against the backdrop of socio-cultural values, interactions and support.

This stage of analysis, yielded new social networks that cut across natural group ties and formed around production of particular modes of knowledge, experiences and practices. The constituents of social representations were identified at this stage. Positive and negative dimensions were identified for the three broad groups.

Data Analysis: Empirical, theoretical and policy intersections (Stage Three)

This stage of analysis took place at the end of the Atlas/ti textual and conceptual work. Having identified the content, sources and functions of social representations, the final stage was to work through the practical implications for interventions. Drawing on the diagnostic aspects of the models developed by Guareschi and Jovchelovitch (2004) and Krause (2003), the central focus was to identify and document productive alliances within and between the three social groups segmented, as well as external groups/networks highlighted within participant narratives as important social actors/sites. The first stage involved mapping out a hierarchy of needs within life-worlds, the public sphere and the medical pluralistic sphere and identifying needs that could be met through productive alliances between and within the groups studied and needs that lay outside the participatory power of studied groups. The second stage involved identifying external resources for unmet needs. This required empirical and theoretical synthesis that involved revisiting expert interview transcripts, policy documents, and theoretical discussions to work through hypothetical alliances grounded in Ghana's political and economic

realities. This process was not linear; there was constant revisiting and incorporation of emerging discussions in the Ghanaian and Regional context, as well as broader theoretical and practical debates on participation.

Table 4.2. Coding frame

		Coding category	Key elements of category
Coding One	Process	Content	Unit of meaning in direct or indirect response to research questions and prompts
		Source	(1) External other (e.g cross-cultural practice) (2) Internal other (e.g inter/intra-ethnic, public sphere, media) (3) Self (inter-personal; intra-personal)
		Function	(1) Memory, peripheral communicative practice; (2) Integral to identity and every discourses and embodied action
		Contextual features	Features (imported from fieldnotes) situating 'ambiguous' codes within broader narratives and social context of interviews: emotional stress, subtle and explicit interruptions, use of euphemisms, pointed silences etc .
Coding Two	Process	Consensus	Shared essence of meaning across codes (individual, group, data corpus). Minor variations and shades of meaning incorporated.
		Conflict /contradiction	Opposed forms of thinking, emotions, actions expressed in codes within group (interpersonal) and individual transcripts
		Absence	Lack of; (unexpected) omission; product of research process (inadequately posed or incomplete questions; inaudible sections of transcripts)

PART TWO

INTRODUCTION TO PART TWO

The current overemphasis cultural and biomedical knowledge, leaves important unanswered questions about other kinds of knowledge drawn on to make sense of health and illness. It was important to examine contents of cultural knowledge, biomedical knowledge as well as other modalities of socio-cultural knowledge that shaped common thinking and feeling about diabetes in Ghana. This introduction to Part Two presents the modalities of knowledge identified through the use of cognitive-emotional polyphasia as an analytical tool.

Analysis identified six modalities of knowledge: cultural, political, religious, scientific, scientized and emotional knowledge. I explain the conceptual process shaping my definition of each modality and outline the key themes that confer each modality with its distinctiveness, as well as the inter-relationships between modality-themes. The sources of the themes are also outlined, as well as the legitimacy conferred to the nature of the themes and the sources from which they are drawn. Because I adopt the critical social psychology view that knowledge production, access and use is inherently shot through with unequal and shifting social and power positioning and relations, I will also outline briefly where unequal knowledge production, access and use appear and the factors underpinning such inequalities. This is particularly pertinent to identification of productive alliances for diabetes intervention and will be taken up in greater depth in Chapter Ten.

CULTURAL KNOWLEDGE

Cultural knowledge was defined as a modality consisting of themes which described Ghanaian tradition. Ghanaian anthropological work demonstrates that while tradition is underpinned by a 'fundamentally indigenous value system...that has its own pattern and its own historical inheritance' (Opoku, 1978, p.9), it constitutes a dynamic evolving system. This openness and dynamism necessitated a simultaneous examination of classical contents of tradition and contemporary versions or transformations.

Cultural themes resonated with well-documented classical Ghanaian (ie the pre-colonial Gold Coast) and Akan cultural knowledge⁸. Themes included shared concepts of health and health maintenance, the nature of illness and illness action and on death and dying. Cultural themes also focused on morality and ethics and their role in social and institutional norms and practices, as well as maintenance of societal health. Finally, cultural themes elucidated emotions called on in collective life and their social psychological functions. The interconnections between morality, ethics and shared/contested emotions in turn highlighted the ways in which culture, as a system, was subjected to collective cognitive-emotional scrutiny, rendering some aspects at once familiar and unfamiliar, legitimate and illegitimate. These processes will be made clear in the chapters that follow. The heterogeneous contents of this knowledge modality underpinned – or mediated the anchoring of - contents of the other outlined modalities. For example cultural emphasis on ethics underpinned shared political critiques of contemporary institutional practices. Similarly, shared cultural concepts of health maintenance and illness action provided the context within which biomedical discourses and practices were understood, used and/or critiqued.

Cultural knowledge was the most widely and consensually shared modality. It was drawn from the broadest sources: microsocial (family, friendships, community) and macro-social (the public sphere). Some themes drew on collective memory, typified by the use of Akan proverbs. Cultural knowledge, and most specifically religious elements, was also scrutinised through juxtaposition with Western culture. Access was independent of identity/social positioning, geographical location, or educational status (some of the key social sites though which unequal production and use of other knowledge modalities and modality-themes occurred). The

⁸ Classical themes were identified through extensive reading and conceptual synthesis of themes appearing in anthropological and historical texts on Ghana, as well as texts on the nature and social functions of Akan language (the dominant language used by rural respondents as well as non-English speaking urban participants). Core texts included Wolfson's (1958) 'Pageant of Ghana' which traces the history of Gold Coast and Ghana over a 400 year period from writings of explorers, colonial observers, missionaries and local intellectual and political authorities; Caseley Hayford's (1903) descriptive text on 'Gold Coast Native Institutions'; a recent compendium of Akan proverbs – 'Bu me be' - by Peggy Appiah and Kwame Anthony Appiah (2001) and anthropological and sociological articles and discussions on Akan culture (e.g Opoku, 1978; Nukunya, 1992; van der Geest, 1980, 2002, 2004). Some of these texts provided a useful historical source for making sense of politicised everyday discourses and practices.

majority of members of the three social groups drew on the key themes outlined in consensual ways. A notable exception occurred in discussions of the spiritual and supernatural dimensions of everyday life, where conflict emerged. Because this particular cultural theme is intricately linked to traditional and contemporary religious knowledge and identities, it is more useful to discuss its dynamics under the religious modality section.

Key dimensions of cultural knowledge

1. Cultural knowledge provided a conceptual framework for making collective sense of a multiplicity of themes: health, illness, individual agency and responsibility, morality, ethics, politics, culture itself.
2. Themes facilitated identification of emotions called on in collective and individual life and their social psychological functions.
3. The heterogeneous contents of this knowledge modality underpinned – or mediated the anchoring of - contents of the other outlined modalities (such as scientific and political knowledge).
4. Cultural knowledge *mediated but did not constrain* everyday life.

POLITICAL KNOWLEDGE

Political themes clustered round ethics, institutional practices, health of the social body; ecological balance, cultural identity and professional identity. Identified themes can be placed under three categories. The first category referred to the impact of unethical national and international institutional practices on societal health and ecological balance. Institutions and unethical practices singled out for attention included biomedical, ethnomedical and faith healer groups, farming communities, informal sector food hawkers, and environmental agencies. Themes in the second category highlighted the impact of unethical institutional practices on national and professional identities. Institutions singled out were biomedicine, ethnomedicine,

faith healing systems, international pharmaceutical companies, Mission Christianity and evangelical Christianity. Discussions on ethics and national/cultural identity drew on race ideology: specific references were made to unequal and exploitative relationships between the 'white man' (denoting Europe) and the 'black man' (denoting Ghana or Africa). The exploitation of ethnomedical intellectual property and the delegitimisation of traditional religious healers constituted the focal points of these discussions. Finally discussions centred on processes through which identified unethical institutional practices could be changed. A minority of participants placed power for societal change within lay society and individual agency. For the majority, the power to effect social change was placed within the government domain. This process of 'conferring power' for social change to the government is particularly pertinent to discussions of addressing practical and policy changes of diabetes care. I will return to this in Chapter Ten. Political discussions were emotive: professional narratives on politicised inter-group relations and conflicts (both national and international) referred explicitly to a lack of trust; lay critiques of unethical professional practices were underpinned by explicit references to mistrust and anger.

In terms of access, some themes were accessible to all participants; others were unequally shared. Aspects of unethical ethnomedical and faith healer practices were the subject of national media debate and were therefore widely known and discussed by the majority of rural and urban participants. Other institutional practices were tied to particular geographical spaces and/or to groups of advanced educational or elite social status. Access to political themes on these practices was mediated by geographical location, professional status, or level of social proximity to professional gatekeepers. For example, unethical biomedical practices constituted a point of discussion for biomedical groups, ethnomedical groups (their immediate professional competitors) and urban elite groups with social access to high-ranking biomedical professionals. Issues of unethical farming practices appeared predominantly in rural narratives, but also within the narratives of urban female market traders, with trade links to rural farmers.

Key dimensions of political knowledge

1. Political discourses were linked to issues of professional and national identities.
2. Political discourses were emotive. Emotional dimensions revolved round the implications of unethical institutional practices for societal and individual health; ecological balance, and for cultural and professional agency.
3. There was an intricate relationship between politics and religion, for those who focused on the impact of Ghana's christianisation on contemporary cultural identity. This relationship was framed by race ideology.

SCIENTIFIC KNOWLEDGE (technical biomedical knowledge)

Scientific knowledge here refers primarily to biomedical knowledge on health, illness and diabetes. Two categories of themes were identified. The first category constituted technical themes drawn from four medical science sub-disciplines: physiology, pharmacology, genetics and endocrinology. These technical themes were drawn from local and foreign (usually UK, US) professional and specialist training, the ongoing use of specialist and international health texts (in particular WHO technical and applied health documents) and engagement in Ghana health service and international health conferences and debates. Some aspects of pharmacological knowledge were drawn from Ghanaian ethnomedicine: research and clinical activities of the Mampong Centre demonstrated the importance of this local resource. Technical knowledge was produced and shared mainly in English.

The second category consisted of simplified technical themes used in public health campaigns and during clinical encounters to inform lay people and patients on appropriate methods of health maintenance, the nature of diseases, treatment profiles and self-care. I refer to this second category interchangeably as scientized or practical biomedical knowledge. Biomedical professionals were gatekeepers of both technical (scientific) and practical (scientized) biomedical knowledge. This public role was underpinned by power and legitimacy

granted to biomedical knowledge, institutions, and practices by the state. In this section I discuss issues of access for scientific knowledge and turn attention to scientized knowledge in the next section.

Technical knowledge was viewed as the domain of specialist medical practice and not central to lay health practices, so unlike practical knowledge, was not disseminated in the public domain or drawn on during clinical encounters. There were two levels of unequal access: first within the pluralistic medical system, secondly between biomedical and lay groups.

There was notable variation in levels of technical knowledge drawn on by different biomedical group members. For example, in the case of diabetes, the specialist and newly qualified houseman drew on specialist endocrinology knowledge, while others drew from basic medical and nursing training. Endocrinological knowledge was deemed essential, in the view of the diabetes expert informant, for technical competence in diabetes care. This variation was linked to different routes of access to technical knowledge through pre- and post-qualification training. There was also unequal knowledge sharing between biomedical and ethnomedical groups, despite the official incorporation of ethnomedical intellectual property into local pharmacological and pharmaceutical knowledge production. This inequality was underpinned by imposition of biotechnological knowledge, by biomedical professionals, as a dominant framework for healthcare. Knowledge of medical science, or the ability to understand medical science, was prerequisite for gaining access to technical medical knowledge. Biomedical groups viewed ethnomedical knowledge as rudimentary and unscientific. This attribute was extended to ethnomedical professionals, who were viewed as useful resources for indigenous pharmacological knowledge but less useful as co-producers of clinical and applied pharmacology. Thus, biomedical groups simultaneously transformed ethnomedical intellectual property into scientific knowledge independent of ethnomedical professionals and barred ethnomedical professionals from accessing biotechnological knowledge and participating in its local development.

Ethnomedical groups bypassed usual routes of biomedical knowledge dissemination and drew technical biomedical knowledge - in particular physiological knowledge - from national and regional conferences, private readings of medical texts, and informal relationships with biomedical professionals. They also drew specialist knowledge from biochemistry perspectives on ethno-pharmacology, acquired through professional training and discourses of Ghanaian biochemists in the media. Biochemistry concepts were used to buttress the legitimacy of similar themes within indigenous pharmacological knowledge. This coupled with physiological knowledge, strengthened the gravitation of ethnomedical professionals towards greater biotech expertise and legitimacy within the competitive arena of chronic illness care. Essentially, biomedical and ethnomedical groups each misappropriated the knowledge base of the other. This situation exacerbated professional conflict, and underpinned explicit references to mutual distrust.

Within lay groups, some educated urban groups and people with diabetes accessed technical biomedical knowledge from foreign clinical encounters, local and foreign media, and health literature (pamphlets, recommended health books etc). Young urban groups drew predominantly from medical textbooks, as part of secondary and university general science education. One urban participant with diabetes drew on his professional biochemistry training. Lay groups drew on technical knowledge mainly to address the gaps left by inadequate dissemination of practical biomedical knowledge in order to make sense of disease generally or implications of living with illness.

Key dimensions of scientific knowledge

1. Educational status and class were central to the production and sharing of technical biomedical knowledge.
2. There was unequal knowledge sharing and misappropriation of knowledge between biomedical and ethnomedical groups. This resulted in professional tensions and mutual distrust, with particular implications for the collaborative health model.

3. Technical knowledge was important when practical knowledge poorly articulated or disseminated, but was inaccessible to poorly educated or illiterate groups.

SCIENTIZED KNOWLEDGE (PRACTICAL BIOMEDICAL KNOWLEDGE)

Two dimensions of practical biomedical knowledge essential to everyday illness action for all social groups were identified: practical physiology and practical pharmacology. Practical physiology constituted nature of disease, including dynamics of onset, progress and implications on life trajectories. Practical pharmacology constituted drug treatment and drug action. Two key points must be made here. First, both practical physiology and pharmacology were highly valued dimensions of socio-cultural knowledge of health and illness. Secondly, biomedical perspectives co-existed with traditional perspectives. This brought the importance of ethnomedical practice and practitioners to the fore.

Practical biomedical knowledge was disseminated in English and local language variations to lay groups through public health education or during clinical encounters. Quality of articulation and targets of dissemination varied. Variation was underpinned by educational and class barriers, language barriers and structural deficiencies. Biomedical groups drew problematic links between illiteracy (ie limiting this term to inability to read or speak English) and cognitive deficiency. This misconception shaped the body of scientized information given out during consultations and the communicative style with which this is presented. Scientized knowledge was generally over-simplified, even when presented in English, however considerable meaning was lost in translation when disseminated in local languages. For example diabetes is referred to as *esikyere yare* ('sugar disease') and hypertension as *mogya broso* ('overabundance of blood'), translations which do not capture complex metabolic profiles of the conditions. This watering down of physiological knowledge had particular implications for poorly educated and illiterate communities. While, educated groups could access technical knowledge to fill in the gaps in knowledge, uneducated individuals were at a disadvantage and

relied on traditional alternatives or second-hand knowledge passed on through proximal relationships or the media.

Restricted access was further compounded by structural deficiencies. One key consequence of the health system's lack of economic resources has been the unequal distribution of biomedical facilities and professionals. While urban groups had the greatest access to formal and informal interaction with public and private biomedical practitioners, rural individuals – and in particular Kintampo residents - faced the greatest barriers to these biomedical resources. A second consequence has been in terms of quality of public health education: health conditions that receive donor funding, for example HIV/AIDS, malaria, and other non-communicable diseases take precedence in health campaigns while unfunded conditions, such as diabetes and other chronic illnesses are marginalized. Therefore both urban and rural groups had little access to chronic illness information through this communication channel.

Biomedical perspectives on practical pharmacological knowledge were highly legitimised in the public. However its importance was undermined by similar dynamics outlined for practical physiological knowledge; unequal access, underpinned by class and language barriers, as well as structural inequalities. One key structural barrier to the use of practical pharmacological knowledge was the high cost of pharmaceutical drugs. In contrast, ethnomedical perspectives on practical pharmacological knowledge were readily available in the public sphere, its access mediated through cultural knowledge as well as aggressive and creative use of the media (audio, visual and print) by ethnomedical professionals. Furthermore, ethnomedical solutions were unhampered by class, language or structural barriers. Thus, ethnomedical and biomedical perspectives were drawn on interchangeably, within the public sphere. In instances where, biomedical perspectives or solutions were inaccessible, ethnomedicine provided legitimate alternatives.

Finally, it is important to note that analysis identified groups who had no professional or personal interest in scientized (or scientific) explanations. These constituted faith healers who

only treated spiritual dimensions of disease and lay people with no contact or close relationships with people living with illness. For them primary or secondary routes to scientized knowledge were not central to their daily social exchanges or relationships. Absences in scientized knowledge of these groups had particular implications on diabetes care.

Key dimensions of scientized knowledge

1. Scientized knowledge was central to everyday illness action. There were two key strands - practical physiology and practical pharmacology – both with corresponding traditional elements.
2. Scientized knowledge was poorly disseminated and in some groups poorly used. Class, language and structural barriers underpinned restrictions to access and use. Access was boosted through second-hand information exchange.
3. Inadequacies of access and use of scientized knowledge brought the public health importance of ethnomedical perspectives on practical physiology and pharmacology to the fore.
4. Scientized knowledge was not central to the daily social exchanges or relationships of some identified groups.

RELIGIOUS KNOWLEDGE

Religious knowledge centred on individual and group relationships with God and more broadly on moral values and systems. Themes revolved round good versus evil, morality vs immorality, sin repentance and redemption, spiritual balance and imbalance, and human misfortune (including illness).

Like cultural/traditional knowledge religious themes were widely shared and broadly accessible regardless of geographical positioning, social or educational status and more crucially religious identity. This knowledge was drawn from micro-social sources (family, friends,

consultations with rural nurses, interactions within the faith healing and traditional healing sphere interactions within the faith healing and traditional healing, Christian fellowship and scripture), macro-social sources (in particular media coverage of faith healer practices) and for one urban participant the international context (from professional consultations with a UK biomedical practitioner). While the content and sources of themes were similar they shaped different practical responses to misfortune and illness. The different practical functions to which shared religious concepts were put were shaped by two distinct religious identities⁹.

The majority of participants were committed Christians. For this group, Christian faith was the sole medium through which one could commune with God and attain Godliness and legitimate moral character. A minority of participants drew on traditional religious identities. This group practiced and endorsed religious pluralism. One participant – a traditional religious healer drew further from cross-cultural indigenous religions. Religious identities were inextricably linked to a cultural/national identity, and viewed in juxtaposition to the outside – predominantly Western – world. Discussions about religious identities revolved round the country's history of colonialism and mission Christianity. For the Christian majority traditional religion belonged to the era before colonialism, Christianity to the era after; Christianity was publicly desired and legitimised as the contemporary religion of choice, which conferred a modern enlightened status to Ghanaian culture, while traditional religion was publicly shunned and delegitimised for its links with an 'uncivilised past'. For the minority drawing on traditional religion and religious pluralism this public delegitimation was viewed as a politicised move to rid Ghana of its cultural character.

These polarised ideological positions shaped cultural and individual identities. Thus traditional religious healers, described by most as social mediators of traditional religion – a role imbued with both respect and fear - were delegitimised in the public sphere. In contrast

⁹ One urban participant described himself as an atheist, although he engaged in a philosophical discussion on the nature of traditional and Christian religion, seeing both as highly similar in both content and social psychological function.

Christian faith healers received public legitimation. However, analysis also revealed discrepancies between public legitimation and private use of these professional groups.

Key dimensions of religious knowledge:

1. Religion permeated everyday life interactions and practices of the majority of participants.
2. Two religious identities were identified. The majority Christian group was closed to non-Christian ideals, while the traditional religious minority espoused religious pluralism. Both groups drew on identical religious themes.
3. Aspects of religious knowledge and discourses were politicised, particularly among minority religious groups who made explicit connections between religious and cultural identity/integrity.
4. Religious narratives and practices were underpinned by emotional conflict.

EMOTIONS (EMOTIONAL KNOWLEDGE)

Akan language has no linguistic equivalent for 'emotion': however there are linguistic categories for a variety of feeling states, which underpin cultural, social and psychological life.

Some identified emotions were rooted in public life and served public functions. These illustrated the ways particular social practices were tied to particular emotional states, such as the link between envy (*ahodɔyaa*), jealousy (*anibere*), and love (*ɔdɔ*) and witchcraft activity. They also illustrated culturally sanctioned modes of responding to misfortune (eg stoicism during illness, suicidal ideation during prolonged misfortune). Another set of emotions highlighted the quality of inter- and intra- group relations. Trust (*awirehyem*) and mistrust in social institutions were dominant emotions underpinning political discussions of institutional ethics; fear (*ehuu*) and respect (*obuo*) of traditional religious healers underpinned religious discussions. These emotions shaped lay engagement with these professional groups. People with diabetes and those in their life-worlds drew on similar emotions in discussions of diabetes

experiences: fear, hope (*enidaso*), anger (*ebufuo*), fortitude (*hyedini*), sadness/misery (*awireho*) depression¹⁰ were key emotions explicitly referred to. Finally, narratives on biographical disruption and observations of everyday experiences of ethnography respondents highlighted emotions rooted in individual experiences of diabetes, which for some individuals underpinned self-constructed or externally imposed 'illness identities'.

Key dimensions of emotional knowledge

1. Emotions operated at different levels of social organisation, shaping cultural norms, mediating social relationships and individual experiences.
2. As mediators of identity construction and social interactions, emotions underpinned knowledge production in the private and public sphere.
3. The eclectic use of an array of emotions in everyday life underscored the theoretical significance of emotional ambiguities and tensions in the examination of socio-cultural knowledge production.

Table A summarises the key contents of the modalities of knowledge, key producers of contents and routes of access to groups who draw on and share these contents.

¹⁰ I should note here that there is no Bono linguistic equivalent for 'depression': individuals referred to a constellation of thinking-feeling states that approximated to the basic western psychiatric notion of depression. These included references to withdrawal into self, not being the same person one was before illness, not engaging in everyday activities like eating and sharing conversations, expressing suicidal thoughts and making frequent references to death.

Table A. Socio-cultural knowledge of health, illness and diabetes : modalities, contents and sources

Modalities	Key contents	Produced, Drawn on, shared by:	Routes of access
Cultural/traditional	All aspects of everyday life: health, illness, ethics (professional/personal), morality, emotions	All members of all groups (contents largely consensual)	Broadest range of proximal/distal communicative and embodied practices; collective memory
Scientific	Physiology, pharmacology, genetics, endocrinology.	Biomedical practitioners (producers) Modernised political herbalists (producers) Educated urban lay groups and people with diabetes	Professional training, biomedical discourse Professional Inter-group relations, media Educational setting; professional training
Scientized	Practical physiology Practical pharmacology	All members of all groups (biomedical groups producers of practical physiology and pharmacology; ethnomedical groups producers of practical pharmacology)	Public health campaigns, media reports, informal proximal conversations
Religious (Traditional religion; Christianity)	The nature of the supernatural, misfortune and illness; spiritual routes to misfortune and illness (list); morality	Broader discussions of religion: All members of all groups (faith healers shape Christian beliefs in public sphere) Spiritual routes to illness: out-there theory; personally held theory; valid theory for professional health care	Broadest range of proximal/distal communicative and embodied practices; international context.
Political	Ethics, institutional practices, societal health, cultural identity, professional identity	Some elements (ethics) drawn on by all members of all groups; other elements (institutional practices, professional identity) drawn on by urban politicised groups.	Shared themes (culture/tradition); urban themes (professional inter-group relations, informal relationships between health professionals and lay people)
Emotions	Cultural(envy, jealousy, love and immoral activity; trust/mistrust and foreign agencies); Social(trust, mistrust, fear, respect inter and intra-group relations). Individual: (fear, hope, anger, depression and illness experience)	Cultural level drawn on by majority of participants; social and individual level drawn on depending on group membership and health/illness status or role in life of individual living with illness.	Cultural level – as cultural and religious modalities above. Social and individual level (proximal/distal communicative practices; lived experiences)

PRESENTATION FORMAT FOR CHAPTERS FIVE TO NINE

In Chapter Four, I emphasised the importance of adopting a systematic analytic approach to the large volume of qualitative data gathered for this research. A similar systematic approach was adopted for the narrative layout and choice of quotes presented in the results chapters. The aim was to highlight the complex dynamics of results, while maintaining continuity and clarity across the chapters. Key aspects of this systematized process are outlined.

Collapsing rural and urban data

The tradition-modernity dichotomy adopted within dominant cultural work usually translates in practice to a rural-urban demarcation. There is an implicit assumption, when cultural researchers segment study sites and participants that the educated (usually urban dwelling) will draw less on traditional categories, gravitate towards biomedical knowledge and therefore – applying the KABP model - comply more readily with biomedical intervention. As the preceding discussion illustrated, there was little difference in distribution of cultural/traditional knowledge: educated (rural and urban groups) and uneducated (rural and urban groups) drew on similar themes for everyday practices. Secondly, although scientific knowledge was inaccessible to urban and rural uneducated or semi-literate groups, there was little differentiation between the ways in which rural and urban groups drew on scientized knowledge. Scientized knowledge, as discussion highlighted, was more relevant to everyday health practices. Therefore rather than a ‘modern’ urban vs ‘traditional’ rural split in health knowledge content, there are similar pockets of consensus, conflicts and absences in both urban and rural narratives. To minimise repetition rural and urban narratives are subsumed in the following chapters. Attention will be drawn to geographical differences, where they occur.

Collapsing health professional group narratives

Clear differences were identified between the three health professional groups. In Chapter Nine, findings are presented under distinct group headings. Some differences were also identified within groups. Discussions on scientific knowledge highlighted unequal knowledge distribution within biomedical sub-groups leading some on-group conflict. Within ethnomedical groups, broader social conflicts stemming from opposing religious identities set up divisions between Christian ethnomedical practitioners and traditional religious healers. Despite these pockets of conflict and knowledge asymmetry of knowledge, the majority of members of biomedical and ethnomedical groups drew on consensual themes in discussing health, illness and diabetes. Therefore to avoid unnecessary repetition, results for doctors and nurses are conflated, as are results for biotech and holistic professionals; conflicts and absences will be highlighted where appropriate.

Presentation of individual and group interview narratives

The complexity of narratives evolved over time in individual interviews, while they tended to be more spontaneous within group interviews. Beyond this, both methods yielded similar content across the empirical categories. Narratives from individual and group interviews with people with diabetes and health professionals are subsumed as a result. However, in areas where meanings unfold over exchange between interviewer and respondent, or over debate between group members, segments of these exchanges or debates are presented to capture essence and context of narrative.

Lay out of subsections

Analysis focused on consensual and contested themes as well as areas of absence. Under each empirical category, presentation of results will begin first with consensual narratives within each social group and then move on to describe – where these appear – areas of conflict, contradiction or absence. The order of presentation of these themes are informed by the

frequency and dominance (1) across all group narratives (life-world, lay, professional) (2) in less than three group narratives (life-world and lay; lay and professional etc) (3) by some members of all groups (4) minor themes in one or two groups (5) idiosyncratic comments in single individual or group interviews.

It is important to reiterate the assertion of qualitative researchers that qualitative research is not about counting opinions, but gathering trends in thought or spread of views. This is the primary position adopted in the presentation of results. However as a key aim is to gather information to guide practical intervention, numerical frequencies are presented where appropriate, to provide a quantifiable context on which interventions can draw.

Quotes

In presenting each quote, my central aim is to present a 'unit of meaning' that captures the essence of narratives and arguments (see Chapter Four). For this reason, lengths of quotes differ. Furthermore, quotes are contextualised within individual/group narratives, broader social groups and within context of data corpus. They are not treated as linear narratives unfolding with each pre-determined research question: line numbers are omitted therefore. When presentation of results refer to consensus between groups, one quote that captures meaning the best will be used as illustration; if there are variations of consensual themes a range of quotes will be presented to reflect variation in views. When results focus on conflict, a range of quotes that capture/illustrate this conflict will be presented.

Language

The majority of Ghanaian language words and phrases used are Akan (mainly Bono, some Twi and Fanti). Two sets of urban group interviews were conducted in Ga: quotes drawn from these will be highlighted. Some Akan phrases or words cannot be translated easily into English. These are presented verbatim with explanations in double parenthesis (see Table B below). Other local terms that require clarification will also be presented in similar fashion. In all local narratives, participants draw on English terms: bilingual expressions will be highlighted. Where

meaning is clear, quotes from these participants are presented verbatim – where clarification is required, this is presented in adjoining parenthesis.

Table B: Transcription symbols

Format	Explanation
<i>Italicised words</i>	Twi if cannot find exact meaning; English, if segment of Twi narrative is in English
<u>Underlined words</u>	Emphasis or emotional stress placed on words or expressions.
()	Empty parentheses indicate inaudible sections of tape
(words)	Words in single parenthesis indicate possible hearings
((words))	Words in double parentheses indicate my descriptions and explanations rather than transcriptions
...	Omission of sentence segment
[...]	Omission of one entire sentence
Participant identifiers	Young/middle-aged/elder → male/female → PWD (person/people with diabetes) / SO (significant other) / LP (lay person/people) / → Accra, Tema, Nkoranza, Kintampo. Ethnomedical professionals: bio-tech herbalist, traditional religious healer

OVERVIEW OF CHAPTER FIVE

This chapter focuses on shared/contested meanings of health, illness and medical pluralism and is presented in three parts. Part One focuses on concepts of health and health practices. Part Two focuses on concepts of illness. Part Three presents perspectives on illness action, contextualised within assessments of biomedicine, ethnomedicine and faith healing. The synthesis that follows focuses on three key findings: (1) the heterogeneity of socio-cultural knowledge of health, illness and chronic illness; (2) the psychological, socio-cultural and material mediation of illness action; and (3) pluralistic health systems as a co-existence of alternatives. The synthesis is placed within the regional chronic illness research context.

CHAPTER FIVE

SOCIO-CULTURAL PERSPECTIVES ON HEALTH, ILLNESS, AND MEDICAL PLURALISM

5.1. SHARED PERSPECTIVES ON HEALTH

Participants conceptualised health in terms of individual balance and collective (societal)

balance: both dimensions were intricately linked.

5.1.1. Health as individual balance

Physical balance was central to individual health. Rural participants drew directly from the Twi expression for 'health', '*apomudini*' which translates literally as 'strong body'. Two sub-themes emerged as explicit symbols of physical balance: health as physical strength and health as the lack of pain. Both notions were linked to mobility and ability to work.

It is about being strong to go about your business. If you are not sick that is when you are able to work
[young, female, SO(Nkoranza)]

When you feel physically or within yourself you are fine, you are ok you are able to carry on all that
you do, your daily duties without having any pains or feeling anything wrong with you, then I think
you are OK. [young, female, SO(Accra)].

When people with diabetes were asked to evaluate their health status, for example, a majority evaluated health on the basis of the severity and duration of physical disruption. Thus, participants who experienced little to no daily physical disruption reported being healthy despite living with diabetes, while those who experienced daily and/or prolonged physical disruptions reported being unhealthy. In all narratives, physical disruption constituted the catalyst that set of a complex range of disruptions to broader life circumstances (see Chapters Six and Seven).

Physical balance was intricately linked to psychological and emotional balance. Health maintenance, discussed shortly, was framed broadly by subjective knowledge of one's unique state of physical and psychological balance. I have termed this inter-relationship between the

physical and psychological balance ‘body-self’ knowledge, borrowing the term from Helman (2000:14) who has identified similar conceptualisations of health as physical-psychological balance in other African contexts¹.

The human being has a mind and a spirit, so there’s the emotional and psychological content. So not only is health the mechanical side of things but also a combination of the balance between the emotional and spiritual. [middle-aged,male,PWD(Accra)]

The intricate relationship between physical, psychological and social dynamics came to the fore in some narratives. Here, social factors were seen to have a significant impact on one’s mental health, which in turn could cause physical disruption. Conversely, prolonged physical disruption could cause and exacerbate psychological and emotional imbalance, especially in the absence of socio-economic support. Two biomedical participants drew on WHO definitions on holistic health, which resonated with these cultural notions.

Health means that the person has a good sound of memory and he is healthy financially, morally, socially, every aspects of life. If the person is okay with that then he is healthy. [middle-aged, female,SO(Accra)]

The WHO definition for health talks about generally or physical, social well-being and not just the absence of disease. So basically if somebody says he's well, you'll be looking at whether the person is physically well, socially we'll be thinking about whether the person is okay, and then whether mentally he thinks he's okay. [doctor(Accra)]

5.1.2. Health as societal balance (a balanced ‘social body’)

Societal health was defined in terms of balance between social relationships and between society and the environment. Participants juxtaposed contemporary societal health with the health of previous generations: contemporary societal health was deemed less balanced. The poor quality of contemporary health was linked to two factors. First, a notable rise in unethical institutional practices; secondly, diminished engagement in traditional health maintenance practices. As both themes relate to societal ill-health, I will return to them in later sections.

¹ This has also been noted in other non-western cultures (eg, Bates et al, 1997; Angel and Guarnaccia, 1989)

5.1.3 Health maintenance practices

For the majority of participants, health maintenance was framed by subjective knowledge of one's unique state of body-self balance. This set up two dimensions of personal responsibility. First, detecting and responding appropriately to unusual or prolonged changes to body-self balance and secondly, engaging in everyday practices that maintained body-self balance

That's why I tell you if you are moving always, you have to know that I've changed, there are some changes in me..[...]. I know if I slept and wake I see some small changes in my body, I have to know what to do so that I'll be relieved. [traditional-religious-healer (Accra)]

I have termed the health maintenance practices outlined by the participants 'proactive health practices' to emphasise their explicit reference to active practices aimed at preventing illness - they are conducted in the absence of illness as opposed to in response to illness. Eight proactive health practices emerged across narratives. Table 5.1 shows the themes, in order of dominance between and within group narratives and the knowledge modalities from which they are drawn.

Table 5.1. Socio-cultural perspectives on proactive health practices

	Proactive health practices	Spread of views	Modalities
1	Dietary balance	All participants	Cultural; Scientific; Scientized.
2	Good hygiene	All participants	Cultural; Scientific.
3	Lifestyle practices	Majority in all three groups	Cultural; Scientific; Scientized.
4	Exercise	All groups (except faith healers)	Cultural; Scientific; Scientized
5	Medical checks	Majority, all three groups.	Scientific; Scientized.
6	Rest	Rural lay, rural people with diabetes	Cultural.
7	Herbal Prophylaxis	Rural/urban lay and people with diabetes; Faith healers, Ethnomedical.	Cultural.
8	Moral integrity	Rural lay and people with diabetes	Cultural; Religious.

Three aspects of proactive health practices that have particular implications for diabetes self-care are worth noting here:

1. Participants noted that while it was relatively simple to respond to sudden changes in physical health, it was much more difficult to engage in proactive health practices. Practices that involved deviating from everyday routines, or those that involved extra

financial cost were difficult to maintain. Medical check-ups, use of prophylactics and exercise fell under these categories.

2. There was broad consensus that while proactive health practices facilitated the maintenance of body-self balance, illness was an inevitable and inescapable aspect of life's natural process.

Somebody can prepare a drug that will keep us from getting sick, but we must know that sickness is part of human nature. [traditional-religious-healer(Nkoranza)]

3. There was a dominant view that a philosophical and pragmatic attitude to illness was as important as engaging in proactive health practice. For elderly participants, this attitude was linked to a broader acceptance of the inevitability - and for some a welcoming - of death.

5.2. SHARED PERSPECTIVES ON ILLNESS

Illness, like health, had both individual and social dimensions. Illness at the individual level referred primarily to body-self disruption; however body-self disruption could be underpinned or exacerbated by social and spiritual factors. Illness at societal level referred to a disruption of societal balance. Table 5.2 highlights the causal themes for individual and societal illness and the sources of these themes.

5.2.1. Body-self disruption

There were three dimensions to discussions on body-self disruption. First illness was characterised by bodily pain: illness was at its most *felt* when there was physical pain.

Sickness is when you wake-up in the morning and you are having stomach aches, head ache and pains all over the body. [middle-aged,male,LP(Nkoranza)]

Second, illness undermined physical strength and mobility: being 'bedridden' or 'physically disabled' gave the clearest indication of illness to self and others. Within both urban and rural

contexts, the level of disruption to mobility constituted a key criterion for granting either 'conditional' or 'unconditional' lay legitimation to the ill.

Illness is what makes you immobile. If a person is laid out in bed, can't get up, that is illness. [middle-aged, female, PWD(Kintampo)]

The third dimension, appeared mainly in biomedical and biotech ethnomedical narratives, and referred to the internal bodily mechanisms of disease. Biomedical doctors referred to pathophysiological changes, which could be detected through low and high biotech examinations.

Table 5.2. Socio-cultural perspectives on causes of illness

Causes of illness	Spread of views	Modalities/Sources of themes
1 Dietary imbalance	All three groups	Cultural; Political.
2 Poor hygiene	All three groups	Cultural; Political.
3 Over-exertion	Rural lay groups; rural people with diabetes	Cultural.
4 Poor lifestyle practices	Majority, all three groups	Cultural: scientific.
5 Poor institutional ethics	All three groups	Cultural; political
6 Moral transgression	Rural lay healthy groups and people with diabetes	Religious
7 Spiritual disruption	All three groups.	Religious (traditional, Christian)
(1) generalized evil	For Urban groups, biomedical	
(2) trad. religious deities	professionals and non-political	
(3) witchcraft*	herbalists spiritual causal theories are 'out-there' knowledge.	
8 Societal imbalance	Majority members, all three groups	Cultural; Political; scientific, scientized.
(1) toxic staples		
(2) poor health maintenance		
(3) sedentary lifestyles		
(4) environmental pollution		

Notes:

1-4: individual domain; 5-6: individual-social domain; 7: spiritual domain;

*I place this under 7 because even though witches can be named and shamed, what they do, and how they carry out these activities is hidden from the realm of everyday observations.

Ethnomedical professionals linked poor physical health to impure blood, and stressed that successful cures were dependent on blood purification.

For a human being, blood that circulates in us is what sustains the body, so if it is contaminated then the body is diseased. Since blood should always be pure, any foreign matter introduced to it, you will create one form of disease or other. So it is the blood that is the main cause of disease. So that if the kidney that purifies the blood is also not effective then you can catch a disease. [bio-tech-herbalist(Nkoranza)]

Body-self disruption was attributed to a range of inter-related causes: neglect of proactive health practices, psychological disruption, spiritual disruption, and societal ill-health.

Neglect of proactive health practices

While the majority of proactive health practices were individualised, participants stressed that most practices relied on social and material mediation. For example dietary imbalance for some groups was linked to economic deprivation and the lack of quality staple foods. And while participants stressed the importance of medical check-ups, biomedical care was expensive and – for some rural groups – geographically inaccessible.

Psychological causes of illness

Psychological causes were discussed in terms of disrupted mental and emotional states. The role of social factors was strongly implicated. Participants noted that illnesses with psychological causes were at root framed by social and economic problems. For example, disrupted family relationships or extreme poverty led to excessive anxiety and worry, which caused illness.

Male discussant 1: poverty also causes disease. There are people who when they don't have money can get sick. They can wake up in the morning and [think and worry continuously] until they fall sick and immediately they get money –

Male discussants 2 and 3: they are healed

Danso: that means that is also psychological -

Entire group: yes. [middle-aged,male,PWD(Nkoranza group)]

When you wake up in the morning with no food to eat and you cannot go out with your friends, it could be a source of worry and can increase your chances of sickness. [young,male,LP(Nkoranza)]

Spiritual causes of illness

This theme appeared in all narratives and in two broad ways. For biomedical professionals, non-politicised herbalists, some urban people with diabetes and urban lay participants, spiritual causal theories constituted out-there theories, intrinsic to Ghanaian cultural concepts of health and illness, but not subscribed to by participants themselves. For the remaining participant sub-groups, spiritual causal theories were viewed as both legitimate cultural as well as personally held beliefs. This second group drew on different three spiritual causal theories, all of which generated some conflict between and within groups and individual narratives.

Spiritual causal theories as out-there belief systems

Three consensual themes were identified. First participants asserted that lay people (out-there) separated illnesses into two categories, physical and spiritual. Illness underpinned by natural or physical causes, such as malaria were easy to cure. Illnesses underpinned by spiritual or supernatural causes, a category under which a variety of chronic conditions were placed, were resistant to cure. According to participants these lay ideas transcended class and geographical boundaries.

That cuts across class, economics - that traditional belief of evil spirit causing chronic disease cuts across, no matter how educated one is. [doctor (Accra)]

The second theme referred to lay spiritual theories in terms of secondary theories. Participants noted that lay people drew on spiritual causal theories, when common sense interpretations and responses failed to provide adequate solutions to prolonged illness.

If I hit my foot against a stool and I get hurt nobody will think it's a spiritual illness, but if I hit my foot and apply all the drugs known to cure it and the bruise is still there, then you might think there is a social cause, there could be a spiritual reason. [biotech-herbalist(Accra)]

Participants argued that treatment practices stemmed from these distinct conceptualisations: lay people drawing on physical or natural causal theories would seek pharmacological treatment

from the biomedical or ethnomedical sphere, those drawing on spiritual causal theories would seek spiritual treatment from the ethnomedical and faith healing spheres. These narratives resonated strongly with the linear models proposed within dominant cultural and KABP approaches.

Those who assume or believe their disease is of spiritual cause will not come to the hospital. If they do, then they've been in hospital after which they don't feel better and then they attribute it that this can't be a natural cause and natural pertains to the fact that they assume it's been caused by a bacteria and unnatural means somebody's spiritually is working against their health so in majority, those who come to hospital will accept the fact that their disease is of bacterial, viral or environmental causes as opposed to a specific individual or group bewitching them. [doctor (GP)(Accra)]

Spiritual causal theories as personally held beliefs

Three spiritual causal pathways were outlined in the narratives of participants who held personal spiritual causal beliefs:

- (1) A generalised notion of evil, out-there and external to self and society, tied strongly to the existence and work of the devil, as well as unidentifiable supernatural entities.
- (2) Spiritual disruption caused by inter-individual conflicts and punitive actions meted out through sorcery and witchcraft.
- (3) Punitive action by traditional religious deities ('*abosom*') and traditional religious healers.

Disruption caused by the devil or evil-in-the-world

Participants made broad reference to illness caused by evil forces in the world. Majority drew on a dichotomy of God representing good and the devil representing evil. According to these narratives illnesses underpinned by evil/supernatural causes were inevitable, as long as the devil - and the evil wreaked on humanity by the devil - existed. The dominant rural expression '*abonsam yare*' (devil's, or Satan's, illness) captured the essence of the devil's role in creating general misfortune and illness. Some references were explicitly drawn from Christian scripture.

As Genesis states, everything God made is perfect. Any illness is caused by *Satan*. [faith healer(Kintampo)]

Rural participants who placed emphasis on moral integrity as a proactive health practice argued that individuals could harness misfortune and disease for themselves and others, if they adopt evil ways, or free themselves of misfortune and disease if they resisted evil.

The *Bible* also says that our disobedience can bring sickness on us but if we turn away from our evil ways, we will be free from sickness. [middle-aged, male LP (Nkoranza)]

Spiritual disruption caused by inter-individual conflict

Inter-individual conflict led to two types of spiritual disruptive activity: sorcery and witchcraft. Sorcery activity was described in terms of '*nto yare*' ('bought disease'). *Nto yare* referred to 'contract' traditional religious ritual paid for by envious or vindictive friends, neighbours or relatives, aimed at causing misfortune or illness. *Nto yare* could occur in three ways: as a result of unprovoked envy or jealousy, as a product of past and ongoing family/social conflict, or as punitive action or retribution for moral transgression.

Madness can be caused by spiritual means. For example say my husband died and left me possessions and the extended family wanted full ownership, and I resisted they would buy madness for me. If you go to the *mental hospitals* you see lots of widows who got mad through those means. [young female LP(Nkoranza)]

Sometimes these things occur through one's bad deeds. For example if you steal from someone, they can buy a disease for you. [young male LP(Nkoranza)]

Within some narratives, notions of '*abonsam yare*' and '*nto yare*' were intricately linked. This link was explained in three interconnected ways: firstly, at a broad level 'demonic' illnesses existed because the devil exists; secondly, the medium through which individuals acquired such illnesses was through human rituals of sorcery and/or witchcraft; and finally spiritual illnesses could not be diagnosed using biotechnological methods. This multifaceted definition of spiritual

illness is illustrated the narrative of a rural carer Alice (see Chapter Seven for participant details).

Alice: The devil exists, so there's demonic illness.

Danso: Can you mention any disease that's usually considered demonic?

Alice: A young lady died here recently. It was alleged that her grandmother bought a disease for her.

Danso: What was wrong with her?

Alice: She used to have chronic stomach ache, which was on and off. She lost weight. It continued for about 2 years and she was never free.

Danso: So when that happened was she sent to the hospital?

Alice: When that happened and she's admitted -

Danso[interrupts]: the doctor diagnoses the disease

Alice: The doctor can't diagnose at all.

Danso: So it means for demonic diseases the doctor usually can't diagnose

Alice: The doctor can't diagnose. She did *x-rays* and all but nothing was diagnosed, yet she was very sick.

Witchcraft as spiritual agent:

Witches had the power to 'infect' unsuspecting individuals with illness, misfortune or witchcraft. Although the 'infection' process was closed to normal human (or technological) scrutiny, the majority of participants asserted that witchcraft activity occurred at night and took effect through dreams². Nkoranza participants, for example, spoke of mysterious illnesses appearing first in dreams and assuming physical realities upon waking. These explanations were drawn from personal experiences.

There was time that I dreamt that I was going to farm with my in-law and she took a cutlass to cut some wood; the cutlass cut my hand, and in the morning when I woke up, my hand was really cut. I showed it to my parents. I became worried all day and didn't eat. [young, female, LP(Nkoranza)]

² This notion of dreams as conduit for witchcraft action has been reported in a variety of anthropological texts on Akan cultural systems and folk psychology. It centers on two key dimensions of the self and personality - the *okra* ('the undying part of man, the part which is given directly by the Creator before man is born into the world' (Opoku, 1978:94-95) and leaves only at death) and the *sunsum*, ('the intangible element which accounts for the character (*suban*), disposition and intelligence of a person" (Opoku, 1978:96)). In contrast to the *okra* which is always constant, unchangeable, and intimate, the *sunsum* is subject to change and shapes visible aspects of personality, including moral character. More crucially "the *sunsum* is believed to be able to leave the body during sleep, and may or may not return to its owner. It is also supposed to be the *dramatis personae* in dreams, and the part of man which is open to attack by witchcraft. At the same time it is the fundamental and most effective antidote to witchcraft." (Opoku, 1978:97). The extent to which one's *sunsum* can fight witchcraft depends on its strength, which can be developed during one's lifetime.

Witchcraft activities were emotionally driven. Envy of the victim's social status or personal attributes (beauty or intelligence for instance) was the dominant theme.

...there may be many people staying with you in the house. You may be the most beautiful one amongst them. And if there is a grand parent who doesn't like you, she could bewitch you or invoke a disease upon you. Others too may put something in your food for you to eat. That is the way people acquire witchcraft. [middle-aged, male LP(Kint- ampo)]

Some participants attributed witchcraft activity to intense love. The argument went that if the victim was a loved one, witches often chose to infect with illness rather than witchcraft. There was a sense here that living with illness, even a stigmatised, incurable, fatal condition like AIDS was preferable to the burden of living as a witch.

R1(m): conditions such as AIDS can be caused spiritually. There are some people who will give AIDS – instead of witchcraft – to their favourite children.

Danso (laughter in voice, laughter among group): *Na kyere se ope na sem nunu* ((so this would be in instances where they love their children))?

R1(m): *Ehe ((Exactly))*. Sometimes, *nanafoo*, ((the elderly)) if someone wants to pass on witchcraft to you, they might not, instead they'll pass this disease on to you. [young,male,LP(Nkoranza)]

Secondly, witches could cause themselves protracted and/or incurable illness. The reasons underpinning such self-directed actions, were not as clear-cut as actions directed at others.

I know someone who was suffering from rheumatism and it was very serious whenever he got an attack. They sent him to many places, not knowing he was a wizard. He confessed that he had hidden scorpions in his body. Since he confessed he has never suffered from the sickness again. [middle-aged,male,LP(Nkoranza)]

Traditional religious deities as spiritual agent:

Traditional religious healers referred to punitive measures meted out by traditional religious deities ('*abosom*') to immoral individuals. The emphasis was on spiritual activity aimed at rebuilding the moral core of the transgressor. Punitive measures were reversible if there was

(pro)active repentance, a two-stage process involving confession and active demonstration of lifestyle change. In this sense traditional religious healers acted as moral guardians in society.

When are tortured spiritually by *abosom* ((traditional religious deities)), then it means it wants you to tell the truth, not that it wants to kill you, so if you go to hospital and you are not conscious of it, the doctor will try as much as he can to no avail. There are others who are tortured by *abosom*, who then take refuge in the church and continually worry the doctors instead of asking (our help)...and if the truth is told, *abosom* will want a confession for the one to be freed, so if you confess then you are freed from the torture, unless you have killed a lot of people. [traditional-religious-healer(Nkoranza)]

Lay groups described traditional religious healers as keepers of mysterious and often dangerous powers. First they had the power, through the action of traditional religious deities, to cause spiritual illness. Secondly, they had the power to foster strong addiction for their services. The role of traditional religious healers as moral guardian was absent in lay narratives

The worst thing about the fetish priest, I don't know but when you go there, you keep going there, because it looks like when they cure you of something, I don't know whether they put something in you, for you to come back again... 'cause you go there with a headache, because they cured you, you go back with a stomach ache. [young,female,LP(Accra)]

Fear was expressed both at the power of addiction and the consequences of overcoming the addiction. Explicit reference was made to the unique power of Christian faith and prayer to break the powerful hold of traditional religious healers and deities.

R2: Someone might have gone to *abosomso* ((traditional religious deities)), which might have brought that curse or sickness on her. When she visits the prayer camp and the Pastor gets that revelation, she will be relieved. [young,female,LP(Nkoranza)]

5.2.2. Societal imbalance (disruption to the social body)

Societal imbalance was attributed to four factors: (1) 'toxic staple foods', (2) Sedentary lifestyles, (3) Poor health maintenance practices and (4) Environmental pollution and ecological damage.

Toxic staple foods

Participants linked the rising prevalence of a variety of illnesses in Ghana to toxic staple foods. Farmers' use of artificial fertilizers and pesticides, the spraying of chemicals on foods to induce faster ripening, and the use of poisons to catch wild game and freshwater fish, were cited as chief contributing factors.

The food we eat today is full of toxins. Everything is sprayed with fertilizer - pepper, onions, tomatoes, garden eggs, plantain, yam - everything is fertilized. Our living is not like that of the olden days. Cocoyam or banana could be in the soil for 3 years and you could uproot and eat it without falling sick. Today ... when pineapple is not fully mature, you can harvest it, cover it, sprinkle *carbide* on it and it will be ripe in exactly 3 days. When you cut it, you see it's not mature. So part of our diseases are caused by the food we eat. [...]. Fishing with poison, and so on. Each time you eat any of these foods, a little amount of poison is deposited in your blood, and this continues bit by bit. [middle-aged,malePWD(Nkoranza group)]

Strong links were made in all narratives between the economic decline of the nation, the rise of unethical institutional practices and deteriorating farming practices. Participants noted that the growing demand for farmers to increase crop yields for both domestic and foreign markets, coupled with the fall in profits from the farming sector, had contributed to the rise in unethical farming practices.

It looks as if these days people believe that when they use these chemicals in cultivating food crops they will grow faster and bigger because of that almost every food crop is grown with these chemicals. For instance I know that *carbide* is used in growing pineapple. Farmers are just interested in how fast they can make money. That is all. [young,male,LP(Nkoranza group)]

For some participants, the scarcity of good quality staple foods was compounded by increased availability and use of unhealthy foreign foods. Urban participants cited the widespread use of processed and canned foods as a key contributor to poor societal health.

In present times, we are affected by a lot of disease which were originally not in our country. Look at the kind of food we eat, for example the kind of water that is used to water vegetables is not good. This can even make you sick when you eat it. You see, we have even stopped eating some foods and now eating different things that are foreign. We drink ice water now; we eat margarine and some other foods, which give us diseases. [young,female,SO (Nkoranza)]

These days there are so many artificial foods. Switch on the TV and there's a woman saying how delicious your food will taste with Maggi Cube' [middle-aged,male,PWD(Accra)]

Sedentary lifestyles

Both urban groups and the younger rural groups attributed poorer quality of health to sedentary lifestyles. Contemporary Ghanaian society was deemed less physical active compared to past generations. Urban participants further argued that contemporary rural communities whose daily work involved physical labour were healthier than urban communities engaged in less physical forms of work.

Collective decline in health maintenance practices

Urban and rural lay groups argued that while contemporary health was poorer, there had been great progress in biomedical advances, and 'the modernisation of healthcare in Ghana' (urban male) which meant that a broad array of diseases which were incurable in the past, could now be cured.

Doctors go to the extent of being able to forecast an impending epidemic and vaccinate people against it. An example is the *CSM* ((cerebro-spinal meningitis)) epidemic. [middle-aged,male,LP(Nkoranza group)]

Some presented a counterargument to this – noting that biomedical advances and successes for Ghanaian public health had paradoxically led to a collective de-emphasis on proactive health maintenance. In other words, people were no longer careful about avoiding health problems because a variety of solutions existed.

We know we have treatment facilities, so we don't focus on health prevention these days.

[young,female,LP(Accra)]

Environmental pollution and ecological damage.

For urban lay participants, people with diabetes and doctors, environmental pollution was seen as problem rooted in the activities of two professional groups; government agencies ('town councils' and 'town planners') and informal sector food hawkers.

As far as I am concerned the majority of diseases in this country should not be handled by the Ministry of Health. It must be handled by the civil engineer. Most of our problems are civil engineering problems. [...] If our pavements are not sorted out, if we don't build things that encourage regular exercise, if we don't have parks that are open for people to leisurely walk around and burn off energy, there is no way that we're even going to deal with the chronic diseases. [doctor(Accra)]

When you come to Teshie- Nungua, where I'm living, you'll see these AMA ((Accra Metropolitan Assembly)) people carrying shit around that place and throw it there. People are living there, when it rains, trouble, you'll see this all over there. How do you expect people to live well? [middle-aged,malePWD(Accra)]

The urban GP raised the issue of ecological damage, a problem he attributed to environmentally unfriendly ethnomedical practices. He argued that given the absence of documented knowledge on indigenous medicinal plants, there could be no systematised effort to re-cultivate depleted resources.

Herbal medicine has one big fault, nobody cultivates that herb, the average herbalists knows the nim tree that is growing wild, he doesn't put one seed on the ground and he goes to take it. If we don't change our attitudes, we will lose out because we would have forsaken the environment really and we would have exhausted the natural resources that is in our hands.[doctor(GP)(Accra)]

5.3 ILLNESS ACTION

Practical responses to illness were underpinned by three key processes: (1) Seeking diagnosis (2) Selecting target-specific (or physiologically specific) treatment and (3) Complying with expert advice.

5.3.1 Diagnosis: lay and professional

The first response to body-self imbalance, all participants noted, was to get a diagnosis. A popular Akan proverb “*Wo ton wo yare a, na wonya ano aduro*” (‘if you sell (discuss) your disease you get a cure’) was quoted by a number of urban and rural participants to underscore the cultural importance of seeking diagnosis. Diagnosis could be carried out within the lay domain or the professional domain depending on the severity of and level of familiarity with the condition. If the illness had been experienced in the past, or was mild, and one had knowledge of effective herbal or over-the-counter medications for the condition, then one self-diagnosed and self-medicated.

When you are sick and you have knowledge of a certain drug or medicine, try that one first before you take the second step to the hospital. [middle-aged, female, LP(Kintampo group)]

If the illness had not been experienced before, or turned serious, then one sought professional diagnosis. For physical illnesses, the first port of call was the hospital or clinic, for the consensual reason that doctors were the most expert at providing accurate diagnosis of physical conditions. Some lay participants (Nkoranza group, one urban group) stressed that all illnesses whether mild or serious required professional diagnosis. They made two key arguments. First, mild conditions could be the start of a more serious, possibly fatal condition: for example a headache could be the beginnings of high blood pressure. Secondly in the absence of professional diagnosis there was a danger that self-medication could lead to the problematic use of pharmacologically incompatible or ineffective drugs.

I think that whatever the nature of your illness, you have to go to the hospital. Because as they say, these drugs work in specific ways. [...] However people persist in going to the drugstore when they are ill, thinking that...if I buy APC ((paracetamol)) to chew I'll get better. Sometimes, the drugs you buy may not be compatible with your blood. So I think if you're ill and you go to the hospital for them to check which drugs works for your ((unique physical make-up)) it will help you get better in the long-term.[young,female,LP(Nkoranza group)]

Illnesses with psychological underpinnings generally did not require professional diagnosis – the very nature of psychological disruption was strongly tied to one's mastery of body-self knowledge and the unique expertise this conferred on identifying unusual psycho-emotional change. For spiritual conditions, most cited faith healers, while some cited traditional religious healers as diagnostic experts. The professional expertise of both groups was highly contested. The reasons underpinning this conflict will be discussed shortly.

5.3.2. Selection of target-specific treatments

The goal for everyone seeking treatment during an illness episode was a rapid return to health. In the case of mild conditions with physical underpinnings, self-treatment was general route. The majority (including those who advocated professional diagnosis at all times), held practical knowledge of effective herbal drugs and range of over-the-counter drugs for several common and mild ailments such as headaches, stomach pains and general bodily pains and more serious conditions such as malaria, rheumatism and jaundice. For more serious conditions professional treatment was required. Initial treatment choices were made depending on whether the condition was wholly physical in nature or whether it was suspected to have other underlying causes.

Physical illness

The key focus was on pharmacological treatment. Biomedical and ethnomedical professionals were cited as experts in the treatment of a broad range of physical conditions. Both groups were deemed to possess a considerable array of drugs for the treatment of common acute conditions and minor physical injuries. There was a general view that ethnomedical and pharmaceutical drugs had similar plant sources and therefore had similar pharmacological benefits.

Some of the herbs have got medicinal properties and to tell the truth, most pharmaceutical companies work from them. They just isolate the radical and improve the properties of it.[doctor-GP(Accra)]

The little I know about it, is that it's the same ethnomedicine that has been converted to biomedicine – ethnomedical drugs are sifted and transformed with machines till biomedical drugs are produced. [middle-aged, female,PWD(Nkoranza)]

Two lines of thought emerged in discussions of ethnomedical and biomedical efficacy in chronic illness treatment. The majority of participants stressed that biomedicine was better placed, compared to ethnomedicine, to treat chronic illness. Biomedical professionals had expert physiological knowledge, as well as diagnostic and pharmaceutical expertise to address the complex profile of chronic conditions; ethnomedical practitioners however had insufficient physiological and diagnostic expertise to apply their pharmacological knowledge effectively in this area. A minority of participants made a distinction between contemporary diseases and what anthropologists such as Horton (1993) have termed 'folk diseases'. Folk diseases such as epilepsy, sickle-cell anaemia and infertility had well-established historical roots in Ghanaian culture, were deemed to have spiritual as well as physical underpinnings, and responded to ethnomedical treatment. Contemporary diseases such as hypertension, diabetes and AIDS were viewed as products of contemporary living, of Westernisation (for some). These demanded new, predominantly biomedical treatment methods. Both views were expressed in both urban and rural settings and generated – within group discussions – considerable debate and conflict.

Female discussant: One of my sister's daughters was suffering from fits. She was sent to the hospital but the situation was not getting better. We went to an herbalist who said he could treat the illness. Truly the child became better.

Danso: Can doctors cure fits?

Male discussant: Doctors have drugs for it but these drugs cannot cure completely especially when it is spiritually caused.

[middle-aged group interviewees(Kintampo)]

Ama: when we talk about sickle-cell, do you know that disease? What can you say about it – is it chronic or not?

Female discussant: With that one if you happen to get medicine, it can be cured. One of my children had it when he was about a year old and I was sending him to Techiman hospital most of the time. He is now

fourteen and has not had the disease since he was four. So I can see that it is curable.

Judith: Can someone else say something about it?

Male discussant (1): Sickle-cell is in two forms, and it is alleged that the spiritual one cannot be cured ((through biomedical methods)). One of my brothers had sickle-cell – presently a metal has been inserted in his leg bone to allow him to walk. But the disease appears everyday. A friend of mine has even died from that disease.

Judith: does anybody else want to comment?

Male discussant (2): it cannot be cured

Judith (to female discussant): *Madam*, do you agree with him?

Female discussant: As for me, the doctor told me that if the person gets it and is diagnosed early, it can be cured.

[young group interviews(Kintampo)]

Out-group professional assessments mirrored lay perspectives on biomedical and ethnomedical ethnomedical expertise. The scientific nature of biomedicine and the particular ability of biomedical professionals to carry out low-tech and high-tech investigative and surgery procedures emerged in all narratives. Dominant views on ethnomedical expertise centred on ethno-pharmacological knowledge and expertise in the treatment of acute conditions and minor physical injuries. Some conflicts also emerged which had some bearing on chronic illness treatment.

Generally, ethnomedical groups asserted that ethnomedical medications had superior pharmacological properties. However there was some in-group conflict about the extent to which herbal medicines could cure all diseases. Bio-tech herbalists made claims of expertise only to specific conditions, such as malaria, chronic back pain and HIV/AIDS, stressing their lack of professional expertise in aforementioned biomedical strongholds. Traditional religious healers claimed expertise in the treatment of all conditions, but drew particular attention to chronic or long-term conditions such as mental illness and infertility, which they argued had spiritual underpinnings, and could not be adequately addressed with biomedical methods.

Psychological underpinnings of physical disruption

Participants expressed the view that physical problems had psychological underpinnings or consequences. For some participants, attending successfully to psychological underpinnings of a physical condition removed the need for physical therapy. Conversely, physical symptoms were unlikely to be successfully treated without attention to psychological underpinnings.

Experience shows that some diseases are psychological diseases, so even if you don't take medicine, it will go because it is the <i>mindset</i> [middle-aged,male,LP(Nkoranza group)]

The key focus of treatment was to examine and address the social underpinnings of psychological and emotional distress. This could be carried out in the social sphere through counselling by family and friends or could be addressed in all three professional health spheres. No professional group was singled out as expert in this area. Successful professional counselling was determined by a professional's ability to communicate with patience and empathy, both key criteria for good health professional practices more generally (see section 5.3.3).

Spiritual illnesses

While faith healers and traditional religious healers were key providers of spiritual treatment, the expertise of both professional groups was highly contested. Within the lay context, traditional religious healing/healers and faith healing/healers characterised the split between delegitimised traditional religion and legitimised Christian religion respectively. To seek traditional religious treatment therefore, for the Christian majority, constituted sinful practice. Furthermore traditional religious healers evoked both awe and fear, in terms of the mysterious and dangerous power they held as social mediators of traditional religious deities. However, despite the public delegitimation of traditional religion, and the emotional tensions evoked by healers, frequent references were made of traditional religious consultations. This suggested a disjoint or conflict between public religious views and private spiritual needs. For example when rural participants discussed treatment of conditions such as epilepsy and sickle-cell anaemia they frequently used the term '*ko bisa*' ('seek answers' or 'conduct an investigation').

Ko bisa is a well-known euphemism for conducting traditional religious investigations. Individuals were careful to distance themselves from this activity however, referring predominantly to friends, relatives and acquaintances who had conducted traditional religious investigations or of circulating rumours of such practices. Some conceded that this reluctance to publicly endorse, use or admit to using traditional religious services was tied to their Christian faith and its condemnation of traditional religion.

R1(female): Please, with *ebiduro*, ((ethnomedicine)) those who give you the drugs, *edunsifoo* ((traditional religious healers)) if you go there for treatment, they can tell you to bring a chicken, or bring this amount of money, or kneel in front of the shrine, to receive the medication. Perhaps you are a Christian, trying out this treatment, being made to do things which I *feel* you might be uncomfortable doing. So I *feel-se* ((feel that)) with ethnomedicine, sometimes you get to the point where going to these kinds of places might not be a good idea.

R(male): It isn't good, don't say it might not be good (some laughter). (young LP group(Nkoranza))

For spiritual diseases sometimes it's the traditional religious healers who cure it, but nowadays, because of the abundance of churches and prayer centers, many people no longer like them.'

[young,male,PWD(Kintampo)]

While faith healers were publicly legitimised, they had two identified shortcomings, according to lay narratives. Firstly, this group overemphasised the spiritual underpinnings of illness to too great an extent and only offered spiritual treatment. Furthermore they had poor knowledge of physiological underpinnings of illness and lacked pharmacological expertise. Given that spiritual theories were predominantly secondary causal theories, and that the majority of lay and professional participants placed emphasis on physical dimensions of illness, faith healers were criticised as providing partial care. Secondly, urban participants viewed some faith healing services as expensive and emotionally exploitative, traits that contravened Christian emphasis on charity and goodwill. Ultimately, for this mix of reasons, the majority of participants preferred private prayer to using either faith healing or traditional religious services.

I know people who will not stay in their room and pray but would rather go to prayer camps for special prayers. For example when you go to the man of God (Osofo X) around this area, you will find a lot mad men tied to trees who have been fasting for a long period. I believe if these people are sent to the

psychiatric hospital they will recover earlier. If I had power in Ghana I would ban all faith healers. You don't have technical knowledge, you can't diagnose disease, yet you admit people and claim to be able to cure them. [middle-aged,female,LP(Kintampo group)]

The Bible even says if you are praying, you should enter your room and pray alone. God has given us all faith to pray. God has given us our will. It is not necessary to go to prayer camps for special prayers. [young,male,LP(Kintampo group)]

Lay critiques were endorsed in traditional religious and faith healer in-group and out-group assessments. In terms of expertise traditional religious healers considered themselves better placed to provide successful treatment for disease as they focused on both physical and spiritual dimensions. The impact of the clash between religious identities and beliefs on professional practice was expressed in two key ways. For faith healers, traditional religious practice was entrenched in superstitious ritual and resistant to Christian principles. Traditional religious healers viewed the clash in broader socio-political terms. The rural traditional religious healer argued that the Christianization of Ghanaian society coupled with the establishment of the new independent churches undermined the integrity of Ghanaian culture as well as the professional legitimacy of traditional religious healers. Crucially, this group espoused religious pluralism.

You see a fetish priest and he'll ask you to bring a chicken, bring some eggs, for a sacrifice. This is against Christian principles. [faith-healer(Kintampo)]

I am not saying that Christianity is bad. This is not what I am trying to say, that, it is not good, but even our father ((the healer's father who was a prominent healer in the region)) was a Christian before he was possessed by the spirit. In the olden days our grand parents' church - the traditional church God gave us, was the one we knew and the one through which we worshipped him, then the white man has added his to ours, so a lot of people feel that ours is ancient so we should stop. The white man comes to take the *abosom* ((traditional deities)) away and we sit here and say it is not good. Then psychologically, people think that we are civilized now that will not consult the fetish. That is why we throw away those traditions that we can improve upon. We are losing our custom so you should research and talk about it, that will help us. [traditional-religious-healer(Nkoranza)]

Societal ill-health

Solutions to conditions attributable to societal ill-health were placed primarily within the government's domain. Discussions appeared mainly in politicised urban discussions on societal health and illness and centred on government intervention of unethical institutional practices.

5.3.3. Compliance

Compliance was a cultural ideal. The dominant view across all social groups was the importance of following and committing to expert health advice. Two interconnected processes mediated treatment compliance: (1) Systematic assessment of treatment outcomes and (2) Critical assessment of pluralistic medical systems.

Systematic assessment of treatment outcomes

All participants placed emphasis on assessing the outcome of treatments, whether pharmacological, psychological or spiritual. Assessment involved paying explicit attention to the effects of treatment on body-self balance. Pharmacological efficacy was seen not only as a function of the intrinsic quality of the treatment agents, but of the body's compatibility with the agent used. Rural participants emphasised that '*obiara nu ni mogya*' ('each individual has their own unique blood' – hereafter 'physiological specificity').

Each individual has their own blood. For me, when I'm sick and I use *ebibiduro* ((ethnomedicinal drugs)) my sickness worsens. Ethnomedicinal drugs are good for some people however. For me it is doctor's medicine that works. [young,female,SO(Nkoranza)]

Emphasis on physiological specificity was a key criterion for selecting and complying with pharmacological treatments. Central to assessment of treatment, was sequential use of drugs. The dominant view was that dual use undermined the process of correctly identifying which drugs worked for or exacerbated particular conditions.

Some people combine. They visit the hospital and take *ebibiduro* (ethnomedicine) as well. You won't be able to tell which one is good. So as human beings when you're sick, if it's [indigenous medicine] that's good for you, take that, if it's [doctor's medicine] that's good for you, take that. But if you combine both you'll not be able to tell and when you get healed, you'll not be able to tell whether it was *doctor eduro* ((doctor's medicine)) or *ebibiduro* ((ethnomedicine)) that cured you. [young,female,SO(Nkoranza)]

Critical assessment of pluralistic medical systems.

A crucial mediating factor for compliance and successful treatment outcomes, for health professionals, was shared belief and trust between patients and their chosen health professionals. Professionals noted that treatment outcomes were likely to be negative if patient health beliefs clashed with professional beliefs, and positive if patients believed in and trusted the practitioner and the efficacy of their treatments. To nurture trust and belief or 'rapport' (a word used frequently in biomedical narratives) between people providing healthcare and those receiving it, it was essential for professionals to communicate openly and empathically with their patients.

If you don't put your trust in any particular medicine you are taking, then you're not going to see anything. The important thing is to put your hope and trust in the medication you're taking. [faith healer(Accra)]

The main thing here in getting people to comply is establishing a rapport with the patient. If the patient accepts that I have to see the doctor to get well and that I'm comfortable with seeing the doctor, I think he knows what he is doing and I'm ready to work with him, that can solve the problem of compliance because whatever the cause of the non-compliance ... these can all be readily discussed once the rapport is in place and I believe there is always a solution to some of them. [doctor (Accra)]

In contrast, belief and trust in health professionals was peripheral to the concerns of lay people. The fundamental need for people with illness was to get better quickly and cheaply; thus belief worked to the extent that professionals and treatments chosen provided such outcome. The legitimisation of one medical system over another, and more crucially subsequent, consistent use within that particular system, was rooted in careful judgement across four shared criteria: technical/practical knowledge of health problems; technological expertise; accessibility and ethics. Criteria assessments were shaped by past and ongoing personal experiences, shared information and observations between friends, family and within communities, knowledge gained through media on professional practices, and comparisons made between Ghanaian and non-Ghanaian medical systems. All three systems had strengths and weaknesses when assessed

according to these criteria. Aspects of these assessments have been discussed in previous sections. Others emerge more clearly in narratives on diabetes. I present a background summary of the strengths and weaknesses of the professional groups across the four criteria in Table 5.3.

Ultimately, the majority of individuals adopted eclectic treatment practices aimed at maximising the key strengths of each health systems. Healer-shopping constituted a practical search for the most effective, affordable treatment for one's needs: this pragmatic process transcended deeply held beliefs in or loyalties for particular medical systems.

Table 5.3. Shared views on biomedical, ethnomedical and faith healing strengths and weaknesses

Assessment criteria	Biomedicine	Ethnomedicine	Faith healing
Professional health knowledge			
(1) Physiological	Comprehensive knowledge	Poor knowledge	Poor knowledge
(2) Pharmacological	Comprehensive knowledge	Comprehensive knowledge (indigenous herbs)	Poor knowledge
(3) Spiritual	No knowledge	Comprehensive knowledge (held by traditional religious healers; benefits contested)	Good knowledge (benefits contested)
Technical expertise			
(1) Diagnosis	Diagnostic experts (physical conditions); epidemiological experts	Poor diagnostic skills (physical conditions); Good diagnostic skills (spiritual conditions)	Poor diagnostic skills (good for spiritual diagnosis)
(2) High-tech expertise	Highest expertise (complex surgical skills)	Some surgical expertise (bone setting)	No surgical skill
(3) Prescribing	High efficacy (target-specific drugs)	Highly efficacious drugs (poor physiological knowledge undermines target-specific prescribing)	Contested (miracle cures vs exacerbation of diabetic complications through poor practices)
Accessibility			
(1) Geographical	Poor rural access	Good access	Good access
(2) Structural	Poorly funded, poorly staffed (undermines usefulness of health knowledge and technical expertise)	Extensive use of media; patient friendly service schemes; outnumber biomedical services statistically (some practices unhygienic)	Extensive use of media and Church activities
(3) Interpersonal	Poor empathetic skills; social class biases	Good empathetic skills; speak language of clients	Poor listening skills
Affordability	Expensive	Most affordable; traditional religious treatments expensive	Expensive (urban setting)
Professional ethics	Strong ethics re patient care Poor ethics re relations with ethnomedical systems	Strong ethics (classical ethnomedicine) Poor ethics (contemporary ethnomedicine and false efficacy claims)	Poor ethics (false efficacy claims; financial exploitation)

SYNTHESIS

This synthesis will focus on three interlinked findings. First, the heterogeneous nature of socio-cultural knowledge of health, illness and chronic illness is outlined. Second, the psychological, socio-cultural and material mediation of illness action is discussed. Finally, attention is turned to the collective view of the three health systems as a co-existence of alternatives and the reciprocal impact this has on professional relationships.

Concepts of health and illness: complexities of natural, social and supernatural causal theories

Concepts of health and illness identified here drew on the tripartite categories of natural, social, and supernatural causes as documented by cultural studies. However these categories existed with considerable overlap. The dominant view of illness underscored physical and psychological causes. The social and material context was intricately linked to body-self balance. Spiritual causal theories were drawn on as 'out-there' theories by some participants, and as personal beliefs for others. With the exception of faith healers, they constituted secondary theories for the majority, drawn on only when dominant primary theories failed to provide acceptable answers for the causes and progression of body-self disruption. These theories applied to a broad range of illnesses including chronic conditions.

Crucially definitions of health and illness were not informed solely by culture. They were drawn from a multiplicity of knowledge modalities: scientific/scientized, political and religious. These modalities were in turn shaped by communicative practices and subjective/intersubjective experiences at a variety of levels of social engagement: life-worlds, broader society and cross-cultural interactions. By examining contents of and interrelationships between these knowledge modalities two key dimensions of socio-cultural knowledge of health and illness emerged. Both undermined the core assumptions of a tradition-modernity dichotomy of health beliefs and practices. First, spiritual causal theories emerged as a complex and contested phenomenon. Spiritual causal theories clearly occupied a central position in cultural-religious thought.

However, they generated great conflict in terms of their legitimacy and their implications for illness and treatment choices. These theories also highlighted the ways in which traditional Ghanaian religion and contemporary Christian religion clashed, setting up opposing religious identities in the public sphere and conflicts between public religious identities and private spiritual practices. Further, the ways in which minority traditional religion adherents and majority Christians drew on religious and spiritual themes highlighted the openness and heterogeneity of traditional religion. Discussions on spiritual causal theories highlighted culture itself as one key site of the unfamiliar around which ideas about health and illness were constructed.

Secondly, elements of cultural knowledge on health and illness resonated with practical biomedical knowledge: proactive health concepts on dietary balance, cultural emphasis on diagnosis and compliance, the role of physiological and pharmacological specificity in assessing treatment outcomes and the emphasis on sequential drug use. These shared themes, mediated the anchoring of biomedical ideas and practices and preference of biomedicine over ethnomedicine in complex areas of healthcare. Furthermore, discussions on professional expertise in chronic illness care highlighted the changing face of 'folk diseases' as another key (contested) site of the unfamiliar for both lay people and health professionals.

Illness action: the complex relationship between knowledge, belief, and practice

Analysis highlighted a complex relationship between knowledge and illness action: drawing on a cultural, religious or scientized concept of health and disease did not predict application to everyday health and illness practices. Individuals who held spiritual causal beliefs, did not necessarily access treatment from the traditional religious or faith healing spheres; groups who drew on and endorsed expert biomedical knowledge did not restrict treatment practices solely to this sphere.

Illness practices were shaped by psychological, socio-cultural and material factors. The first and recurring point of focus when ill was to regain body-self balance. Cultural emphasis on pragmatism as a response to illness, identified in narratives, highlighted the role of culture in

shaping publicly accepted illness identities and coping styles. Analysis also showed how compliance, a cultural ideal, was shaped by subjective dynamics, as well as broader social, material and structural factors. Lay critiques of pluralistic medical systems set the structural parameters for practical treatment choices. Healer-shopping essentially constituted pragmatic choices made between competing pluralistic medical systems with publicly identified strengths and weaknesses. These findings challenged another key assumption made by dominant cultural studies and KABP studies, that health beliefs predict illness practice.

The public legitimization of medical pluralistic systems cast some light on the extent to which alliances struck between lay people and health professionals mediated the treatment process. Here the second key assumption adopted by dominant cultural studies, that shared belief in holistic health between ethnomedical practitioners and their clients is drawn on for healing was challenged. While traditional religious healers engaged in holistic treatment practices, the majority of ethnomedical professionals applied a predominantly biologically and pharmacologically centred approach to healthcare. Crucially, despite drawing on a holistic healing repertoire explicitly informed by traditional knowledge and practices, traditional religious systems appeared to be the least accessed within the pluralistic medical sphere. Further, lay assessment of ethnomedical practices suggested the relationship between ethnomedical professionals and lay people to be one shaped by scepticism and mistrust, rather than shared belief and unconditional loyalty.

Medical pluralism: a co-existence of alternatives

All three systems were subjected to public critique in terms of technical/practical knowledge of health problems, technological expertise, accessibility and ethics; all three had key strengths and weaknesses across these criteria. Treatment choices within the pluralistic medical sphere were therefore shaped by practical negotiation; maximising the strengths and minimising the weaknesses of one's chosen health system(s). This demonstrated that the three systems were not conceptualised as hierarchies, but as a co-existence of alternatives, as critical cultural studies stress (Lasker, 1981; Nyamwaya, 1987; Davis-Roberts, 1981). In-group and out-group

professional assessments generally mirrored these lay assessments. Recognition of the lay legitimation process underpinned professional competition and rivalries. Biomedical and ethnomedical practitioners conflicted over shared pharmacological goals, while traditional religious and faith healer groups conflicted over spiritual treatment goals. The implications of these conflicts on the collaborative health process are further discussed in Chapter Nine.

OVERVIEW OF CHAPTER SIX

This chapter focuses on perspectives of people with diabetes on diabetes experiences and illness action. Participant narratives are presented on the following four research questions: (1) Content and sources of diabetes knowledge; (2) Biographical disruption and meanings ascribed to disruption; (3) Illness action – coping strategies and styles undertaken to maintain, maximise, or undermine health and (4) views on improving health and diabetes care. Three key findings are discussed in synthesis: the heterogeneous nature of socio-cultural knowledge of diabetes, the intersubjective nature of biographical disruption, and the psychological, socio-cultural and material mediation of illness action.

CHAPTER SIX

INSIDER PERSPECTIVES ON DIABETES (I): Individual and group interview narratives

6.1 SOCIO-CULTURAL KNOWLEDGE ON DIABETES

Two key questions were posed regarding diabetes knowledge; the first related to general pre- and post-diagnosis social knowledge (what causes diabetes?) and second to post-diagnosis subjective knowledge (what caused your diabetes?). Six causal theories of diabetes were identified: dietary imbalance (sugary, starchy, fatty foods), poor lifestyle practices, heredity, physiological disruption, ‘toxic staples’, and spiritual disruption. All participants drew interchangeably on the six themes to make sense of diabetes, either in terms of ‘lived’ or ‘out-there’ knowledge and experience. Table 6.1 provides a summary of the content of diabetes knowledge, the spread of views and the knowledge modalities from which they are drawn.

Table 6.1. Content and sources of diabetes knowledge: people with diabetes

Content	‘Spread of views’	Modality
1 Diet (Sugar, starch fat)	All rural and urban groups	Scientizied; Scientific
2 Lifestyle	Some rural and urban groups	Cultural; Scientizied.
3 Heredity	Majority rural and urban groups	Scientizied.
4 Physiology	All urban, some rural groups	Scientizied; Scientific.
5 Toxic staples	All rural, some urban groups	Cultural; Political.
6 Spiritual disruption	Majority of rural, some urban groups	Religious; Cultural.

6.1.1. Dietary imbalance (Sugar/Starch/Fat)

Rural and urban participants interviewed in Twi, Fanti and Ga, described diabetes using the Twi term ‘*esikyere yare*’ (‘sugar disease’), the simplified definition of diabetes coined by public health educators to reach non-English speaking communities (see Introduction to Part Two). While English-speaking participants did not use this term, they nevertheless made similar links between sugar and diabetes.

I used to eat a lot of sugary things. I guess that is the cause. [young, female (Accra)]

It is probably because of tea, sugar, fried eggs and not doing a lot of work that is the cause [middle-aged male (Accra)]

Discussions of sugar as a causal agent were embedded in a broader theme of dietary imbalance. There was recognition that not only was excessive sugar implicated in diabetes onset, but that excessive fat and starch in one's diet could also cause diabetes. Some participants attributed their diabetes to non-dietary causes and explicitly rejected the sugar theory.

I for instance I don't like sugary things, so I believe the sickness is hereditary. [young female (Accra)]

I've realised it isn't plenty intake of sugar that gives diabetes. It is organ malfunctions. My elder sister doesn't take excessive sugar yet she has it. I know some people who take a lot of sugar yet haven't contracted the disease. [middle-aged, female (Accra)]

I don't like sweets, so if someone tells me it was sugar that caused the illness, I would not agree. I would tell the disease has become an epidemic rather than a sugar disease. [young female (Nkoranza)]

6.1.2. Lifestyle

Two sub-themes emerged in discussions on lifestyle. Diabetes was viewed as a disease of the wealthy and as a product of poor individual health maintenance practices.

Lifestyles of the wealthy

'*Esikafoo yare*' ('disease of the wealthy') was used simultaneously with '*esikyere yare*' within both rural and urban narratives. This had two dimensions. The first dimension, which was conflicting in both rural and urban narratives, linked diabetes onset to wealthy lifestyles. The majority of rural participants and low-income urban participants argued that since sugary and fatty foods were the preserve of the rich, in terms of access and acquired taste, diabetes was

likely to be more prevalent within this social group. Some high-income participants endorsed this view.

The belief we have about diabetes is that it is a disease for the rich. That is because if you don't have money you can't afford sweet things. People with diabetes also have a special diet and that involves a lot of money. So what we knew was that if you are not poor, you won't have it. Because if you are rich you can afford a lot of rich foods. [middle-aged,male(Nkoranza group)]

Mine is I think good living, good living in the sense that, I must be frank I was in soldier during Gold Coast time you know, and then when I left the army, I had a very good job I was a manager... so as I said good living you know I can eat you know, baking and that sort of thing drinking on top. [elder,male(Accra)]

The majority of high-income participants and the remaining rural participants contested this view, however, noting that diabetes was non-discriminatory and was likely to affect a cross-section of socio-economic and age groups. Those who used the services of specialist diabetes clinics, such as the Nkoranza and Accra group discussants, drew on their observations of children and young people seeking treatment for diabetes to buttress this point. Others linked the non-discriminatory nature of diabetes to the impact of toxic staples on societal health (see section 6.3.5).

Children of six years and ten years also have the disease so we have seen now that it is not a disease for the rich. It is a disease that attacks everyone. [middle-aged male(Nkoranza)]

The second dimension was consensual in both urban and rural groups and linked successful diabetes care to high income. Participants argued that as biomedical treatment was expensive, only wealthy groups could afford and therefore access the best treatment on offer. In other words to live without complications from diabetes in Ghana one had to be wealthy.

The drugs are just expensive that's why people say it is for the rich. [middle-aged,female; Accra]

What they think in our villages for instance, those who have been identified as being diabetic feel so scared because they think it's some kind of disease or ailment that would demand very expensive treatment and I share their view ... a few weeks ago I was buying () at the Korle Bu pharmacy shop at ₵36,000 ((£3.60)) now today it's ₵75,000 ((£7.50)). [middle-aged male;Accra]

Individual lifestyle choices

This theme was linked to cultural emphasis on proactive health practices and in particular dietary balance. Drawing on the notion of ‘*akonodie*’ (the good things in life) rural participants noted that individuals who engaged in over-indulgent eating practices were likely to get diabetes. A few urban participants made reference to the role of sedentary lifestyles, attributing their diabetes in part to this.

6.1.3. Heredity

Some rural and urban participants had a family history of diabetes: their explanations drew on genealogical accounts as well as scientized knowledge from clinical encounters. Remaining participants drew solely on scientized knowledge.

Any way, diabetes tends to be hereditary, it runs in families. [...] You know, my uncle was diabetic all his I think 2 or 3 of his children are all diabetic. My grandmother from my father's side was diabetic and my half brothers and sisters they are diabetic, none of my father's children are diabetic, from the first one, but my ... half-sister...has diabetes, her brother has very bad diabetes in fact he died as a result of that, but it runs in her mother's family. [elderly,male; Tema]

Diabetes runs through my family. Three of my sisters have diabetes. Most of the women on my mother's side of the family have diabetes. [young,female;Nkoranza]

The link between heredity and diabetes was not clear-cut for all participants with a family history. For some, hereditary was cited as the primary cause of their diabetes. For others heredity was a secondary cause. Participants under age forty-five cited age as chief reason: there was a sense that while relatives had lived with diabetes, and while ultimately unsurprised at their diagnosis, participants did not expect to get diabetes when they did.

If you look at my sisters, most of them are in their menopause and when you look at me, I am very young. Under no circumstance should I get such a disease. [young, female;Nkoranza]

Some participants drew on scientized genetic theories revolving round notions that diabetes affected particular lines of the family or skipped generations.

I was born into a family that has a history, but from what I have heard or what I know, it misses a generation so I was of the impression that if anything at all, it was going to affect my children and not me. [elderly,male;Accra]

A third subgroup drew on biomedical risk factor theories, noting that while they were predisposed to diabetes because of their family histories, lifestyle and diet factors had a more direct impact on diabetes onset.

I must have inherited this through my father. I was diagnosed diabetic in 1992. But I believe it must have started much earlier, because I remember, I believe in 1991, I was taking in a preparation which I think was bitter lemon, but there was so much sugar in it. [elderly,male;Accra]

One female Nkoranza participant, who had six sisters also living with diabetes, attributed her diabetes to family misfortune caused by witchcraft activity (see section 6.1.6).

6.1.4. Physiology

Physiological definitions of diabetes ranged from simple to complex. The complexity of explanations increased as the level of participants' education increased, with technical aspects of biomedical constructs of diabetes (both physiology and pharmacology) more pronounced in the narratives of people with science backgrounds. Explanations provided by uneducated rural groups converged around simple notions of the 'blood-borne' nature or internal structural processes underpinning diabetes, such as unspecified blockage in the stomach. These came mainly from Nkoranza participants who drew their knowledge from the self-help group context.

What I have heard the doctor say is that everyone has something in their stomach and when there is a blockage, it brings about diabetes. [middle-aged,female;Nkoranza]

Rural and urban participants with secondary education or higher presented more technical physiological explanations revolving round pancreas malfunctioning and insulin irregularities.

The end result is that your body is not producing enough insulin or not utilizing it. There are 2 forms they say: One that comes on before the age of 40 between ages 1- 40 and the type 2 is the one that comes after 40. [elderly, male;Tema]

All definitions were drawn exclusively from the biomedical context, through clinical encounters, general interaction with biomedical professionals, reading literature or via second-hand accounts. There were no explicit references to drawing diabetes knowledge from public health education.

6.1.5. Toxic staples

Some rural and urban participants argued that the rising prevalence of diabetes had to be contextualised within the context of deteriorating societal health. As discussed in Chapter Five, poor societal health was partly attributed to the influx of toxic staple foods.

People are aware that the kinds of foods particularly city dwellers eat is creating this problem. Why diabetes in Accra? Even fourteen year olds are getting it.” [middle-aged,female:Accra]

Discussions on diet management practices suggested that toxic staples were seen not only as causes of diabetes, but also a key problem undermining successful diet management (see section 6.2.4).

6.1.6. Spiritual disruption

This theme appeared only in rural narratives and had two sub-themes: sorcery and witchcraft. Some discussed sorcery in terms of retribution for their moral transgressions. Family members were the dominant group implicated in sorcery activities.

I once went to a place ((traditional religious healer)) where I was told the cause is from my family. They bought the disease for me. [young female;Nkoranza]

A notable source of information on *nto yare* emerged in the narratives of three Nkoranza women. During early clinical encounters when biomedical diagnosis had returned inconclusive results on the nature of their illness, nurses attributed their ‘mysterious condition’ to *nto yare*. This attribution drew on the cultural-religious logic, which attributed spiritual causes to conditions resistant to biotechnological diagnostic methods. As members of a publicly

legitimised health professional group, the nurses' secondary diagnosis carried an authority that shaped the women's early (unsuccessful) engagement with ethnomedical treatment.

I didn't know it was that disease so I went [...] and the doctor examined me and saw nothing. One nurse told me that my sickness must be *abonsam yare* (demonic) and that I should go home and find another means of cure. I became so frightened. [young, female; Nkoranza]

Some participants attributed their diabetes to witchcraft activity. One participant, who had six sisters living with diabetes, attributed the family's experience of diabetes to witchcraft rather than heredity. Drawing on a complex story of misplaced community rumours and accusations, she asserted that diabetes had been 'planted' in her family as an act of retribution against alleged witchcraft activity by her mother.

The disease is not a family disease. It was ((planted)) in the family by witches. According to some sources my mother feasted on somebody's child; after four days the child died. So they used disease to disgrace us. It is not a family disease. [middle-aged, female; Nkoranza]

There are four critical points to note about the spiritual causal theory of diabetes. First, all participants who subscribed to the theory, subscribed to some or all of the other causal theories for diabetes outlined above. Secondly, placed within the broader narratives of each participant, it appeared as a secondary theory of diabetes in the sense that participants drew on it only if there was dissonance between their pre-diagnosis social knowledge of diabetes and subjective experiences. Thus participants drew on '*nto yare*' for example because none of the cultural or scientized versions of diabetes they drew on pre-diagnosis resonated with their experience of diabetes onset. Thirdly the sources of spiritual causal theories were varied: participants drew information from their life-worlds, communities, the ethnomedical sphere and for some rural participants, nursing staff. The importance attached to the theory one held was linked to the credibility and legitimacy of the source. Finally although effective treatment of spiritual illnesses was generally placed within the domain of traditional religious and faith healing practices, admittedly with some conflict, as Chapter Five highlighted, few participants accessed either arena for treatment (see Section 6.5).

6.2. BIOGRAPHICAL DISRUPTION

Diabetes disrupted five interrelated dimensions of everyday life: body-self, identity, economic circumstance, diet/food practices, family relationships and social relationships. Each disrupted aspect of everyday life held significant importance and consequences for psychological and emotional well-being as well as illness action for all participants. The order of presentation is not to impose a hierarchy of importance – but to reflect the frequency with which themes are mentioned and discussed across narratives.

6.2.1. Disruption to body-self

All participants lived with a range of symptoms, from minor problems such as general weakness, dizziness, headaches and persistent wounds, to major problems such as visual impairment, extreme weight loss, sexual dysfunction and physical disability. Some rural and urban participants lived with other serious chronic conditions such as hypertension, arthritis, asthma, gout and prostate cancer (see participant profiles in Appendix D). Hypertension and prostate cancer were ranked as more serious and life-threatening than diabetes. The predominant and persistent response to physical disruptions was emotional and centred, for the majority, on fear of disability and death. For low-income participants this fear was compounded by perceived and actual implications of the financial burden of diabetes. Further, rural and urban participants living with weight loss expressed fear and anxiety of being labelled as AIDS sufferers.

While fear was a dominant response, most participants expressed reflexive awareness that such fear was unfounded if diabetes was managed adequately. Ideas on ‘management’ and ‘control’ were drawn explicitly from the biomedical sphere and were linked to particular biomedical methods of drug and diet management.

There's been a difference now, because we are told at the meeting that if you take your medication and eat only the things you are supposed to eat, you can be well. So now I don't fear as much as I used to do when we hadn't been taught all this. [young,female;Nkoranza]

When I was made to understand that this is a silent killer and that it will be doing all sorts of things to your eyes and your kidneys etc. that sunk in. And I was also made to understand that look, if you handle yourself well, then you can avoid these other consequences. [elderly,male;Accra]

Two additional factors fed into responses of body-self disruption and by association committed drug and diet management. First was the cultural emphasis on systematically assessing health and treatment outcomes, and for older participants a stoic attitude to illness experiences. Secondly, body-self disruption evoked religious responses. While scientized and cultural meanings called for individual agency (to buy drugs, eat recommended foods or make regular visits to the doctor), religious responses went beyond this, foregrounding the power of God and prayer in mediating efficacy or curative properties of drug and diet regimes.

If God doesn't bless the drugs you take it might not be effective even though it is efficacious. [young male;Accra]

It is only God who can intervene. It is only God who can let you meet a doctor who can cure you of the disease. [young male;Nkoranza]

6.2.2. Disruption to identity

Three sub-themes on identity disruption emerged in narratives. First, rural and urban participants highlighted the negative impact of body-self disruption on social identity. Weight loss appeared in a significant number of rural and urban narratives. Second, the impact of physical disability emerged in the narratives of the three participants who had had limbs amputated. Thirdly the impact of diabetes on family roles and responsibilities appeared in the narratives of mostly male urban and rural narratives.

Most participants had experienced rapid weight loss due mainly to excessive urine excretion pre-diagnosis. Some continued to live with marked weight loss post-diagnosis due to poor diet and drug management. Rural participants noted that in their communities, rapid weight loss was commonly associated with AIDS, a highly stigmatised condition. Six Nkoranza and five Kintampo participants had faced varying levels of stigmatisation and ostracism.

I grew very lean and in this town when you grow lean they think you have *AIDS*. [young female;Nkoranza]

For those who had experienced and continued to experience stigmatisation, the dominant response was depression. Some made references to having suicidal thoughts.

If you are not able to get money to go for injection, you will grow lean. There are times when you want to drink poison to kill yourself. [middle-aged,female;Nkoranza]

The association of rapid weight loss with *AIDS* also appeared in some urban narratives but did not appear to have an explicit impact on social identity in this context. Urban narratives suggested an awareness of the risk individuals faced, in contemporary Ghanaian society, of being tagged with an *AIDS* label at the first sign of rapid weight loss. For the majority of participants, this awareness was underpinned by a sense of relief that they had yet to experience of stigmatisation and ostracism and a determination to avoid such an experience. Fear surrounding *AIDS* labelling shaped social interactions and communicative practices. Some rural and urban participants adopted secrecy as a self-protection strategy, keeping their diabetes status from friends and partners.

For me I don't reveal my health problems to anyone. In this town if you make people aware of your health problems they will associate you with HIV/*AIDS*. You may not even find a partner. So since I had the disease about two year and more now, I have not informed anyone. [young;female;Nkoranza]

For the three participants who had had legs amputated, identity disruption was characterised by visible changes in body-image and restricted mobility. Both undermined their ability to participate fully in social life and fulfil social roles.

Some urban and rural male participants discussed the impact of diabetes on their capabilities as dominant providers for their nuclear and extended families. They noted that they had to deal simultaneously with the high cost of diabetes care and their financial responsibilities to dependants. The older among this group expressed considerable concern about the impact of diabetes on the legacy they would leave behind for their children. Death itself was not a

fearsome prospect; however the possibility of dying prematurely and leaving behind financial insecurities for their children caused great anxiety.

I was worried a bit as that man said because of the children, for myself, I don't fear that death but because of my children and who will care for them that is mostly why I was afraid [middle-aged,male; Accra]

6.2.3. Disruption to economic circumstances

Disruption of economic circumstances occurred at two interrelated levels; loss of earnings due to an inability to work and increased expenditure due to high cost of pharmaceutical drugs and recommended foods.

Forty percent of rural participants were farmers. The majority of remaining participants engaged in similar physically demanding occupations, such as market trading or food hawking. Disruption to body-self compromised physical strength and diminished their ability to work. This affected their income.

It is a disease that when you get you can't walk. I also used to sell yam, charcoal and maize, but for five years now I've not sold anything so even if you have money it will get finished. [middle-aged,female;Nkoranza]

A lowered standard of living was further compromised by the high cost of drugs. This affected people with IDDM more acutely. For example, the cost of a monthly supply of insulin ranged from ₵60,000 to ₵90,000 (£6-£9 at the time of the study) according to participants. This constituted 60% of the monthly income of a person on minimum daily wage of ₵5,000 (50p). Economic disruption exerted the strongest impact on illness experience and action in the sense that lack of money undermined any practical attempt to overcome the ongoing body-self disruption. The predominant response to economic disruption was a combination of fear and worry about exacerbating disruption to body-self.

When I am due to see the doctor but I am unable because of financial problems, I think a lot, because I am afraid that my situation will worsen. [middle-aged,male; Kintampo]

Prolonged disruption to economic circumstances and body-self coupled with ensuing fear and worry about disability and death, constituted key intersecting factors underpinning biomedical non-compliance and healer shopping among low-income and unemployed respondents. Low-income individuals abandoned expensive biomedical treatment and searched for cheaper treatment alternatives within ethnomedical systems to minimise physical disruption. It should be noted however that healer shopping was not underpinned solely by economic deprivation. Within narratives of wealthier rural and urban participants reports of non-compliance and healer shopping emerged. For this group, non-compliance and healer shopping were underpinned primarily by the psychological-emotional burden of body-self disruption. The types of alternative treatments sought within this group, as section 6.4 will outline, was also qualitatively different from the low-income group.

6.2.4. Disruption to diet/food practices

All participants noted that they had adopted recommended diet changes prescribed by their doctors. However successful diet management was undermined by four interlinked factors: psychological, economic, social, and nutritional. I present these factors in terms of the spread of views and frequency with which they are mentioned and discussed within narratives.

Psychological cost

All participants described psychological cost in terms of the difficulty of giving up foods they liked.

For me for instance, I used to eat cocoyam, you could eat yam, you could eat anything, cassava. This disease doesn't like starchy food, so you have to eat plantain mainly. So it's brought changes in the eating pattern [middle-aged,female;Nkoranza]

Sometimes there's food that you like very much, but you can't eat because of this disease. (young,female;Nkoranza)

Economic cost:

For low-income urban and rural participants the difficulty of giving up foods they liked was compounded by their inability to afford recommended alternatives. There were recurring themes

of individuals making do with whatever food they could afford, because the right foods were inaccessible to them. This compromised their nutritional status and further exacerbated disruption to body-self.

Before I had diabetes, there were certain foods I could eat which I can't eat now, but those foods are very cheap. So you are forced to eat what you are not supposed to eat. [middle-aged, male;Nkoranza]

I wish I could have vegetables, salads and things like that, which I can't afford. [elderly male;Accra]

Social cost:

This appeared in the majority of narratives and was described in terms of renegotiating dietary needs during social gatherings such as parties, weddings and funerals. Shared eating and drinking practices at such events cemented one's identity with one's peers and acquaintances. Social cost referred to one's inability to join in these shared practices and the burden of dealing with negative or critical social perceptions and responses.

It's an illness isn't it, and it affects your social life. Sometimes I'd like to have a beer or something but I'm afraid and people are surprised when they ask me to take a sip of whisky and I stand my ground and take minerals ((soft drinks)). I have to explain to them that this and that, which sometimes is hard.
[middle-aged;male;Accra]

Nutritional cost:

Rural participants argued that since the quality of staple foods was compromised by harmful agricultural methods, following diet recommendations did not necessarily ensure better health. They noted that while biomedical advice was valued, professionals did not pay attention to the possible threat recommended staples posed to the diabetes status. This was an important argument, since the theme was absent in biomedical narratives (see Chapter Nine).

The doctor says, 'eat plantain', but the plantain is grown with fertilisers, it's all white inside. What can you do?
[middle-aged,female;Kintampo]

6.2.5. Disruption to family relationships

This theme appeared in rural narratives. With the exception of six participants who received financial support from relatives living in urban cities or abroad, all participants had experienced varying levels of family disruptions, which were linked strongly to the economic impact of diabetes.

When you are sick no family member helps you. They only help when you are dead. [middle-aged, female; Nkoranza]

I don't have any family member who takes care of me. My mother's family - I don't want to talk about it. Even if you are dying there is nobody to help you. It is always left with you and your God. [middle-aged, female; Nkoranza]

For some, family disruption constituted minor disagreements stemming from prolonged financial dependence. For others the burden of care caused permanent relationship breakdowns. Three Nkoranza women for example had gone through divorce since diagnosis, a process they attributed to the inability of their ex-husbands to deal with the socio-economic burden of diabetes. Other women had been abandoned by their boyfriends, when they were labelled with an AIDS identity.

AA: There are lots of people with diabetes here, but the majority are embarrassed to talk about the disease'.

Danso: Why is that, there are all sorts of illnesses, diseases, diabetes isn't something to be ashamed of or embarrassed about

AA: I had this friend who stopped talking to me after he found out I had diabetes.

Ama: Why would he do that?

AA: I heard from another friend that he said diabetes was something he couldn't handle, that it was contagious, so he couldn't have anything to do with me. Many people think like this in Nkoranza.

Some participants argued that abandonment of the chronically ill was commonplace. They discussed the double standards operating in their communities within which families shirked collective responsibility of supporting individuals living with long-term illness, yet welcomed

the economic benefits brought on by the death of abandoned individuals through *nsawa* (material donations provided by mourners to bereaved).

Other participants recognised that family members were themselves low-income earners and could not be expected to provide financial support. For heads of families – mostly male rural and urban participants – the economic cost of diabetes was further compounded by their ongoing financial responsibilities for both nuclear and extended families. This group had little recourse to financial assistance from their families.

If they can help you financially they will, but they also don't have money so they are disturbed that you don't have money for treatment and they can't help either. [middle-aged,male;Nkoranza]

A third group noted that although disruption to body-self was a continuous process, this did not always lead to culturally legitimised signs of illness. Thus family and friends often misconstrued a lack of visible illness signs (for example reports of pain, visible lack of strength or immobility) for a return to health, and denied the legitimacy of participants' need for ongoing support.

When you are sick you can't do any work. But as you are not bed-ridden, nobody will assist you financially. When it started everyone knew I was sick so they helped. But now they think I'm cured, which isn't the case. [young,male;Kintampo]

6.2.6. Disruption to social relationships

While family support was integral to coping with diabetes, broader community or social support played a peripheral role for many participants. '*Ayonko fa*' (excessive dependency on friendships) was frowned upon. Participants drew on this to explain why they did not actively seek or expect social support beyond the lifeworld of close relatives and friends. There was a sense that in sickness as in health relying on a selective and longstanding group of friends and dependents had greater benefit for one's well being than relying on an extensive but ultimately weak network of friendships and acquaintances. However those living with extreme and rapid weight loss and labelled with an AIDS identity, faced community intrusion into their private lives, or exclusion from participating in mundane everyday social life.

The Nkoranza self-help group played a significant role in minimising the impact of physical and social disruption. Those who had faced stigmatisation, ostracism or disruptive relationships, received social and emotional support from other self-help members. Participants discussed their role in providing self-care information and moral support, particularly to newer group members.

When I look at their cards I encourage them and tell them not to be sad. I tell them they won't die because they have the disease. So we, the old members, advice the new members. [middle-aged, male;Nkoranza]

A certain girl called ((X)) who also got affected with the disease wanted to commit suicide. I advised her not to commit suicide because when I got affected I reduced greatly in size. The people in the town thought I had AIDS. I could not even get a man to talk to me. So I don't have a husband or a boyfriend. I have taken my job as my husband and boyfriend. So I tell her she should not commit suicide. [young;female;Nkoranza]

6.3. ILLNESS ACTION: STRATEGIES AND STYLES ADOPTED IN RESPONSE TO BIOGRAPHICAL DISRUPTION

This section will describe strategies and styles participants initiate and manage in order to live with – or overcome – biographical disruption. Strategies are discussed first under four identified themes: drug management, diet management, prayer and routinized lifestyle change. In the following section I discuss three identified styles of long-term coping that participants adopted and oscillated between in response to changing social and personal circumstances: management, cure-seeking and inaction.

6.3.1. Illness action: coping strategies and mediating factors

Drug treatment

Dominant coping strategies centred on accessing and using appropriate drug treatment. Cultural notions of health maintenance and illness action, as well as scientized knowledge of diabetes management framed these efforts.

Initial treatment choices and practices were influenced by three factors: the persistence of physical symptoms, the need for accurate diagnosis and advice by significant others. With the exception of five rural participants, all participants accessed biomedical care in the first instance. A consensual reason for initial biomedical consultation revolved round the investigative and analytical nature of biomedicine and the exclusive ability of doctors to diagnose complex physical problems.

Participants who accessed traditional religious healers in the first instance did so because the suddenness and mysteriousness of their symptoms was attributed to spiritual disruption. However, as physical symptoms increased, despite traditional religious intervention, they turned to biomedical care, their decisions framed by biomedical diagnostic expertise and target-specific treatment.

I used the traditional method, I did not know I had diabetes. But since the doctor told me I have stopped going to all those places. [elderly,male;Kintampo]

All participants engaged in healer shopping, a practice underpinned for all by psychological-emotional burden of disruption to body-self, and for low-income groups the added burden of economic disruption. 'Hope for a cure' underpinned all accounts of healer shopping.

I want to be healed so I will follow up whenever I hear of somebody who can help. [middle-aged,female;Kintampo]

If you can tell us there is a medicine that will cure you today today we'll all draw to it. [elderly,male;Accra]

These accounts revolved round the burden of disruption, anticipation of more successful biomedical advances in diabetes care and also the future potential of ethnomedical drugs. 'Hope

for a cure' was also strongly underpinned by Christian belief in God's power to heal. This power transcended scientized knowledge of the incurability of diabetes. There was a consensual line of argument that if God created life (for those offering simple physiological explanations), or the pancreas (for those offering complex explanations), then the prolongation of life or the healing of the pancreas ultimately lay within God's domain.

As long as God lives, there is no sickness that is not curable. If God has been able to create man, how then can he not supply all man's needs and also perform wonders. [young,male;Nkoranza]

There are some of us who believe that God made the different parts of the body and the pancreas so that if one part is not working well, through prayers, it can be healed. [elderly,male;Accra]

The healer shopping process varied: some participants healer-shopped solely within the ethnomedical system, the majority within and between biomedical and ethnomedical systems. Ethnomedical treatments were accessed because they were viewed as effective and affordable. Rural participants drew attention to the usefulness of ethnomedical flexible payment systems.

Politicised participants selected ethnomedical and alternative treatments on the basis of a 'scientific stamp of approval'. Some urban politicised groups had sought treatment at the Mampong Centre in the past or were receiving treatment at the centre during fieldwork. Others used foreign complementary therapies approved by biomedical professionals. All participants advocated sequential use rather than dual use. An alternative method of dual use emerged in the narratives of the group who healer-shopped exclusively within ethnomedical systems, where such individuals used different ethnomedical drugs sequentially, and supplemented this with biomedical dietary advice.

As I sit here I use traditional medicine, but I follow the instructions given by the doctor. He told me the foods to avoid and the foods to eat. That is exactly what I do. [middle-aged,male;Kintampo]

With the exception of those who used ethnomedical treatment exclusively, all participants reported negative experiences with treatment from unregulated ethnomedical professionals. Problems revolved round unspecified dosage levels, unclear information about drug action, and drug side effects. Urban groups who had used the Mampong centre service in the past, singled

out the benefits of the centre in terms of its use of standardised herbal drugs. At the time of study, the majority of participants were using biomedical treatment exclusively because it offered the very benefits ethnomedicine did not offer: specified dosage levels, clear drug indication and fewer side effects. Others were exploring options for trying out new ethnomedical treatments advertised in the media, in response to prolonged burden of body-self disruption.

Successful drug management was undermined by two main factors. Firstly, the psychosocial burden of drug treatment, which affected all participants and secondly the high cost of biomedical - and some ethnomedical - drugs which affected mainly low-income and unemployed participants. Thus while all participants went through temporary periods of unsuccessful drug management, low-income participants reported prolonged periods of unsuccessful drug management.

Diet management

Diet management was the second major component of daily illness action. All participants used food as a marker for controlling the diabetic state. For four urban participants who had diabetes tester kits, direct connections could be made between food intake and blood-sugar levels.

It is quite clear that whenever you go off the diet programme, then you're in trouble. Now I have all the equipment to check my sugar levels and I think I'm doing quite well. If you're a bit off, you trace to see whether it was kenkey or fufu or something of the sort. [elderly,male;Accra]

For the majority, food was used as a common-sense marker to regulate physical symptoms equated with an uncontrolled diabetic state, such as frequent urination and general weakness.

If the food is good for your body you will know and if it's not good for your body you will know that as well. Right now if I eat even one orange in the day I will urinate about *ten times* during the night. Just one orange! So for about *two years* now I've refrained from eating oranges. If I crave oranges and make the mistake of eating any, that day the disease will be worse. [middle-aged,female;Nkoranza]

Since dietary balance was a key proactive health practice (and a cultural ideal) rooted in individual responsibility and agency, successful diet management was strongly linked to a sense

of personal control and autonomy over one's health. Participants with tester kits expressed a greater sense of control over their condition compared to the majority and reported less anxiety and worry over disruptions caused by diabetes. With tester kits, they could measure their blood-sugar levels whenever it suited them. They could therefore, without the help of a doctor, regulate factors that caused an increase in these physiological functions, eat less of a particular type of food, or more of another type, slow down or increase activity, or make an appointment to discuss with the doctor the need to reduce or increase medication.

As section 6.3 showed, successful diet management was undermined by psychological, economic, social and nutritional dynamics. Psychological and social costs of giving up established food practices constituted a common problem for all participants. For low income and rural participants, this was further compounded by the high cost and/or unavailability of nutritious staples and alternatives.

Prayer

Prayer was an integral aspect of illness action for the majority of participants. Participants stressed that for drug treatments and/or diet management to work successfully a spiritual element had to be incorporated. While some participants had accessed traditional religious and faith healing practices pre biomedical diagnosis, the majority of respondents preferred to 'pray privately' for successful treatment rather than seek intervention from either system. This rejection of traditional religious healing and Christian faith healing was rooted in the conflicts surrounding issues of professional and religious legitimacy (see Chapter Five).

Rural participants who had sought diagnosis and initial treatment in the traditional religious sphere, viewed traditional religious healer treatments as ineffective in comparison with biomedical treatment.

Rural and urban participants who had sought faith healing drew attention to damaging faith healer practices. Fasting, a key component of the faith healing repertoire was singled out in the majority of narratives as particularly damaging to the diabetes state. This shared critique drew from out-there knowledge of faith healing failures as well as negative personal

experiences. One rural male participant, for example, attributed his diabetes complications and resulting amputation to inefficacy of faith healing practices. Urban participants drew attention further to the financially exploitative practices of urban faith healers.

If I were to advice somebody I would tell them not to attend those prayer camps that people attend. If they attend and are made to fast they will die. I fasted once and I nearly died. [young;female;Nkoranza]

I've been for prayers before. That caused my leg to be amputated. When my leg started, I went to the hospital several times. [...] As for the hospitals, I went to several of them. Now everyone said my disease was demonic so I should go for prayers. I went to Goka and spent 3 months there. Then my leg began to rot. No medicine was applied there. It was just prayer and fasting. I could not sleep at night. [elderly,male;Nkoranza]

I have tried a lot of faith healers. Nothing happened – I saw nothing. I would leave home at 6am, pay ₵40,000 ((£4)) to stay there till evening. They are only interested in money. There was one place I went to, when the pastor called people to the front ((to be healed)), the bidding started at ₵200,000 ((£20)). [elder,female(Accra)]

Despite awareness of faith healer shortcomings, low-income individuals who lived with chronic suffering, were more likely to rely simultaneously on professional spiritual help and private prayer.

Routinized lifestyle change

All participants referred to the importance of general lifestyle change in controlling diabetes. However two groups took active steps towards this objective. The first group constituted those living with conditions such as hypertension and cancer, perceived to be more life threatening than diabetes. The second group had lived with diabetes long-term (ie over five years).

Within the first group, different aspects of participant-specific lifestyle practices that were perceived to be risk factors for complications were actively addressed. For example, participants who drank alcohol before diagnosis had given up alcohol; others had taken up regular exercise. While these routines were taken up to minimise the physical impact of other conditions, they facilitated the control of diabetes in the process.

I stopped alcohol, the spirits, a long time ago, but beer was a bit of a problem stopping. But with the onset of the prostrate thing, now I've completely cut out. I don't drink anything anymore. That's it the prostrate has compelled me to be a little more careful. [elder;male;Accra]

For the second group, particular methods of negotiating drug treatment and diet management had been incorporated into individuals' broader lifestyle. There was a sense that participants had become committed to biomedical management routines as a result of negative healer shopping experiences. In addition their diabetes status was known and accepted by significant others, which minimized the social burden of living with diabetes.

6.3.2. Illness action: coping styles and mediating factors

There are three identifiable coping styles individuals adopted and oscillated between, depending on life circumstances and psychological-emotional states: management, cure-seeking and inaction. Management and passive cure-seeking approaches tended to shape strategies of individuals who wished for prolonged periods of stable health. Active cure seeking was underpinned by an overriding motivation towards attaining permanent health and complete eradication of diabetes. Illness inaction was adopted as means of ending chronic suffering.

Biomedical management as a coping style

This style was adopted by individuals with three distinct or interlinked experiences: individuals who had lived with diabetes long-term; individuals on whose lives diabetes had exerted few or no disruptions; and individuals who lived with other serious conditions. For this broad group, practical daily routines were geared towards controlling symptoms through biomedical (or ethnomedical) drug compliance, adherence to recommended biomedical diet restrictions and routine lifestyle change (drinking less, taking up exercise). Individuals who had lived with diabetes long term, noted that committed management practices and lifestyle changes reduced physical disruption considerably. For the majority, passive cure-seeking was often adopted alongside a management style.

Cure-seeking as a coping style: passive and active cure-seeking

Two types of cure-seeking were identified: passive and active. As noted in section 6.4.1 all participants expressed hope for a cure. Thus even individuals who espoused management as their personal goal, oscillated between management and healer-shopping. For example they would follow up news of 'breakthroughs' usually coming from the ethnomedical sphere either via the media or via recommendations by family and friends. Politicised participants – and mainly urban high-income groups - healer shopped carefully within ethnomedical systems: ethnomedical drugs chosen had to be scientifically tested and approved, they therefore gravitated mainly – though not exclusively - towards credible practices modelled on the Mampong Center or bought alternative health supplements endorsed by health foods experts. For low-income urban and rural groups ethnomedical drugs would be used only if recommended by trusted friends and family. I term this process of turning periodically to healershopping outside the biomedical sphere in hope for a cure, 'passive cure-seeking'.

Passive cure-seeking is distinguished from the active search for a cure identified in the narratives of a small number of mostly rural participants. This group consisted of individuals recently diagnosed with diabetes and people going through an acute phase of body-self disruption. All were low-income participants. They explicitly engaged in healer shopping and constant prayer to achieve their goals. Their consistent search for a cure was based on the fundamental belief that diabetes could be cured through Christian faith. The majority tended to access and healer shop only within the ethnomedical sphere and place strong 'faith' in the efficacy of ethnomedical treatments on the basis that their ethnomedical drugs of choice were effective.

Inaction as a coping style

This appeared in the narratives of four rural and urban individuals who lived with persistent disruption to body-self, identity, economic circumstance and family/social relationships. This group lived with chronic suffering due to chronic lack of social and material support.

Participants reported living with depression and frequent suicidal thoughts. There were repeated references to death as a desirable alternative to chronic suffering.

A common activity all participants engaged in was prayer. Prayer was conducted privately or within the church context and had two functions. On the one hand individuals prayed for death as an end to chronic suffering; on the other hand, they prayed for a miracle (change in socio-economic circumstances, a benefactor etc) to have their health restored. The psychological and social-cultural context of this emotional conflict towards chronic suffering is captured in the life-world of a rural woman, described in the next chapter.

6.4. IMPROVING DIABETES CARE

Participants suggested five ways of improving diabetes care: addressing drug costs, food availability and cost, public health education, lack of self-care equipment and the misappropriation of ethnomedical intellectual property by formal health institutions.

All participants placed drug costs on the top of the list of approaches to improve diabetes care. For low-income rural and urban participants the high cost of biomedicine was a primary cause of healershopping for cheaper ethnomedical alternatives. Individuals on insulin treatment were hardest hit by biomedical costs. They also constituted the group that had no real alternatives within the ethnomedical sphere – as the standardised ethnomedical drugs in current use are only effective for NIDDM diabetes. The special plight of people on insulin treatment was singled out for discussion by the majority of rural participants: both people on oral medication and insulin discussed the urgency of financial support or access to drug subsidies for this group.

The cost of food was a dominant focus of discussion for all low-income rural and urban participants. The unavailability of good quality staple food appeared in rural narratives. The onus was placed on the government to address both issues; legislative action against unethical farming was a dominant recommendation in rural accounts.

Rural and urban participants stressed the importance of public education, while urban participants discussed the importance of improving the quality of practical biomedical information given out during biomedical consultations to facilitate better self-care. The focus for participants was the relevant aspects of biomedical knowledge that helped individuals through the daily complexities of managing diabetes. Nutritional information was singled out for particular attention.

Politicised participants held the view of ethnomedical practitioners as guardians of an array of potential cures. Ownership was deemed threatened by biomedical and global pharmaceutical exploitation. With particular respect to diabetes care, this group noted firstly that ethnomedicine had potential effective drugs for diabetes and could therefore provide more affordable drugs for diabetes care. The treatment offered by the Mampong Centre was used as evidence. Secondly they stressed that these drugs required standardization before being introduced to the public health arena. Thirdly, for standardization to occur issues of distrust between ethnomedicine and biomedicine, stemming from biomedical appropriation of ethnomedical intellectual property had to be addressed.

Finally, some urban participants recommended the provision of tester kits to people with diabetes to facilitate better daily management and personal control over their health.

SYNTHESIS

This synthesis focuses on three key findings: (1) the heterogeneity of socio-cultural knowledge of diabetes; (2) the intersubjective nature of biographical disruption; and (3) the psychological, socio-cultural and material mediation of illness action.

Diabetes Knowledge

Participants attributed diabetes to five interrelated causes: dietary imbalance, poor lifestyles, heredity, physiological disruption, toxic staples and spiritual disruption. These causes were shaped by cultural, scientific, scientized, and religious knowledge, as well as subjective experiences. The sources of these knowledge modalities were eclectic. For example the dietary imbalance theme was drawn from public health information as well as one's subjective experience of dietary practices. Spiritual causal theories and coping strategies were drawn from life-worlds, the ethnomedical sphere, but equally from rural biomedical centers and foreign clinical encounters.

Diabetes causes were not shaped solely by cultural knowledge, nor were they exclusively subsumed under a supernatural causal category, as dominant cultural studies suggest. Diabetes was at once naturally caused, socially caused, supernaturally caused. Natural causes were drawn mainly from scientized knowledge. While both scientific and scientized knowledge were highly legitimized within the public sphere, participants placed greater emphasis on practical biomedical knowledge than technical knowledge. Key aspects of the former - diet, lifestyle, and heredity – were known by the majority and drawn on explicitly in their everyday experiences and illness action. Technical biomedical knowledge - physiological disruption - unequally distributed along educated-uneducated lines, was peripheral to daily lives. Social causes were linked to politicized debates on the impact of toxic staples to contemporary Ghanaian health. Finally, spiritual causal theories constituted a secondary, rather than central, theory drawn on by a minority of participants when diabetes onset and impact on lived experiences did not hold up to common sense scrutiny. Ultimately, drawing on spiritual

causal theories did not lead to predictable use of use of traditional religious or faith healer treatment. This finding suggested a clear distinction between drawing on cultural concepts and beliefs and applying them to everyday life practices.

Biographical disruption: impact on people with diabetes and life-worlds

Body-self disruption constituted the initial and recurring focus of biographical disruption. It constituted the site of the unfamiliar for people with diabetes and their significant others. Body-self disruption set up and was exacerbated by a chain of disruptions (economic, nutritional status, family and social relationships) that brought the broader social dimensions of living with diabetes to the fore. Individuals living with prolonged loss of strength could not work, for example, or individuals living with prolonged weight loss risked ostracism due to AIDS labeling. Prolonged body-self disruption also intensified psychological-emotional responses to lived experiences, which depending on one's broader life circumstances and support structures could mediate or undermine illness action goals. Psychological-emotional responses overrode cultural norms of health and illness behaviour for some participants.

Narratives on family disruption also suggested – and ethnographies will highlight more clearly – that family and caregivers lived with biographical disruption. These experiences were also underpinned by the dual burden of symptoms and society. What emerges in this chapter is the social dimension of biographical disruption of the family, where, economic burden and community responses to people with uncontrolled diabetes leads to abandonment and diminished quality of care-giving.

Illness action: coping strategies and styles

All participants adopted similar strategies in response to diabetes: taking medication, eating recommended foods and praying. Some participants had adopted and were committed to routinized lifestyle changes, brought on in part by living with more serious conditions or having had negative healer-shopping experiences in the past. The longer-term styles, which framed these daily strategies – management, passive and active cure seeking, and inaction – led to

positive and negative outcomes. Management and passive cure-seeking constituted positive illness action (action most likely to improve the health status), while active cure-seeking and illness inaction, on the other hand constituted negative illness action (actions most likely to undermine healthy status). All three coping styles highlighted the ways in which biomedical (non) compliance and (poor) self-care could be a consequence of rational process rooted in social and material realities, as well as the psycho-emotional disruptions caused by body-self imbalance.

Thus while healer-shopping and dual use are usually conceptualised as negative culturally mediated practices, they had positive benefits for a number of participants. For example the politicised wealthy healer-shopped for the more effective standardised ethnomedical drugs. To provide another example, some rural participants, who used ethnomedicine exclusively, drew on biomedical dietary advice to manage their diabetes, thus highlighting some positive dimensions of dual use. More generally healershopping and dual use choices were shaped, not by 'faulty' cultural knowledge, but by flexible and creative use of social logic: the careful weighing of effective affordable options available in a complex pluralistic medical sphere.

Finally, those adopting inaction as a coping style faced severe economic deprivation, which exacerbated body-self disruption, family abandonment, ostracism for some, depression and suicidal ideation. Inaction, in effect, could be understood to constitute a rational response to chronic suffering. Underpinning this rational response was intra-personal emotional conflict: individuals simultaneously expressed desire for death and hope for economic support to alleviate chronic suffering.

The complex socio-psychological and material factors underpinning coping strategies and styles emerge with greater clarity in the ethnographies described next.

OVERVIEW OF CHAPTER SEVEN

The central aim of conducting ethnographic work was to move beyond documenting narratives on social knowledge and experience of diabetes, to observing the ways in which knowledge and experience framed practical responses of people with diabetes and their significant others. The focus of this chapter therefore is to describe and discuss what the three people with diabetes and their significant others *say* and *do* about the experience of diabetes over a six-month period. This chapter is presented in three parts. In Part One, I present narratives on sources and content of diabetes knowledge from the three life-worlds. Elements of consensus and conflict as well as absences within and between life-world narratives will be highlighted. Part Two describes how members of each life-world make sense of and respond to their experiences. Documented observations of practices are incorporated in this part. Part Three, the synthesis, returns to broader discussion of the links between cognitive-emotional polyphasia, inter-subjective experiences and illness action. Three inter-related findings are discussed: (1) the heterogeneity of socio-cultural knowledge within life-worlds; (2) the physical and psycho-emotional impact of diabetes on the lives of people with diabetes and significant others; (3) the co-construction of coping strategies and styles within life-worlds and the mediating role of subjective, inter-subjective and structural factors.

CHAPTER SEVEN

INSIDER PERSPECTIVES ON DIABETES (II): Ethnographies

For ease of reference I present profiles of the key participants in the three life-worlds in Table 8.1 below. All names have been changed to preserve participant anonymity. I make references to official and unofficial home visits – the former refers to formally booked appointments with participants, the latter to informal drop-ins. Informal drop-ins evolved over the course of fieldwork, when I got to know participants better: they were unscheduled visits, sometimes made to say a quick hello (for example when carrying out individual and group interview work in Nkoranza), to make money and food donations. When presenting quotes from or making reference to narratives from informal discussions I draw from fieldnotes, which capture the essence of recollections, ideas and arguments rather than verbatim accounts.

There is considerable overlap between life-world narratives on diabetes and biographical disruption and narratives of people with diabetes presented in Chapter Six, and some similarities with lay and professional narratives to be presented in the chapters that follow. Because content and sources of themes on diabetes resonate with those described in the previous chapter, I will keep presentation in Section One brief first, to avoid unnecessary repetition, and secondly to allow space for more in-depth discussion in Section Two. For example I have omitted views on improving diabetes care, as these mirror views expressed in individual and group interviews with people with diabetes. Illustrative quotes will focus on narratives that present a different perspective on discussions presented in Chapter Six. In instances where narrative content is identical between life-worlds and this in turn is identical to content of broader narratives outlined in preceding chapters, I will select one illustrative quote from one life-world. Where there is variation in content, between and within life-worlds I will present the range of conflicting comments to set the context for further discussion in Section Two.

Table 7.1. Profile of ethnography participants

Life-world	Participant profile
URBAN: John's life-world	John ^{EL} , [diabetes duration – 8yrs]; retired servicemen; Diane ^{EL} , wife; primary carer; 60; retired bank clerk; Hannah ^{EL} , daughter; carer; 30; teacher/university student *Patricia ^{EL} , Diane's sister; 50s; employment status unspecified *Charles ^{EL} , son; carer; apprentice 'technician' Patrick ^{EL} , associate, lay preacher
RURAL GROUP 1: Maame Efua's life-world	**Maame-Efua, 70yrs; [diabetes duration -8yrs]; [retired trader/bar owner] Alice; daughter/primary carer, 32; hairdresser (lives with diabetes) Grace; daughter/occasional carer; teacher
RURAL GROUP 2: Ruth's life-world	Ruth, 50yrs; [diabetes duration -6yrs]; food hawker. Adjoa, daughter, 29, trader Cynthia, [niece], 40; teacher; George ^{EL} ; family friend [self-help group secretary] *Jane; neighbour; unemployed; self-help group member

Key:

^{EL} – Interviews conducted in English

* - Participants with asterisked names were not formally interviewed (ie with semi-structured guides) but were informal discussants, members of the household or community, who joined in group discussions during home visits and/or informal conversations before, during or after home visits.

** - 'Maame' means 'mother' when used in family context. However it is also used as a general term of respect and endearment for an older woman. Because of her age and because her daughters and friends prefixed her real name with Maame, it was important and appropriate to use this term.

7.1. SOCIO-CULTURAL KNOWLEDGE ON DIABETES

Four causal categories were identified in the narratives of the three family-associate groups: sugar, lifestyle, heredity and spiritual disruption. While the content of knowledge resonated with broader narratives, the spread of views on these causal categories differed between and within family-associate groups as Table 7.1 highlights.

Table 7.2. Content and sources of diabetes knowledge : life-worlds

Content	'Spread of views'	Modality & Source(s)
1 Sugar	All three family-associate groups	Scientised
2 Lifestyle	John and Ruth's group	Cultural; Scientized.
3 Heredity	John and Maame-Efua's group	Scientised
4 Spiritual disruption	Ruth and Maame-Efua's group; [Patrick – John's group]	Religious; Cultural.

7.1.1. Dietary imbalance (sugar)

All three family-associate groups attributed diabetes in part to high-sugar diets. This notion of diabetes as a 'sugar disease' was consensual across as well as within the three life-worlds. For example John and Ruth attributed their diabetes onset to high sugar diets pre-diagnosis, as did all their family members.

Some people tell me about some changes. I ask them whether it is because of the sugar I eat or what?

For me, I really like sugar. [Ruth]

When we say someone is sick of diabetes, then it means there's too much sugar in the body. I think, she likes sweet foods that is why she contracted the disease.[Cynthia]

7.1.2. Lifestyle

This theme appeared in John and Ruth's life-worlds. The content mirrored narratives of people with diabetes, with discussions revolving round two sub-themes. For Ruth and her family, diabetes was perceived as '*esikafoo yare*' a 'disease of the wealthy'.

For me, when I came of age, what I had seen is, it affects only the rich. This is because they have money and can eat all sorts of foods. When I was a child, that was all I knew, that is the disease for the rich.

[Ruth]

This notion was strongly contested by George who discussed the negative impact of being labelled rich in poor communities, drawing from his own diabetes experiences and observations of experiences of self-help group members. He noted that to be labelled in this way had two consequences. First individuals living with chronic illnesses such as diabetes would be blamed

for engaging in wealthy lifestyles that caused diabetes. Secondly such a view delegitimised individuals' need for financial and moral support.

They think the disease is for the well to do, the rich class. They accuse us of eating, behaving and living so ostentatiously and that has accounted for our fate. This is the public perception, *Esikafoo yaree*, you have taken in so much fatty meals and other things so they don't regard any other cause, they feel its your lifestyle that has lunged you into that. So that sympathy is not there at all. They don't have sympathy for those in this category. (George)

Diabetes was also linked to individual lifestyle choices. John and Ruth, as well as their significant others, attributed their diabetes to poor lifestyle practices. Drinking was highlighted as a causal factor for John and his family; smoking as a causal factor for Ruth.

Mostly I will say its drinks because he was a border guard sometime but he had the chance of meeting people and though there are diabetic people in the family, he had through drinks and the type of food he was taking. [Hannah]

She told us, when she was young, she learnt how to smoke. Right now, she realized that, this smoking has given her this illness. [Adjoa]

7.1.3. Heredity

Heredity appeared as a consensual theme within the life-worlds of John and Maame-Efua, both of whom had family histories of diabetes. Discussions were underpinned by knowledge of family history, as well as biomedical explanations of genetic risk factors.

Diane: His is hereditary.

Ama: Because you said his mother had it?

Diane: The grandmother, and then the senior sister had it, the brother has got it, one mother one father, the senior brother has got it.

Ama: So you think that it would have happened anyway because it's hereditary?

Diane: yes

Ruth's family noted that diabetes could be inherited, although none recalled family histories. Rural participants drew solely from the biomedical context in their discussions of the heritable nature of diabetes.

7.1.4. Spiritual disruption

This theme appeared only in the life-world narratives of Ruth and Maame-Efua, as well as the narrative of Patrick, John's lay preacher friend, as personally held beliefs. George, Ruth's family friend, discussed spiritual causal theories of diabetes within the context of broader out-there views on chronic illness circulating rural communities. Those who attributed diabetes in part to spiritual disruption discussed two causal routes: supernatural action (power and agency of the devil) and inter-individual action (through sorcery or bought disease).

Abonsam yare (devil's illness)

Spiritual disruption caused through this route defied the natural order of things, according to participants. Observations of children contracting diabetes or dying from diabetes was a dominant example drawn on to illustrate the unnaturalness or the supernatural underpinnings of such spiritual disruption.

...when I hear that someone is dead, I think that person must be elderly, but in today's world you see a small girl dead, a young girl and she's dead. So I feel that if a small innocent child God has created into the world can have diabetes, then it is a spiritual disease that has come into the world that people can contract. [Adjoa]

Sorcery ('bought disease')

This notion appeared in Ruth's narratives and the narratives of Maame-Efua's daughters. In both sets of narratives the individuals who bought disease were family members. Ruth attributed her diabetes to sorcery activity carried out by her brother. Neighbourhood rumours and speculations provided the primary source of this attribution. Although Ruth admitted to having a high-sugar diet and implicated this in her diabetes, her low-income status, coupled with a lack of family history of diabetes, gave the rumours of sorcery activity legitimacy that transcended the sugar theory.

Ruth: In my mother's family, there is no one who is sick of diabetes. In my father's family too I can't tell. But ... a certain woman came here to work. She worked with my brother. [...] One day, she and my brother had a quarrel [...] In the course of the quarrel, she told my brother "You have bought disease for your sister". This is what the woman told my brother.

Danso: You mean the woman said this to your brother?

Ruth: After the woman has said this, I said, "oh, brother, thank you for doing this to me". My brother did not say a word.

Danso: In your own view, what do you really think brings about this diabetes disease?

Ruth: Some people tell me about some changes. I do ask them whether it is because of the sugar I eat or what? For me, I really like sugar.

Danso: Does that make you think that, it is because of the sugar that you eat too much?

Ruth: For me, what I think could be the cause, is my brother.

Maame-Efua's daughters drew on '*nto yare*' to explain the complications that led to amputation of her leg. Alice noted that despite the family's best efforts to prevent further deterioration of her mother's leg, her mother had to undergo surgery within a month of experiencing complications. Juxtaposing her mother's experience with observations of the experiences of other people with diabetes who lived with complications for relatively longer periods before having amputations (if at all), Alice drew on the possibility of sorcery activity to make partial sense of her mother's amputation.

Sometimes they think it's a demonic disease. Because of how her leg became sore and had to be cut immediately. In some cases, the leg will be treated for about a year and then if it doesn't respond to treatment, then it's cut. This was however cut just after a month, so in fact sometimes one is tempted to think that it's her family that doesn't want her to be cured. [Alice]

7.2. BIOGRAPHICAL DISRUPTION AND ILLNESS ACTION: ACCOUNTS AND OBSERVED PRACTICES FROM THE THREE LIFE-WORLDS

For each life-world, I begin with an outline of disruptions for both person with diabetes and their family, and intersubjective responses to these. I then move on to discuss the coping strategies and styles adopted and the mediating factors.

7.21. Maame-Efua's life-world

Biographical disruption and intersubjective meanings ascribed

Maame-Efua had had a leg amputated due to complications of diabetes months prior to ethnographic work. In addition to this disability, she lived with another major condition hypertension (onset of which preceded diabetes) and impairments she classed as minor, including recurring backache, blurred vision and bowel problems. Despite the extensive physical disruption faced by Maame-Efua, her broader life circumstances remained in relative balance. Unlike John and Ruth, physical disruption had not caused disruption to her identity, nor had it affected her economic status, family or social relationships.

This lack of disruption was due to an intersection of subjective and intersubjective dynamics identified in narratives and observations namely: (1) Maame-Efua's identity as a loving mother and (2) a cohesive family structure.

Identity before and after amputation: the loving mother

Prior to her amputation, Maame-Efua had been retired and financially dependent on her family. Consequently, while her complications and resulting disability had had some impact on her family's economic resources, her own personal financial circumstances had been unaffected. Furthermore her identity and role as mother and grandmother pre-amputation had not changed. Accounts of her daughters and observations and interactions during home visits suggested that Maame-Efua's central role in her family had not diminished as a result of her disability. This

central role was observed during home visits, where Maame-Efua babysat her grandchildren (Alice's children) while Alice did house chores.

Family relationship before and after amputation: a cohesive family unit

Alice and Grace spoke of strong ties between Maame-Efua and her immediate family. Her children had been solely responsible for her since her retirement; they had contributed to build her retirement home and paid for her diabetes treatment. When Maame-Efua developed complications and had to undergo surgery, a family meeting was held to choose a live-in carer (Alice) to provide daily support. Maame-Efua's family's support pre-amputation and commitment to taking care of her financial and physical needs post-amputation was strongly underpinned by her children's emphasis on her role as 'a good and caring mother'. These discussions were underpinned by explicit expressions of love for their mother and a fear of losing her if she was not taken care of. This co-existence of emotions – familial love, fear of loss – underpinned the sense of duty and commitment to provide for her financial, physical, and emotional needs.

When I got married to my husband, we lived together in [X] and I had my *kiosk* where I used to work. But the marriage was not good. The man was very bad. I used to really get angry because of my small child. Then also, I didn't have a penny. Had it not been for my mother's help, I would have been dead. [...]. So if my mother is sick, I'll not stay in that marriage and leave my mother to die. [Alice]

It can happen that maybe you've meant to buy maybe a dress or a pair of shoes, or you want to have your hair done and you think that you have to do something for your mother, you can't go ahead and do what you planned and watch your mother suffer.[Grace]

Maame-Efua's family's appreciation of (and love) for her and the sense of duty this evoked, overrode the disruptions they experienced as her principle caregivers. This disruption occurred at two levels: financial (for all involved), and physical health (for Alice, her primary care-giver). Both daughters spoke of financial constraints brought on by the cost of medical care.

Osei: Has the illness brought a financial burden on the family?

Grace: Yes, a lot.

Osei: In what ways has this been a financial burden to you?

Grace: For instance, when she was admitted at the hospital, she stayed there for long. So that was a lot of money. And when she was discharged, we also bought this wheelchair that she uses. And also in her eating, everyone always contributes money for her upkeep.

Secondly, Alice spoke of the physical burden of caring for her mother, particularly in terms of lifting and carrying her on a daily basis. Alice, had NIDDM diabetes, a fact which emerged during the second official home visit. Thus the physical burden of daily care-work was compounded by the physically disruptive nature of her diabetes. However, Alice spoke little of her own problems during fieldwork and focused mainly on the care her mother needed and deserved.

I always get tired, but what can I do? She's my mother so I don't worry about it, because she also didn't have it easy when she gave birth to me. Because whatever the case, she's your mother, she's no one else's mother. Therefore whether I'm tired or not, I don't care. [Alice]

The responses by Maame-Efua and her daughters to disruption were consensual and consistent and remained so for the duration of fieldwork. First, there was a strong emphasis on dealing with the practical aspects of physical disruption: complying with biomedical drug treatment and diet advice was a key concern. They drew particularly from biomedical knowledge gained from self-help group meetings in this regard and also cultural emphasis on dietary balance.

The second consensual family response to Maame-Efua's condition was religious. These religious responses were predominantly stoic: while misfortune was inevitable, God's power to alleviate personal misfortune was unquestionable. Within this context, diabetes was conceptualised as a problem that could be solved permanently or in ways that minimised the full extent of disruption, if one's Christian faith was maintained.

I'm a person who depends on God because there are many problems on this earth. So when I have a disease as such, I put all my hope on *Jehovah* because only He can heal me. [Maame-Efua]

Maame-Efua also drew on a philosophical approach to death. For her death, like illness, was inevitable, especially at her age. More to the point, she had lived a full productive life, raised successful children who respected, loved and cared for her in her old age and therefore had little to fear from death. There was implicit allusion in her discussions on the subject to the classical Akan notion of 'good death' defined by Akan ethnographers as the cultural ideal of death as the calm end to a long, healthy, and (morally and socially) successful life (van der Geest, 2002,2004).

The controlled nature of Maame-Efua's diabetic state, her improved health and vitality post-amputation, the dynamics of her family life and shared cognitive, emotional and spiritual responses within her lifeworld shaped her coping strategies and styles.

Illness action: strategies and styles

The daily strategies Maame-Efua and her family adopted were (1) biomedical drug management (2) diet management and (3) private prayer. The broader coping style was commitment to management and prevention of complications. This shared goal between Maame-Efua and her family remained consistent through fieldwork.

Analyses of formal narratives and informal conversations suggest that this consistency was mediated by three factors: firstly negative experiences with past attempts at healer shopping; secondly, efficacy of biomedical treatment as well as good relationships with her healthcare providers (in terms of face-to-face consultations and active membership within self-help group); thirdly and crucially, committed family involvement and support in her care.

As noted in Section One Maame-Efua like John and Ruth, had healer-shopped in the past. However, she had experienced complications and subsequent amputation of her leg, as a result of using an ethnomedical drug provided by one of her children as a cure for diabetes. This negative experience, coupled with the efficacy of biomedical treatment in reversing the extreme physical and emotional disruption she faced prior to amputation, had put an end to healer-shopping and the use of ethnomedical drugs. During fieldwork, Maame-Efua used oral hypoglycaemic drugs exclusively.

Since she fell ill, like she said, it's only one of her children who brought her some medicine and she had the sores after she'd tried it. Since then she's not used any herbal medicine in addition to the treatment she receives from the doctor. [Grace]

In addition to biomedical drug efficacy, Maame-Efua and her daughters all stressed the positive relationship Maame-Efua had with the doctors and nurses in charge of her care. The quality of the relationship was assessed in terms of knowledge gained from these healthcare providers and in particular the self-help group, as well as the respectful and empathic communicative style used by her health professionals during clinical encounters.

At St. Theresa's they have patience and treat her well. She is not disrespected. [Grace]

Finally, Maame-Efua's family's commitment to her daily care – in terms of physical, moral and financial support – contributed to the consistent and successful nature of a mutually constructed illness action goals. This commitment was explicit not only in narratives on family's active role in illness action process, but also during observations of family relations and practices. For example Alice was present during every official and unofficial home visit. Three out of the five 'official' home visits, Grace was present, at other times other family members and neighbourhood friends would be present. During each self-help group meeting attended during fieldwork, Maame-Efua was present and accompanied by Alice. At the end of fieldwork, she was using biomedical treatment exclusively, attending self-help group meetings regularly and receiving committed support from her family.

7.2.2. John's life-world

Biographical disruption and intersubjective meanings ascribed

John's experience of diabetes mirrored that of Maame-Efua at three levels. Like Maame-Efua he lived with diabetes and hypertension, and had had a longer history with hypertension. He had also had a leg amputated, although his experience of amputation was more recent (having undergone surgery three weeks prior to fieldwork). He lived within a supportive family environment, with round-the-clock care provided by his wife and older children. And like Maame-Efua and her family, much of the emotional and practical focus for both John and his family was on diabetes. However, unlike Maame-Efua and her family, whose disability was stoically accepted by both her and her family and adapted into their existing family relationships and roles, John's disability evoked a pervasive negative emotional response that set up conflicts within his lifeworld.

Physical disability disrupted four key areas of John's life: his identity, economic circumstances, food practices and towards the end of fieldwork, his family relationship. For John's family, three areas of their lives were disrupted: economic circumstances, physical health, and psycho-emotional well-being. Disruptions to John's life and his family's life and responses to these disruptions were intricately linked. In this section I will attempt to capture the interrelated and intersubjective nature of these experiences and responses, by presenting the key disruptive dimensions from dual perspectives – John's and his family's.

Economic disruption

Although John had retired from his long-term career as an army serviceman, he had had a casual job as a security guard prior to his hospitalisation. The amputation and confinement to a wheelchair had put an end to work for the foreseeable future. The loss of income had two crucial implications. First, since the family household budget drew on his income, this loss affected the family's economic status. Secondly and more importantly for John's illness action goals, the family's struggle with a diminished budget was compounded by the ongoing need for expensive insulin treatment and diet management.

Yes we were OK. ...he was able to go on his normal duties, earn some little money, bring it home and then we live on it. But right now, he will by all means come and stay home without any financial support. So that is going to drain us. How are you going to eat, live and he being diabetic too, he can't eat everything we... take. We have to put him on special meals. Taking bread for example, his will be special; any meal of his will be special. So if we have been than using about ₦10,000 ((£1 at time of research)) to cook for the whole family, you have add some little more to get his special meal for him.”
[Diane]

These financial difficulties had a critical impact on a range of practical activities essential to John's diabetes care, as will be discussed shortly. However like Maame-Efua's family, John's family was determined to provide adequate care for John, regardless of financial cost. This focus on providing appropriate care was strongly linked to the nature of his complications (his recent amputation and slow healing of his amputated limb), and fear of further complications. The family adopted a common sense and religious approach to the problem of constrained economic resources. They relied on John's and Diane's small pension, on periodic financial contributions from a daughter abroad as well as other relatives. They also prayed for financial support and drew religious support from church and regular home visits by Patrick.

Disruption to identity

The loss of his leg and his inability to 'move around freely' or more to the point his dependence on his family for mobility constituted a major recurrent problem for John.

I am carried from my bed, to the sitting room, from sitting room to the bedroom. I want my leg to be o.k. Doc says I should have patience in exercising the feet. So I'm just waiting. [John]

This lack of mobility also affected his ability to engage in the social activities he used to when he had both legs, like playing football or taking weekend breaks.

Ama: How has diabetes made an impact in your everyday life?

John: oh yes, formerly I used to play football regularly but now I can't. Now I stay indoors.

John's accounts of his dependence on family to get around and the changes to his social identity were underpinned by a sense of frustration. This did not diminish throughout fieldwork. During

the early weeks of fieldwork, his family revealed his state of depression, and often challenged his accounts of emotional stability during my interviews or conversations with him.

Field note extract 1 [Official visit 1, 15.02.01]:

During interview with John, I asked if he had any particular problems, he said no, mother and daughter sitting at the opposite end of the living room, shook their heads vigorously, spontaneously, said '*obua*' (he's lying). Diane made a comment about his swollen leg at that point. At other times during the interview, Diane interjected, outlining other problems – stress of caring for John, (disability, dependency, worrying about John's well-being), the expense of diabetes (John is on insulin which is very expensive), uncertainty about his and the family's future. John may have got to these problems eventually, even through his reticence, but there seemed to be a greater need for Diane to get the pressing issues out in the open at our first meeting.

John's disability impacted on his family in two ways. Firstly it caused disruption to the physical health of his immediate carers. Secondly changes to his emotional state and personality undermined family role expectations and cohesion.

Diane as primary caregiver suffered the greatest physical burden in terms of constant lifting and moving John around the house. She also suffered disruption to her sleep patterns, a problem she attributed to constant worry that John would require assistance during the night.

You see I think about him too much. If I sleep, I have to wake up in the sleep and then go round him may be has soiled himself and that I have to change him. So I don't have enough time for myself. [Diane]

There was an underlying sense in Diane's narratives, that the family – and in particular Diane – was living a restricted life, that some members, such as their son Charles, had had to put their life and goals on hold in order to provide John with round-the-clock care. Diane noted that burden of care could be diminished if the family had recourse to greater financial support. With more money, the family could hire professional home support, which would allow them more time and freedom to attend to their own needs.

Yes. Right now if I want to travel or if I want to go out, there is nobody who can stay with him in the house to look after him before I come back. I can't get somebody to stay with him for me to leave the house. So I have to spend every time with him in the house... If I go out now to look for somebody, I have to pay him but then I haven't got money too and that problem too is reducing my weight. Taking him up and down every time, I think is a tedious job for me. It's ruining my health. [Diane]

Interwoven with this concern to overcome lives restricted or put-on-hold, was the added worry of the implications of John's depression to the family's collective identity and John's life trajectory.

Diane and Hannah strongly asserted that the amputation had undermined John's core identity: he was no longer the husband and father he used to be. Hannah noted that John had lost his characteristic vitality and 'happy persona'. He was withdrawn, no longer initiated family activities and she no longer spent quality time with him. Hannah worried about her family's ability to cope and was fearful of an uncertain future for her father.

My life has changed drastically. You see the family used to be a very happy family. My daddy was a very happy man. He used to crack jokes a lot... He used to say "oh Hannah, lets go to this place, lets go to Akropong" his hometown. Every weekend we used to go to places. These days we don't go anymore. All my Saturdays I have to spend with my daddy. I used to go to church but these days I don't go. As I was at Cape Coast I was thinking about my daddy, how is he faring, how are they coping with him? Everywhere I go, my mind will not be settled. I will be thinking about him, how many years is he going to stay with us? So it has changed our lives. [Hannah]

Diane's concerns also revolved round the impact of John's changed identity on their marriage, as well as the emotional well-being of the family. she discussed the changes in John's attitude and responses to the sexual dimension of their marriage.

Now, I don't have 'enjoyment' ((used as euphemism for a healthy sex life)), now he is sick he can't enjoy very well and so I have had 2 or 3 years without that enjoyment, I am not happy. [Diane]

She noted that the family's collective concern for John's well-being had generated a state of unhappiness and weariness.

Diane: Socially, it's letting us down.
Ama: How is it letting you down socially?
Diane: we don't have the enjoyment or the happiness in the house. Everybody is thinking about him. Now that he can't walk, we have to carry him up and down. My son, for example, [Charles], is now learning a trade. Since about one month now; he's in the house. So our social interest is getting down.

Both Diane and Hannah attributed the personality changes in John, and the changes to their relationship with him, to his depression. This empathy expressed at the psychological burden of

disability shaped practical responses to John's emotional state. They made explicit plans to engage in daily activities to cheer him up, with the hope that once John had overcome depression he would become the husband and father they remembered.

At times he cries. Yesterday for instance there was a lady who came to visit him and I don't know what happened he was wiping the tears from his face. If I see that I don't ask him any question, the only thing is just walk out. He does cry. So what I have planned doing is we don't leave him alone, go near him, advice him and play some music for him with cassettes that he usually likes...[Hannah]

Disruption to food practices.

Because of his recent amputation and the slow healing of his amputated limb, John's family had stepped up diet management. Diane was committed to sourcing recommended foods for him and cooking food according to biomedical instructions provided by John's nurse sister, as well as other diet advice offered by family and friends (see fieldnotes extract 2 below). I should note here that the special foods Diane prepared for John – the staples like plantain, and non-staples like cabbage and lettuce – were expensive and sometimes unavailable in their local market. Despite his family's efforts, John had difficulty complying with diet restrictions. There were periods when he would not eat sufficient amounts of prepared meals, other times he would eat prohibited foods when left on his own.

John's problem with diet management was a key source of family conflict. This emerged both in the narratives of his family and in observations during visits to their home (see fieldnotes extracts 3 and 4 below).

Fieldnotes extract 2 [Official visit 2 / 10.04.01] :

Patrick had this salt theory that he launched into a couple of times, first to make a connection between hypertension and diabetes, then as a way of explaining the cause of John's four day constipation. Diane had mentioned that John had constipation, she asked how that could have come about and we were in the middle of discussing diet changes, trying to locate the cause of the problem). Patrick talked about links between 'salt' and 'nerve cells' and 'blood flow' and constipation, in that order. He spoke authoritatively. He asked if Diane had been giving John salt. She said yes she had, then 'it's true, it's true, it is the salt'. Patrick said 'you have to stop the salt' then urged drinking lots of water. Diane agreed wholeheartedly. John will be put on a no-salt diet and copious amounts of water by dinner today.

Fieldnotes extract 3 [Official visit 3 / 19.04.01] :

Along the way, Patricia dished out advice. Patricia (and I paraphrase): “you must eat the salad leaves, mix it up with the stew if you don’t like it much, with diabetes you need leaves, more leaves, to help ease your bowels, when you eat oranges eat all of it, the fibre and juice, you must try, you know if you’d started taking the drugs earlier you’d be much better” At this point John cuts in, saying “oh the medicine is good”, possibly referring to Daavi’s herbal medication.

Fieldnotes extract 4 [Official visit 3 / 19.04.01] :

We got to Daavi’s ((the herbalist)) place. Hannah and Patricia went to the house to see if anybody could direct us to Daavi’s daughter’s house. While John and I sat waiting, a food vendor walked past the car. He called out to her. He asked what she was selling. She said it was ‘*atadwi milk*’ ((porridge made with tiger nuts and milk)). He asked how much it was. She said 700, 800 and 1500 ((cedis)). He said he’d like a 700 jar. Just before she served him I asked if there was sugar in it. She said yes. I turned round to John and asked, “aren’t you supposed to avoid sugar?”. He said “well, once in a while, it doesn’t hurt”. I said to the woman, “he doesn’t eat sugar so he can’t buy this”. But he protested. He said his blood sugar level was ‘negative’. I said to him “Hannah isn’t going to be happy with this”. Anyway, John bought his *atadwi milk*, ordered extra milk to go with it and proceeded to eat. In the middle of all of this Hannah returns with Aunt, they see the vendor, then see him eating. Hannah says ‘Dada, what are you doing? What are you eating?’. She turns to me, remarking in a tone of frustration “this is what he always does, the moment you turn your back he is eating something he shouldn’t.” Patricia gives a short stern lecture about the dangers of eating sugary foods. John finishes the snack calmly and in silence, hands the jar to the vendor and we drive off, drop Patricia off and head back home.

Disruption to family relationship

Disruption to John’s family relationship evolved over the course of fieldwork and revolved mainly round changing and conflicting emotional responses to John’s disability. At the beginning, both John and his family expressed fear and worry about the state of his amputated limb and remaining leg. The nature of fear was shared – it focused on the state of his remaining leg in the immediate sense and the risk of further more serious complications on his life trajectory. His depression, though not acknowledged and discussed by John himself, was recognised and legitimised by his family as the underpinning factor for the change in his identity and non-compliant behaviour. Identification of this root problem formed part of the basis for the coping strategies John’s family constructed for him. The consensus was that if the

family managed to raise John's spirits, this would in turn lead to better self-care and restoration of family balance.

But as the weeks and months wore on, John's moods began to oscillate between depression about and anger at his changed identity. According to family narratives, while depression led to withdrawal from his family, anger led to periodic verbal aggression towards his family.

Oh he always at times will be annoyed. Yesterday morning when I was bathing him, I was not quick because we sat him and I was about go and bring his sponge and what have you and when I came he had started doing something so when I came back I had wanted him to carry on with it. So I said 'dada, I have seen that you are doing it so carry on'. Oh he was annoyed and I had to cool him down. Sometimes he gets a bit furious, the little things even when you ask him a question, he says your bothering him so you have to keep quiet. [Hannah]

This change in John's emotional state, caused his family some emotional strain. A recurring subject in my conversations with Diane and Hannah during this period was their increasing inability to cope and the need to explore new ways of responding better to John's mood swings and non-compliant behaviour. My advice was sought on possible ways forward. Explicit references were made of growing physical and emotional fatigue during these conversations. These changes in turn changed the dynamics of family cohesion and the coping style. Fear remained for his diabetic state, but also crucially for their own physical and emotional health and the implications of the changes on their abilities as caregivers.

Illness action: coping strategies and styles

It is important to note that narratives and observations of John's family dynamics strongly suggested that John's coping strategies were constructed by his family and in particular his wife and daughter. This stemmed in part from the worry and fear the immediate family expressed about the risk of more serious complications post-amputation, but perhaps more crucially because John remained depressed and largely withdrawn for the greater part of fieldwork and seemed less expressive and pro-active about his practical everyday needs and routines.

The daily strategies constructed by Diane and Hannah remained constant throughout fieldwork. These involved taking medications, eating foods recommended by the doctor, weekly measurement of John's blood-sugar level (using a tester kit provided by their daughter living abroad), prayer and periodic physiotherapy. The broader coping style changed however, from active cure-seeking (healer-shopping between ethnomedical and faith healing spheres) to biomedical management. These changes were mediated by four main factors: (1) John's disability and shared fear about further complications and implications on life trajectory; (2) the family's disrupted economic circumstance; (3) the absence of support and continuity of care by John's health care professionals (both biomedical and ethnomedical) and (4) the changing nature of shared emotions within the lifeworld.

Active cure-seeking

During the first half of the fieldwork period, John's family actively healer shopped for the most efficacious treatment for his diabetes. This goal was underpinned by frustration towards the slow healing of his amputated leg, the deteriorating state of the remaining leg and fear of complications and potential amputation in the future.

For now we can't stand on one argument, we cannot stand, and we are just trying something. We just want to know whether it will heal. We've given him some medicine to take so we've given him sometime to see if his medicine will be able to do something. [Diane]

The decisions the family made about which treatments to use, particularly within the ethnomedical sphere, were mediated by concerned family and friends.

People come in and they say you spend a lot of time on the orthodox medicine why not try the traditional ones? Somebody has healed this person with the traditional medicine and it has helped him, so why not go in for this medicine why not call this man to come and help you. You see, that is why we too as human beings being so anxious for the person to get up quickly, I feel when they call in that person; he too can help them get him healed quickly. [Diane]

I should make a note that, family and friends did not only offer advice, but they brought in a variety of herbal medicines for John's diabetes. This activity was observed throughout the fieldwork period. There was a corner table in the living room that housed rows of bottles – and sometimes a small gallon or two - of various herbal remedies.

After the first official home visit and set of interviews with the family, Diane and Hannah discussed their decision to discontinue biomedical drug treatment temporarily and begin ethnomedical treatment for John. Diane's sister, Patricia, whose husband according to Hannah 'was cured of diabetes' by using the chosen treatment, exerted great influence on this decision. At this stage, the focus was on drugs that could heal the amputated limb faster, improve the condition of the remaining leg and prevent further complications.

All other practical routines – diet management recommended by doctor, prayer, physiotherapy – would remain unchanged. They expressed great confidence in the efficacy of their chosen ethnomedical treatment and noted that in the rare event that this treatment failed, they would 'switch back to' insulin treatment.

By the next home visit, in the second month of fieldwork, John had received ethnomedical drugs from the herbalist. This occurred without face-to-face consultation. Patricia had delivered the drugs. Insulin treatment had been abandoned for exclusive use of this new treatment. In addition to this switch in drug treatment method, the family decided to consult faith healers to strengthen efficacy of treatment. Similar reasons were expressed for this treatment choice – frustration that John's leg was not healing fast enough and fear of further complications.

Ama: what are your reasons for using these types of treatment?

Hannah: so that my dad gets healed fast.

Ama: Tell me some more.

Hannah: ok we've tried the western type of medicine for a long time [...] but its not getting better as we would want it, we want see the other aspect the traditional and the religious one, see whether it will help him to be fine, even if he will be able to stand on the other foot or use the clutches since some people have been able through the religious line have been able to cure some people who are lame and who are not able to walk.

They chose a prayer camp, based in a neighbouring town, which advertised its services on radio and TV, and whose 'miracles' had received some endorsement within their community.

We have heard about some people in the media being able to walk as the help of the religious leaders and also the traditional leaders. So he is giving it a try. He is not relying on it but giving it a try whether it will help. [Hannah]

The first consultation with the principle faith healer at this camp proved positive, according to the accounts of John's wife. The faith healer expressed conviction at his ability to cure John of diabetes and advised regular visits for the treatment process to take place. The prayer camp was attended on two further occasions, before the family abandoned this mode of treatment due to cost of travel.

Management

The family experienced problems with their choice of ethnomedical treatment. The treatment had proved to be ineffective. Furthermore the family had no access to the herbalist for advice on how to maximise efficacy either through varying dosage levels or frequency of medicating. For a considerable period of fieldwork the herbalist had taken time off work to attend to family responsibilities. By the fourth month of fieldwork, the family had returned to exclusive use of biomedical treatment as a practical daily routine and for adjunct spiritual support, private prayer and regular visits from Patrick. This continued for the remainder of fieldwork. Friends and family continued to bring in a variety of herbal remedies for John's diabetes, although discussions with John and his family suggest that these remedies were not used.

7.2.3 Ruth's life-world

Biographical disruption and intersubjective meanings ascribed

Ruth lived with severely uncontrolled insulin-dependent diabetes. The prolonged and severe disruption this caused to her physical body and physical capabilities, precipitated disruptions to her broader life circumstances. Unlike Maame-Efua and John, she had no committed family support, a situation stemming primarily from the low-income status of her family and the burden of cost for insulin-dependent diabetes. Despite the observed lack of family presence/support in Ruth's daily life, key themes in her account of the nature and severity of biographical disruption resonated with accounts of the family members and community members interviewed as part of ethnographic work.

Disruption to physical body

Ruth lived with severely uncontrolled diabetes with a mix of chronic persistent complications – loss of appetite, severe weight loss, joint pains, bodily sores – that made her state of disability more acute compared to John and Maame-Efua. Her entire family-associate group, as well as self-help group members, talked extensively about the impact of body-self disruption to Ruth's life.

Now I experience bodily pains. Also pains in my bones is another thing. When I experience these pains I can't sleep in the night. I can't sleep at all. [Ruth]

In fact, from what I can see it is not going down, at times, she cannot even sleep. She will cry till daybreak, complaining of pains in her bones and body pains. She is always laying down to be massaged. Every time children would be massaging her. [Adjoa]

The severity of physical disruption affected Ruth's ability to carry out daily activities: the simplest house chores had become unmanageable.

I am unable to do any work. Even if a load is prepared for me I cannot carry it. Recently I decided to cook food and sell it. I got burnt by coal pot fire. I am unable to cook and eat. [Ruth]

Ruth's physical disruption and her diminished ability to carry out everyday roles, led to a redistribution of roles, which caused her immediate family some physical stress. For example, while Adjoa did not describe herself as her mother's official caregiver, her mother's inability to take care of their home for example had shifted the housekeeping responsibility on her.

Every time, right from bed, whatever my strength will allow me to do, I have to do it for her. Where we live now, if I leave her, she can't wake up and pick a broom to sweep. She can't do anything. I have to bear it.[Adjoa]

Disruption to economic circumstance

Like John, Ruth had had a job (as a self-employed food hawker) and earned an income before she got diabetes. Two factors affected her ability to earn an income. First, extreme body-self disruption had affected her ability to engage in the strenuous nature of food hawking – walking long distances with heavy trays of food. Secondly, she had experienced severe weight loss, which disrupted her body-image. Community interpretations of this weight loss in terms of AIDS, and subsequent fear of her food as contaminated food.

When I sent food to the school to sell, the children wouldn't buy, because the teacher told them I have HIV/AIDS. [Ruth]

With job abandoned, Ruth had lost her sole source of income and ability to fund diabetes treatment.

Before I got affected, I could work to earn money to use in attending hospital. [Ruth]

I pity her so much, because she can't even work to earn money to look after her children. I really do brood about her situation." [Cynthia]

Disruption to identity

Ruth's lack of money and inability to treat her diabetes exacerbated her weight loss. For a middle-aged woman who prior to getting diabetes and prior to abandoning regular treatment had had a healthy body image, the sudden change to her physical identity had caused some shock to her family and community.

In fact, we were all shocked to see how a fat woman like her would reduce in size like that. [Adjoa]

As weight loss persisted, shock turned to community speculation and gossip that Ruth may have contracted AIDS. The AIDS identity conferred on Ruth had two interrelated consequences. First, she experienced disruption to her social relationships, a problem I will discuss in the next section. Secondly, her family became 'tainted' with this identity. For example Adjoa's attempt to take over her mother's food hawking business failed, because people were unwilling to buy food from an individual living in close proximity with a supposed AIDS sufferer. According to Adjoa, the community expressed fear that the food might be contaminated as a result of it being prepared by Ruth (to be sold by her daughter) or prepared in close proximity to Ruth.

Adjoa: You see, at first, my mother was selling *rice water* (rice pudding). Due to her illness I had to take over and sell it but people didn't buy it anymore. They were thinking something different.

Osei: Something like what?

Adjoa: Some people thought she had got AIDS. This perception hung over her and made people to stop buying her *rice water*.

Disrupted social relationships

The disruption to Ruth's social life stemmed mainly from being labelled with an AIDS identity. Much of what changed her life circumstances, her family relationships and undermined her attempts to get better was intricately linked to ostracism underpinned by AIDS labelling. I will focus here on direct relationships between Ruth and the wider community and move on next to discuss the impact of social disruptions to changes in her family relationships and close friendships.

Ruth was ostracised by her community. She spoke of being laughed at and jeered when she left her home, an experience shared by other people with uncontrolled diabetes in Nkoranza, as Chapter Six showed.

When I walk on the streets, children just look at me and laugh at me. But whatever the problem is, it's in the hands of the Lord. [Ruth]

Crucially, these community responses undermined Ruth's attempts to improve her economic circumstances. For example she was denied the opportunity for casual work. She noted that community members unaware of her alleged AIDS status were sympathetic to her economic problems and offered practical forms of support, but that sympathy and support was withdrawn when the AIDS allegations became known.

Yes. Recently one of them at the market, said to me, I am in the house doing nothing, so I should come and help her in selling her fish. And I said to myself that, I would go, because I would get some to cook food in the house. But someone must have told her I had contracted *HIV/AIDS*. So the day I went to the market, she sacked me. And I asked her why she would offer me a job only to sack me. And she told me I have got *HIV/AIDS* so I should not come there again. [Ruth]

Ruth's accounts of her experiences resonated with accounts of people in her lifeworld. Self-help group members noted that while they all faced varying forms of physical disruption, Ruth experienced a particularly heavy social psychological burden. Her life circumstances were presented in some interviews and informal discussions as an acute illustration of the fate of rural poor living with diabetes.

People were saying it was AIDS because she was growing lean. She used to cook and sell maize porridge. When she sent it to the school, the children would not buy it because a teacher had told them that she was suffering from AIDS. If you are not careful, you will take poison and die. [...] So you see, how I have grown lean? She was also a big woman. We all have problems but hers is worse. [Jane]

Disrupted family relationships

Ruth described the reasons for family disruption in two ways. Firstly, in terms of the economic burden of diabetes; she noted that at the early stages of her illness, her family (both close and extended) contributed to hospital treatment, however as the illness progressed and the cost increased, her family abandoned her.

My relatives from my father's side took me to Takyiman ((neighbouring town)) when my illness began. When they did this for about two years, they became fed up. For my mother's side, no member has given me a penny. [Ruth]

Secondly she described family disruption in terms of the impact of her changed physical identity on her family's perceptions of her. Ruth's narratives on her family life were couched round highly emotive notions of family, friends and even church members as 'wicked', 'uncaring' or acting on negative community perceptions of her as 'an AIDS patient' or a 'witch'. This conviction was borne out of recollections of poor treatment she had received from family and friends. She noted that her family, and her children in particular labelled her as a witch. This label shaped her children's attitude towards her – her daughter for example did not offer her food, when she cooked for herself and her children. She recalled an incident with a former close friend, who refused to give her water, because of fear that her glass might get contaminated with the AIDS virus. She spoke of her church members not visiting her when she was hospitalised. From Ruth's perspectives, all the important people in her life had abandoned her.

I gave birth to twelve children, but there are only nine left. There are two young ones among them. Those that are with me here are not responsible for my living. When they cook they don't even give me some to eat. They claim I am a witch. As a result they don't even give me food to eat. [Ruth]

Ruth: I have two close friends. But since I became sick they don't come to me anymore. Recently, I went to my brother for some money at the other part of the town. [...] When returning home, I was very thirsty, so when I reached one of my friends who is a *chop bar* (a very basic restaurant that serves local food) owner on the way, I passed through her bar for some water, she didn't give me.

Danso: She didn't even give you water?

Ruth: Yes she didn't give me. Because I would drink from her cup.

The church members are all very wicked. When I was admitted at the hospital, could you believe that they didn't pay me any visit? [Ruth]

Sometimes, when probed further on relationships with particular family members, a different picture emerged, of some family members doing what they could to help when they had resources. For example, while she expressed strong conviction that her children wanted nothing to do with her, it emerged that her son had assumed responsibility for making her yearly health insurance payments to the Nkoranza Community Health Insurance Scheme.

Danso: I understand there is an Insurance Scheme here, that's when you contribute money and you go to hospital you don't pay. Are you a contributor?

Ruth: Please, I do contribute.

Danso: You do contribute to the scheme?

Ruth: Yes please I do.

Danso: So have you paid this year's contribution?

Ruth: As for that, my child takes care of it. He pays it every year.

Ruth's family's narratives resonated with this latter picture of a low-income family, sympathetic to the psychological and emotional impact of diabetes on Ruth's daily life, but unable to provide sustained practical help, due to financial constraints.

Like Ruth, their accounts centred on the impact of cost and impact of changed identity on family relationships. However the nature of these issues was conceptualised and experienced in different ways. Adjoa and Hannah noted that during the first two years of her diabetes experience, Ruth had received committed support from her extended paternal family. The family had suggested going for biomedical tests, when she thought she had malaria and was self-medicating. They had subsequently contributed towards hospital costs and general self-care (bringing her recommended foods for example). However as her illness persisted and the cost of care had increased, financial support had ceased. Fundamentally Ruth's immediate family was poor, most of her seven adult children were living away, those who lived in Nkoranza, including her daughter were low-income earners. Ruth was on insulin treatment, which was very expensive.

In the family there are people who are worried. You could see that, if the person had been a well to do person, he/she would have helped. Some also, have just blocked her out of their mind. They don't even visit her and even to greet her. At the moment, all of her children too, are young. We don't have our own professions and so we haven't enough money. If we had money, we would have made everything possible for her to be well again but we have no money. [Adjoa]

During fieldwork, some members of her family continued to provide financial support when they could afford to do so. Hannah spoke of providing periodic financial assistance. Adjoa – contrary to Ruth’s assertion – spoke of cooking for her mother when she had sufficient money and food.

Oh! I really support her. At times, if she comes to me, I give her money. Also, when she comes and I have food available, I give her some to eat. So I help her a lot. [Cynthia]

Well, I actually don't have enough money, so what I do for her is that, after selling my wares, I then go to the market to buy foodstuff and come home to cook some meal for all of us to eat. This is what I am able to do. If I have, I give her. If I don't have too, I make her aware that I don't have it. [Adjoa]

Changed identity: The stigmatisation and ostracism of Ruth by the community did not only affect Ruth’s sense of self, but her family’s collective and individual identities. As noted earlier Adjoa’s attempt to take over her mother’s food hawking business was undermined by negative community attitudes to her. But perhaps more crucial to internal family dynamics, community rumours of Ruth’s AIDS identity evoked fear in her immediate family, that the rumour might have some truth. This mix of factors – fear of a close relative with AIDS and the risk of a ‘tainted family identity’ by association – led to abandonment of Ruth by some of her close family members, including her long-term partner.

When she got the disease at first, she had a partner but as she reduced in size, the man became afraid. People told him to be careful, because it could be that deadly disease. They even suggested to him to leave her. So after the man left him, she did not marry again.” [Adjoa]

Danso: are you with your husband?

Ruth: Please, the moment, I got this disease the man told me he could not stay with me again.

During fieldwork, the alleged AIDS identity was no longer the central factor undermining family cohesion for the family members interviewed. There were no references to or fear expressed about Ruth as a person with AIDS.

Adjoa: At the initial stages, I was very much afraid.

Osei: Why?

Adjoa: People used to say a lot of stories, so I was very much afraid. Later on I realized that it was not this deadly disease, AIDS but rather it was diabetes. I became a bit relaxed.

Just as the family did not draw on the AIDS label, contrary to Ruth's convictions, no references were made about witchcraft. There were other issues of identity, however, that reshaped the quality of family relationships, particularly between Ruth and her daughter. These centred on changed family roles. Adjoa's narratives strongly suggested that Ruth's prolonged illness had undermined her role as a grandmother. Adjoa was a widow with three young children. She worked long hours for a meagre income. Prior to Ruth's complications and extensive physical disruptions, she had hoped for childcare assistance from Ruth to lessen the combined burden of full-time work and single parenting. Ruth's prolonged illness and body-self disruption had undermined this envisaged role. The disappointment Adjoa felt at this was expressed a number of times during her interview. Adjoa made references to praying for Ruth to get better, to improve Ruth's life circumstances, and by association Adjoa's own circumstances.

What I used to think over was that, my husband died after having three children with me, and so I was thinking that, if my mother had not become ill, she would have given me a helping hand in caring for the children. Because of her sickness she cannot help me, because of this, I do think over it always. Every time, I pray to God to have mercy on her and to cure her of the disease. Even if, she had sinned, God should forgive her. [Adjoa]

The disappointment also fed implicitly into criticisms of Ruth's lack of strength of character and defeatist attitude to her condition. Here the emphasis was on the need for Ruth to adopt a broader reflexive view and more stoic response to her problem.

Many people fall sick, but see what has happened to my mother. I complain to my friends and sometimes, when my mother is complaining, I tell her "stop crying because you can't have all good things in life. Now what you have to do is to pray. Someone is blind and wants to just see, but can't. God has given you the ability to see. Some people are paralyzed and they wish they could walk and would rather have diabetes. Everybody has his own disease. But as for you, you can stand up and you have eyes, you can stand and walk, so thank your God". [Adjoa]

Ultimately, Adjoa's broader narratives suggested that the conflicting emotional responses to her mother's condition and ongoing life circumstances were underpinned by a dual struggle to cope with her own life circumstances (low income, self-employed single parent with three children) and attend to the extra daily burden brought on by her mother's physical disability and dependency. On the one hand she stressed her intention to provide support. On the other hand, she hoped for – and sometimes prayed for – an end to her mother's suffering, either through a miracle cure or death, to ease the emotional burden she lived with. It's worth noting that unlike the official carer role adopted by Maame-Efua's daughter Alice by family consensus, Adjoa's carer role seemed to have been thrust upon her by default, since she was the only adult child living with Ruth in the family home. And unlike the other families, Adjoa received little to no carer assistance from her other siblings or close family members.

I am under pressure. I have realized that, in Nkoranza, if you have no one to help you in times of trouble, you worry a lot. Sometimes, I even want to travel out of town. [...] [...] when the impact of the disease increases, I feel a lot of pressure. She worries me a lot and so I make up my mind to travel and leave her, if we leave and later we hear that she is dead, and then we come back and bury her. But I have second thoughts and then decide to stay and take care of her." [Adjoa]

Illness action: coping strategies and style

As outlined earlier Ruth had insulin-dependent diabetes and lacked financial resources to pay for insulin treatment. Ruth engaged with biomedical care, sporadically, when she received money from well-wishers or had treatment costs waived by sympathetic doctors at St Theresa's.

During fieldwork, Ruth had discontinued biomedical treatment, due to lack of money. She was hospitalised once during fieldwork, due to complications stemming from uncontrolled diabetes. She had no resources to engage in diet management, and usually ate when she received donations from community members and friends.

Unless I go out for somebody to help me with about ₵1,000 ((10p)), I go about without food. Since morning, I must confess I have not eaten anything. I have not eaten. I only bought one egg worth ₵500 ((5p)). That is the only thing I have had today. [Ruth]

However, she adopted three regular strategies to address some of the disruptions caused by diabetes. First she took herbal tonics to regain physical strength. This activity – like her food practices - was dependent on financial donations from friends and family.

When someone gives me ₦500, I will buy *Aberewa Bebo Ball* ((lit trans: “old ladies will play (foot)ball” - a popular brand of herbal reenergizing tonic)) and will find some food to eat. [Ruth]

Ruth stressed that ethnomedical treatment was not an option, firstly because she had insulin-dependent diabetes, secondly because a past attempt at using herbal medicines recommended by a friend had resulted in severe complications. However, in addition to these herbal tonics, she sometimes took diabetes specific herbal medicines, recommended or brought to her by friends. This practice was underpinned by her need to reduce the physical disruption of diabetes and her inability to afford biomedical care, a dynamic both Ruth and her family discussed. The use of herbal medicines exacerbated her symptoms.

Even last time, a certain woman came to tell me I should chew these flowers which are red in colour. I chewed it and I had a running stomach. I have since stopped chewing that flowers. This is about two weeks ago. [Ruth]

Secondly, she prayed and attended church regularly for spiritual support. Sometimes she stayed for entire days or overnight in the adjoining prayer camp of her church. On two occasions home visits had to be rescheduled because she was at the prayer camp. Finally she attended self-help group meetings regularly and drew advice and support from this group.

Ruth’s interview narratives and conversations were dominated by despair. She expressed despair at the extent and severity of the impact of diabetes to her life and at her family abandonment. She frequently cried during interviews and during informal visits. She spoke of crying over her chronic suffering on a daily basis.

I have even wept about three times today. Because I don’t have anybody to help me, I am overwhelmed by misery and sadness. And because of this I really cry and sometimes passers-by will calm me down [...]They tell me not to be overwhelmed by sadness, that that can also make me sick. When they tell me this, I wipe away my tears. [Ruth]

While narratives of her daughter and cousin suggested that she still received support from them, Ruth's family abandonment was particularly visible. Unlike John and Maame-Efua, who always had family members with them during official and unofficial home-visits, there was never an adult family member with Ruth during home-visits. She usually lay on a mattress under a tree in the family's compound, with her two youngest children playing nearby. She attended self-help group meetings on her own; sometimes she wandered the hospital grounds on her own³. Her frequent church attendance could perhaps be interpreted in terms of a need for adult company and conversation, as well as spiritual support. Ruth made recurrent references to death as end to her chronic suffering. This was expressed as much to her family, as well as during interviews.

She is still in fear because since she got the disease, she has the feeling that she would die at any time. That's all she has been saying. At times when she comes to me, she would ask me, when at all is death coming for her? So, with these sayings, you could realize that she is in fear. [Cynthia]

There were also recurrent contemplations on suicide. However, even as she was repeatedly drawn to suicide, she noted she was unable to go through with such a course of action, because her Christian faith abhorred suicide as a response to life's misfortunes.

Ruth: Recently, I even thought of committing suicide by poisoning myself.

Danso: Is that true ((Really))?

Ruth: Yes. I have said that. And I say it each day. But I remind myself later on that, it is the Lord who brought me into this world. And if I make my mind up about poisoning myself there would be a punishment for me one day. But I think of it very much.

³ Observations made during frequent trips to St Theresa's during fieldwork in Nkoranza. Ruth lived within walking distance of the hospital.

SYNTHESIS

Three inter-related findings are briefly outlined: (1) the heterogeneous nature of socio-cultural knowledge within life-worlds; (2) the intersubjective nature of biographical disruption; and (3) the co-construction of coping strategies and styles within life-worlds and the mediating role of psychological, socio-cultural and structural factors in these processes.

Diabetes knowledge

Shared knowledge of diabetes within the three life-worlds mirrored the key findings outlined in Chapter Six. Diabetes was at once naturally, socially and spiritually caused. Natural causes - dietary imbalance, heredity, poor lifestyle - were drawn from scientized knowledge and tended to be consensual within all three social worlds. Spiritual causal theories appeared in only one urban lifeworld narrative, but were dominant in rural lifeworld narratives. Like broader narratives, spiritual causal theories constituted a secondary theory, drawn from cultural and religious knowledge. The sub-theme of sorcery/bought disease, constituted a site for perceived and real family conflict, as family members were key targets of the sorcerer label. While none of the participants attributed diabetes to witchcraft, community attributions of prolonged cases of mysterious illness to self-directed witchcraft, shaped Ruth's discrediting self-definitions.

Biographical Disruption: impact on individual and family

Diabetes caused biographical disruption not only for the three people with diabetes but also for their significant others. These experiences were intricately linked and revolved principally – though not exclusively - round the unpredictability and consequences of body-self disruption. In all three life-worlds episodes of extreme physical disruption changed the social and psycho-emotional balance of social relationships. The unfamiliarity and unpredictability of body-self disruption undermined family cohesion and support in three key ways: first in terms of impact to mobility and physical demands made on caregivers; secondly in terms of changed identity

and the emotional process of coming to terms with this change; finally in terms of community responses to changed body-image and the dual impact on family and self-perception.

Body-self disruption and physical demands

At its most extreme body-self disruption caused physical disability for people with diabetes. John and Maame-Efua lived with amputated limbs and although they had relative mobility with the use of their wheelchairs, both relied for the most part on caregivers to lift, carry and assist them around and outside the home. This had a significant impact on physical capabilities of caregivers. In both John and Ruth's cases, physical dependence on their family contributed to a restriction of their social lives.

Impact of internalised or externalised emotional responses to biographical disruption

The psycho-emotional response of people with diabetes to body-self disruption had a significant impact on self-care and family cohesion. Maame-Efua's response to living with diabetes and disability was stoic and philosophical. This response mirrored that of other mature people with diabetes, highlighted in Chapter Six. Stoicism was mediated in Maame-Efua's case by the quality of support within her lifeworld, and quality relationships with healthcare providers. Maame-Efua's stoicism, in turn strengthened emotional balance in her life-world. Stoicism and pragmatism, as Chapter Five discussed, was a desired socio-cultural response to illness. Adjoa's strong critique of Ruth's lack of stoicism, which delegitimised the pervasive impact of Ruth's disability, highlighted the ways self-legitimation, as Bury (1997:125-6) argued, required simultaneous negotiation of 'cultural competence' as well as 'personal authority in the face of threat'.

Depression was a dominant lived emotion for John and Ruth and had been in the past for Maame-Efua.. Two consequences of depression were identified. First, depression underpinned loss of self/loss of participation in one's society and lifeworld, in the classic sense of not being quite who one was, withdrawing from daily social life and interaction and being physically inactive. Maame-Efua, John and Ruth had all experienced this state of depression,

according to their lifeworld narratives. Depression also coexisted with anger at a changed self: this was evident in John's verbal aggression towards family, Ruth's blaming of family and friends for misfortune and/or lack of adequate support, and periodic 'rebellion' against treatment regimes highlighted most clearly in John's attitude to diet management.

Fundamentally, when physical disruption caused considerable disruption to one's identity and agency, there appeared to be simultaneous acquiescence to and rebellion against illness (a process similar Radley and Green's (1985, 1987) identification of the coexistence of opposition and complementarity of self in relation to illness). This contradictory process was underpinned by co-existing emotions: in the case of the life-worlds observed here, depression and anger. The everyday communicative and social practices underpinned by this co-existence of opposing emotions in turn evoked conflicting emotional responses from significant others. Loss of self and withdrawal from social life evokes worry/fear about a relative's will to live and implications on their life-trajectory. Non-compliant behaviour evoked worry that relative's complications might worsen or anger at their self-destructive behaviour. Ultimately, conflicting emotional responses identified within the life-worlds of John and Ruth disrupted family role expectations, caused collective psycho-emotional strain and undermined commitment and ability of caregivers to provide support.

The impact of society and culture on family and self-perceptions

Severe weight loss was another consequence of body-self disruption for people with diabetes. This change in body-image led to AIDS labelling for some rural participants, and to anxieties of possible AIDS labelling for some urban participants, as Chapter Six highlighted. In Ruth's case, AIDS labelling impacted her identity as well as the identity of her family and friends. In extreme cases like Ruth's (and also in the cases of some Nkoranza women), the tainting of family identities or the fear of being tainted contributed to family disruption. Thus severe and prolonged weight loss essentially thrust the wider community into the life-worlds of people with diabetes and undermined family cohesion and levels of support. This process in turn highlighted

the ways broader social factors can evoke and exacerbate a sense of isolation not only from one's community, but also crucially from one's lifeworld.

Illness action: psychological, socio-cultural and material dimensions

Analysis highlighted the complex subjective, intersubjective and structural dynamics underpinning illness action in all three life-worlds. The historical context of family life and of illness experience was also of key importance.

In Maame-Efua's life-world biomedical management was mutually endorsed and followed as a coping style. Commitment to this style was strengthened by social psychological and structural dynamics, namely Maame-Efua's philosophical and stoic attitude to illness and continued role as a good mother/grandmother, the family's committed economic and emotional support despite economic and physical burden of care giving, the quality of care provided by her healthcare professionals and the self-help group, and positive relationships within her community. It is also worth noting that Maame-Efua had NIDDM diabetes, which cut down the cost of drug treatment considerably.

John moved from active cure-seeking at the start of field work to biomedical management by the end. The adoption of cure-seeking was shaped by extreme physical and psycho-emotional disruption, shared family fear about complications and John's life trajectory, dissatisfaction with John's biomedical care, and availability of alternative treatment endorsed by trusted family sources. The shift towards a management style was also a product of intersecting social psychological and structural factors: John's depressive-angry state and shift from collective concern to emotional and physical fatigue within family, economic disruption which undermined the healer-shopping process and finally the failure of ethnomedical treatments. In John's case, strategies and styles were to a considerable extent developed and enforced by his family; this was in turn a product of John's withdrawal from self and lifeworld.

While Ruth received support from some members of her family, the self-help group and periodically from her health professionals, this support did not address fully the extent of economic deprivation, wider family abandonment and ostracism she faced. Ruth's style was

inaction: this constituted a complex mix of periodic embodied action and constant spiritual action. Spiritual action was underpinned by emotional and religious conflict. On the one hand, Ruth sought, prayed for and talked about the release of death; on the other, she hoped and prayed for a material benefactor to alleviate her chronic suffering. The complex dynamics framing illness inaction clarified two characteristics of biographical disruption. First, illness inaction illuminated the intricate interconnection between 'meaning as consequence' and 'meaning as significance': practical and symbolic responses were mutually reinforcing. Second, this coping style highlighted the ways in which 'meaning as significance' - within the context of extreme economic disruption - ceased to constitute questions about one's life, death and the unknown, but certainties about impending mortality.

OVERVIEW OF CHAPTER EIGHT

The chapter presents narratives of lay participants on three empirical questions: (1) Sources and content of diabetes knowledge; (2) Meanings attributed to people with diabetes and diabetes experiences; and (3) views on improving diabetes care. The synthesis that follows briefly outlines three key findings: the identification of (1) urban-rural asymmetry in socio-cultural knowledge of diabetes; (2) overlap between lay views of biographical disruption and views of people with diabetes and their significant others; (3) the positive and negative ways in which lay perceptions and daily interactions impact on illness action.

CHAPTER EIGHT

PERSPECTIVES OF LAY HEALTHY INDIVIDUALS ON DIABETES

8.1. SOCIO-CULTURAL KNOWLEDGE ON DIABETES

Participants attributed diabetes to four causes: dietary imbalance (and sugar more specifically), hereditary, physiology, and spiritual disruption. The sources and spread of views are presented in Table 8.1.

Table 8.1. Content and sources of diabetes knowledge: lay perspectives

	Content	'Spread of views'	Modalities
1	Sugar	All urban and rural participants	Scientific; scientized
2	Heredity	Urban participants	Scientific
3	Physiology	Urban participants	Scientific
4	Spiritual disruption	Urban participants	Cultural

8.1.1. Sugar

Rural participants described diabetes as '*esikyere yare*' ('sugar disease'). While urban participants attributed diabetes to high sugar diets this was placed within the broader context of diabetes as a complex physiological disease. *Esikyere yare*, for this group, was a simplistic 'out-there' theory.

The lay perception is that diabetes is caused by too much sugar, eating too much sugar. What I believe is this, diabetes is simply a lack of insulin in the system.[young,male;Accra]

8.1.2. Heredity

Heredity appeared within urban narratives, again as part of a complex causal profile for diabetes. Participants distinguished between 'acquired diabetes' which one got through poor lifestyle practices and 'inherited diabetes' which one got through a genetic predisposition.

We have acquired diabetes and inherited. You might not have anyone in the family who has it and you can get it, or you get it because someone in your family has it.[young,female;Accra]

While the theme was absent in rural narratives some participants, like urban participants, had family members living with diabetes.

8.1.3. Physiology

This theme appeared only in urban narratives and was drawn from textbook knowledge on diabetes. Participants drew on technical biomedical definitions of diabetes, distinguishing between distinct metabolic causes of diabetes.

R3(male): Diabetes develops into different areas like syndrome X.

2respondents (simultaneously): what is syndrome X?

R3(male): Syndrome X, it is like when the protein cannot control the amount of insulin levels in your body. That's syndrome X.

R4(female): It seems we're only talking about one type of diabetes. I know that there we have two types – the mellitus and the insipidus. The insipidus one is the water one, like when your water level is too much in your body, that one too is the type of diabetes and then the other one is when the sugar level is too high, that's when your body is unable to break down the sugar into hydrogen.

While this theme was absent in rural narratives, some participants made reference to common physical symptoms characterising diabetes onset and complications, such as frequent urination.

8.1.4. Spiritual disruption

Urban participants referred to spiritual underpinnings of diabetes in terms of out-there beliefs about chronic illnesses. Participants noted that diabetes was likely to be attributed to spiritual causes since people held similar beliefs about chronic illness.

Sometimes people think it's a spiritual illness. Because it's a curse, because of sin, they ascribe a spiritual dimension to diabetes.[young,male;Accra]

No explicit or implicit links were made between diabetes and spiritual disruption in rural narratives.

8.2. LAY ACCOUNTS ON DIABETES EXPERIENCES

The aim of examining lay accounts of diabetes experiences was to map out areas of consensus, conflict and absence between the two social groups and better understand the social context of daily experiences and illness action. I should note that like diabetes knowledge, explanations of biographical disruption were not as detailed as broader health and illness knowledge (and even knowledge of other chronic conditions such as epilepsy and hypertension). However participants touched upon five areas of disruption, which resonated with narratives of people with diabetes: body-self, food practices, economic circumstance, family relationships and community relationships.

8.2.1. Disruption to body-self

This theme appeared in both rural and urban narratives. Urban participants noted that diabetes could be dangerous, causing a myriad of physical complications if left uncontrolled. They commented on changes to body-image, referring to premature ageing, hair loss and changes in skin tone. They also drew attention to the psychological and emotional impact of living with prolonged physical disruption and the long-term demands of biomedical compliance.

Everyday you have to take medication. You can't eat certain foods. Cuts can turn into huge complications. You have to be extra careful. You look different, older. [young, female; Accra]

Rural participants focused on frequent urination and the discomfort this brought on everyday life. They also highlighted the psychological distress borne out of the impact of economic deprivation on self-care. Suicidal ideation was a dominant theme in these discussions.

8.2.2. Disruption to food practices

In Chapters Six and Seven I outlined four dimensions to the impact of dietary disruption: psychological, economic, social and nutritional. In rural and urban lay narratives, two dimensions were discussed: psychological and economic costs. Rural groups focused on the

burden caused by having to give up staple foods. Urban groups discussed the psychological impact of changing food practices. Some noted that psychological difficulties could undermine biomedical compliance even for groups who held full knowledge of the risks of poor diet management.

My dad is a doctor and he doesn't comply with the diet advice. Sometimes he'll eat things he is not supposed to. [young,female;Accra]

Some urban participants drew attention to the availability of alternative diabetic snack foods, which could lessen the psychological burden of dietary changes. However they noted that these diabetes-specific foods were expensive, thus only accessible to wealthy individuals.

8.2.3. Disruption to economic circumstances

Both urban and rural groups discussed the financial impact of living with diabetes within the broader context of chronic illness and high cost of biomedical care. Rural participants drew on knowledge of people living with other chronic conditions who had experienced severe disruption to their economic circumstances. In these discussions links were made between economic disruption, chronic suffering and suicidal ideation. The implication was that people with diabetes were likely to live with similar psychosocial burden.

I had a friend who suffered from a chronic disease for a long time that he became fed up with life. He drank DDT to poison himself to death. [middle-aged, male(Nkoranza)]

8.2.4. Disruption to family relationships

Some rural and urban participants had close relatives living with diabetes; they drew on their own experiences in making a strong case for the need to provide social support. However, rural participants noted that long-term illness was seen as an economic burden in their communities.

In this town, when you are sick nobody cares about you. They see you as a financial burden.' [middle-aged,female;Nkoranza]

Participants argued that since people with diabetes required drugs to stay healthy, social support without a financial dimension was unlikely to provide long-term solutions. This had particular implications for low-income individuals in terms of their ability to provide the right kind of support (social and financial) to relatives with diabetes.

8.2.5. Disruption to social relationships

This theme revolved round community perceptions of the links between rapid weight loss and AIDS identities. As outlined in section 8.1, rural individuals displayed no knowledge of the physiological causes of diabetes. However the exploratory grading exercise on chronic illness perceptions (see Appendix B) yielded two findings that had particular bearing on the impact of perceptions and social practices on diabetes experiences. First participants displayed greater scientized knowledge of chronic conditions such as hypertension and AIDS. Secondly, while AIDS and epilepsy were seen as both life-threatening and contagious, and highly stigmatised as a result, diabetes was perceived as less life-threatening. However, because lay people had poor knowledge of the physiological impact of diabetes and because rapid weight loss characterised public health images of AIDS, individuals living with uncontrolled diabetes faced stigmatisation by association. While participants did not implicate themselves in the stigmatisation or ostracism process, they spoke of the risks faced by people with diabetes as a result of lay fear of contagion.

The way in which health workers describe AIDS symptoms, the first impression you'll have of somebody who loses a lot of weight is that they have this bad disease. Your family will be afraid.
[middle-aged,female; Nkoranza]

8.3. LAY VIEWS ON IMPROVING DIABETES CARE

Participants outlined three ways in which diabetes care could be improved: through biomedical compliance, reduction of drug costs and through improved public health education.

All participants stressed the importance of hospital care and drug and diet compliance for people with diabetes. Drawing on broader cultural emphasis on medical compliance, participants argued that the health of people with diabetes was likely to be compromised without this key dimension of self-care.

Participants noted that low-income people were unlikely to afford long-term biomedical treatment. Two solutions were presented. First, reducing the cost of biomedical treatment. Second, some urban respondents suggested making standardised ethnomedical drugs available for low-income groups.

Rural participants stressed the importance of public health education. Concern was expressed about the impact of poor knowledge on lay diabetes prevention. Improved knowledge, in their view, would facilitate better food practices and reduce risk factors. Secondly, improved education could facilitate better social support, particularly for groups living with uncontrolled diabetes.

SYNTHESIS

The synthesis that follows briefly outlines three key findings are discussed. First, factors underpinning the urban-rural asymmetry in socio-cultural knowledge of diabetes. Second, the nature of overlap between lay views of biographical disruption and views of people with diabetes and their significant others. Finally, the positive and negative ways in which lay perceptions and daily interactions impact on illness action are outlined.

Diabetes knowledge

There were clear differences between rural and urban knowledge on diabetes. Urban groups drew on both technical and practical biomedical knowledge, describing diabetes as a complex disease, drawing together themes of diet imbalance, genetic underpinnings and physiological irregularities. They also referred to spiritual disruption, but as an out-there theory of chronic illness generally. For rural groups, who drew on practical biomedical knowledge, sugar was the dominant causal theme - other themes emerging in urban narratives (and also broader narratives outlined in previous chapters) were absent. Within lay narratives therefore, there was greater emphasis on natural and social dimensions of diabetes; the spiritual, while acknowledged as a legitimate collective representation for some, did not constitute a central personal theory.

Two key absences emerged which had possible implications on diabetes prevention among lay populations. First, while urban participants referred to the genetic underpinnings of diabetes, those with family histories did not discuss this in terms of personal risk. Rural participants did not draw on genetic theories even though some had family histories. Secondly, while the role of toxic staples in the deterioration of contemporary societal health was a dominant theme in discussions of health and illness, this theme was not drawn on to explain causes of diabetes. People with diabetes and their significant others, as previous chapters

showed, viewed toxic staples as a causal factor for diabetes, as well as a barrier to successful diet management.

Knowledge and perceptions of biographical disruption

Lay people highlighted a range of disruptions likely to arise from diabetes. For some this knowledge was drawn from close relationships with people with diabetes. Others drew from general knowledge of the impact of living with chronic illness in Ghana. Participants discussed biographical disruption in similar terms to people with diabetes and their significant others, highlighting disruption to five key dimensions of everyday life: body-self, economic circumstances, food practices, family relationships and social relationships. Discussions of biographical disruption highlighted the emotional dimensions of perceptions and social practices. For example sympathy was expressed for the economic plight of low-income groups with diabetes; this shaped practical treatment advice given to relatives and friends with diabetes, as well as social support. Fear of contagion, rooted in a lack of knowledge of the physiological profile of diabetes, was highlighted as a possible factor underpinning stigmatisation and ostracism of rural groups with diabetes.

Lay meanings and mediation of illness action

Lay narratives as well as narratives of people with diabetes and their significant others suggest that lay people have an impact on everyday illness experiences and action in two ways: in terms of treatment advice and social support.

Treatment advice

Participants generally emphasised biomedical management as the key approach to attaining health. However, confounding factors were highlighted, chief among which were the burden of cost, the burden of biomedical treatment regimes and the psychological burden of dietary change. Participants recognised the implications of these factors on self-care and family support. These views shaped lay treatment advice. On diet management all participants recommended

that people with diabetes eliminate sugar from their diet. On drug management a consensual theme was to seek and comply with biomedical treatment. Finally urban narratives focused on the potential role of (standardised) ethno-pharmaceuticals in reducing the economic burden of diabetes.

The distinction made by urban participants between standardised and non-standardised ethnomedical drugs was important as narratives of people with diabetes and biomedical professionals (see Chapter Nine) indicate that non-standardised ethnomedical drugs are likely to lead to complications, particularly for people with IDDM.

Given that classical ethnomedicine is publicly legitimised, is generally cheaper, and ethnomedical professionals run aggressive media campaigns to promote efficacy of their chronic illness treatments, there is a likelihood that people who do not make this distinction can give problematic advice to people with diabetes. Rural and urban narratives on the nature of support provided to people with other chronic illnesses suggested this to be the case. Interview narratives and ethnographies of people with diabetes, suggested that urban lay people were as likely to give problematic advice as rural people.

Social support

Within both urban and rural contexts, biographical disruption was deemed to have an extensive impact on everyday life experiences of people with diabetes. The majority of participants stressed the importance of social, but underscored a greater need for long-term financial support. This emphasis highlighted the material context of self-care and social support and simultaneously the implications for groups living in low-income communities.

A second problem identified in relation to social support was the inadvertent link made between uncontrolled diabetes and AIDS. The stigma and fear of contagion surrounding AIDS, lay people noted, was likely to affect people with uncontrolled diabetes. Rural people with diabetes who had lived with severe weight loss, as previous chapters highlighted, had experienced stigmatisation and ostracism within their communities due to lay misconceptions about the nature of their illness. This group lived with the multiple burdens of economic,

physical and psychological disruption as well as disruptions to their moral integrity. Lay discussions highlighted the primary source of the problem as the discrepancy between extensive public AIDS education and minimal to non-existent diabetes education.

OVERVIEW OF CHAPTER NINE

This chapter is presented in three parts. Part One presents shared/contested diabetes knowledge across the three professional groups. In Part Two, the treatment practices and goals of each professional group are discussed in turn. In-group and out-group assessments, as well as professional perspectives on people with diabetes, diabetes experiences and illness action are incorporated. Views on improving diabetes care and collaborative practice are outlined. Part Three presents a synthesis of results. Three areas are singled out for attention: (1) dynamics underpinning production and access to diabetes knowledge within the pluralistic medical sphere; (2) areas of knowledge overlap and absence between professional groups and people with diabetes; and (3) the nature of professional alliances and conflicts and implications on the collaborative health process.

CHAPTER NINE

HEALTH PROFESSIONALS' PERSPECTIVES ON DIABETES

9.1. HEALTH PROFESSIONALS' KNOWLEDGE OF DIABETES

Five causes of diabetes were identified across professional narratives: dietary imbalance (sugar, starch and fat rich foods), individual lifestyle practices, heredity, physiology, and spiritual disruption. Table 9.1 summarises the content, sources and spread of views.

Table 9.1. Content and sources of diabetes knowledge : health professionals

	Content	'Spread of views'	Modalities
1	Diet (Sugar)	All participants	Scientific; scientized
2	Lifestyle	All participants	Scientific; scientized
3	Heredity	Biomedical and ethnomedical	Scientific; scientized
4	Physiology	Biomedical and ethnomedical	Scientific; scientized
5	Spiritual illness	Ethnomedical and faith healing	Cultural; religious.

9.1.1. Sugar

Dietary imbalance was a dominant theme across professional narratives. For ethnomedical groups and faith healers sugar rich foods were singled out as the dominant cause of diabetes. They like the majority of lay people and people with diabetes, described diabetes as '*esikyere yare*'. Rural faith healers were less specific, attributing diabetes to 'some foods' without qualifying the kinds of foods that caused diabetes.

Biomedical groups offered more comprehensive explanations. They stressed that while sugar played a key role in diabetes onset, it was important to single out not only foods known to have high levels of sugar, but to include foods that converted to sugar. This implicated the entire range of starchy Ghanaian staples. Secondly fatty foods had to be included in the list of problematic diabetogenic foods. More crucially for this group, dietary imbalance had to be viewed as part of a broader profile of diabetes as a complex metabolic disease. Most noted that

while sugar was a precipitating factor for Type 2 diabetes, the lay definition *esikyere yare*, obscured the complex nature of the condition.

The local term, "esikyire yare", which literally means sugar disease, is a wrong definition. Diabetes is not one disease, it's a syndrome, a group of diseases that have a common fault, a problem with insulin. Some [people] don't make it and others have it or don't have enough of it or they have enough of it but their cells don't have a means of using it. [doctor(Accra)]

However, this problematic lay definition was developed, disseminated and reinforced within public health campaigns. I will return to this theme later in the chapter since it emerges strongly when participants discuss problematic patient practices and the factors underpinning such practices.

9.1.2. Lifestyle

This theme centred primarily on sedentary lifestyles. For biomedical participants, sedentary lifestyles were not only a key cause of diabetes, but also implicated in the rising prevalence of contemporary 'diseases of lifestyle' among adult populations in Ghana. For this group, the role and impact of sedentary lifestyles, dietary imbalance and heredity had to be subsumed with a broader view of diabetes as a complex metabolic condition.

9.1.3. Heredity

Ethnomedical professionals made superficial references to heredity as a cause of diabetes. Biomedical explanations were placed within the broader context of physiological disruption and are better described in the following section.

9.1.4. Physiology

Biomedical participants described three types of diabetes. Type 1 diabetes was attributed to a malfunctioning pancreas, was largely congenital and genetic in origin and affected predominantly young people. It was perceived as non-preventable and the most life-threatening

form of diabetes. Type 2 diabetes, termed a disease of lifestyle and also of heredity, affected individuals in their middle age and was caused or precipitated (in the case of people with a family history) by a mixture of a fat rich, sugar rich diet and a lack of exercise. Some secondary causes of Type 2 were further highlighted such as the effect of sustained steroid use on insulin levels and the effect of viral infections on the pancreas. Type 2 was perceived as largely preventable. Gestational diabetes was defined as a diabetic condition caused by hormonal changes during pregnancy. This third type of diabetes was described as temporary and curable although it placed the sufferer at risk of Type 2 diabetes later in life.

Physiological explanations appeared only on the narratives of the bio-tech ethnomedical practitioners. Most noted that diabetes could be caused by pancreatic malfunctioning and insulin irregularities. Rural groups made connections between diabetes, hypertension and stroke, asserting that living with one condition predisposed one to the others.

Diabetes is caused when the pancreas is not working, when it is not functioning. [biotech-herbalist;Accra]

Diabetes, stroke and hypertension are in the same line and it starts with hypertension and then you develop diabetes, and when the diabetes is developing, - when the Diabetes is becoming more serious then you get the stroke, you see. [biotech-herbalist;Accra]

These physiological explanations were scientized: the subtleties of the physiological profile of diabetes in terms of types and groups affected by certain types highlighted by biomedical groups, were absent in ethnomedical narratives. Crucially, the majority of participants noted that while they drew on technical biomedical knowledge, this knowledge was peripheral to their expertise of curing diabetes. I will return to this shortly.

9.1.5. Spiritual disruption

This theme appeared in all narratives but in varied and conflicting ways. For biomedical and bio-tech herbalists, spiritual causal theories of diabetes were out-there phenomena: while lay people believed in spiritual causal theories, members of this group did not hold personal beliefs of spiritual causation or apply the theory to their professional practices. A dominant theme in

the narratives of this first group was that people with diabetes often attributed the condition to spiritual causes. This in their view suggested that people with diabetes were more likely to seek spiritual treatments.

A second group, consisting of politicised bio-tech herbalists, drew on spiritual causal theories of diabetes as a valid theory for both lay groups and themselves. They did not offer spiritual treatment since their area of expertise was pharmacological. However they referred patients to spiritual experts - either faith healers or traditional religious healers - when cases with spiritual underpinnings were suspected.

A third group, consisting of faith healers and traditional religious healers, drew on spiritual casual theories of diabetes as valid out-there theories, as well as personally held beliefs. In addition they drew on spiritual casual theories for their professional practice. The predominant mode of spiritual causation of diabetes, for this third group, was through generalised evil. Both groups noted that diabetes had two dimensions: the spiritual dimension described as the underlying – unobservable - cause of the condition, and the physical dimension expressed through observable symptoms. In addition both noted that the spiritual was difficult to cure, while the physical was easy to cure.

There are two forms of diabetes. One is physical, one is spiritual. The physical is easy to cure, the spiritual is not easy to cure. It can be cured if you put your trust in the saviour. [faith-healer;Accra]

9.2. PROFESSIONAL TREATMENT PRACTICES, GOALS AND ASSESSMENTS

In this section I focus on the treatment practices, goals, and self-assessments of each professional group in turn. I incorporate in-group and out-group assessments on diabetes care and perspectives on people with diabetes, diabetes experiences and illness action. Views on improving diabetes care and collaborative practice are outlined.

9.2.1. Biomedical treatment practices and goals and mediating factors

The biomedical treatment repertoire constituted diagnosis, treatment dictated by type of diabetes and continuous assessment of treatment outcomes. The goal was to manage symptoms or prevent complications.

Diagnosis was carried out through a mixture of low-tech methods (of measuring fasting blood-glucose levels), observation and taking patients' histories. Effective treatment and management of diabetes required a strict regimen, which depending on type, involved some or all of these three elements: medication with insulin or oral hypoglycaemic agents, diet and exercise. Participants placed great emphasis on regular monitoring and 'control' of blood-sugar levels as the fundamental basis for prevention of complications. Control was perceived and described in three ways.

First, control was viewed as the responsibility of the person with diabetes, since a large proportion of diabetes management occurred outside the biomedical sphere. This was a dominant theme.

No the disease is not curable we can only control diabetes; the control depends on the patients.
[Nurse(Accra)]

Two participants (one urban doctor and the urban nurse) referred to control in terms of shared responsibility, a collaborative effort between patient and a multidisciplinary medical team. However, expertise was viewed in top-down terms, as provided by medical and adjunct professionals.

...it is the diabetic patient himself or herself who has to go according to certain norms to keep healthy and those norms are helped by a group of people. One person can't do it. So depending upon the diabetic patient, say with the help of a doctor, with the help of a nurse, with the help of a diabetic educator, with the help of a pharmacists and with the help of other doctors, like ophthalmologists, those may come as a team and then help the diabetic patient who has to respond well and then agree with the things included, otherwise the health state of the diabetic patient won't go on. [doctor(Accra)]

The final theme - expressed by the rural nurse and urban private doctor – centred on control as the responsibility of an empowered individual with good body-self knowledge. Both discussed the individual's power over their own health: the expertise stemming from body-self knowledge they argued had to override the expert knowledge of a biomedical professional.

I always tell my diabetes patients they are the best doctors of their illness. Why do I say that? Because they do observe themselves. After taking this meal, I feel like this, the only thing is that if I don't feel well after taking that meal... I take myself off it. So that is how I educate them. So they shouldn't be depending on like maybe you're saying take this, this, this and you take it and you see that you're not feeling well and you still continue to take it. [Nurse(Nkoranza)]

One urban doctor compared successful control to the subjective state of being 'healed'.

There is always a mental or psychological aspect to everybody's condition and the patient may need counselling especially with patients who may have chronic illnesses that you can only control but cannot heal like hypertension and diabetes. Those people really have to be counselled and talked to, to learn how to live with the condition so if the people do accept the condition and are able to work with the doctor to always keep their health optimum, we can say with reasonable certainty that even if the disease condition still remains but is being controlled, we'll say the people are healed. [doctor(Accra)]

Biomedical in-group assessment

Positive biomedical in-group assessment

Positive assessment revolved round two main themes: the scientific nature of biomedical knowledge and practice and professional emphasis on ethical practice. The scientific nature of biomedicine was characterised by the ability of professionals to carry out objective investigation of physiological causes of disease, to control the treatment process and conduct systematic assessment of treatment outcomes.

We tend to have more control over the things we do, the surgeries that we perform, even before we make mistakes we know these are the mistakes one can make when doing this particular procedure. We know what our medications are going to cost, we are aware of our side effects.[doctor(Accra)]

Discussion on ethics centred on professional self-regulation and the way this reinforced accountability to wider society. Professional regulation, for others, facilitated openness about the strengths and limitations of biomedical expertise. For example some participants noted that in the area of chronic illness care, internal professional regulation prevented individual professionals from making false claims about cure.

We tend to have more control over the things we do, the surgeries that we perform, even before we make mistakes we know these are the mistakes one can make when doing this particular procedure. We know what our medications are going to cost, we are aware of our side effects.[doctor(Accra)]

Negative biomedical in-group assessment

Negative critique revolved around three broad themes: the impact of the double burden of disease on diabetes care, the psychosocial burden of biomedical regimes on patients, and the impact of the shifting technical definition of diabetes on diagnosis and treatment.

The double burden of disease

Participants singled out two problems for attention. The first problem centred on technical and human resources for diabetes care. The majority highlighted the lack of basic technical equipment for diabetes care across the country. Urban public sector doctors argued that beyond the basic knowledge provided during general biomedical and nursing training, few doctors and nurses had specialist diabetes knowledge. They argued that this widespread lack of knowledge could undermine the health-seeking efforts of people consulting poorly trained biomedical practitioners.

So everybody knows that polyclinics are some of the first line well staffed health centres in the country. And when you get there is no equipment for diabetes, there's no knowledge of diabetes, there is no dietician at sight, there is no advice, there's nothing. It's just writing prescriptions for diabetes drugs. So that is what I see as the problem of diabetes and not only the prevalence, but what goes beyond it. The way it's cared for and the attitude towards diabetes care in the country in general. A lot is said about it but very little is done about it.[doctor(specialist)(Accra)]

The second problem centred on accessibility of biomedical services. The problem of inaccessibility was threefold and outlined as geographic, cultural and economic. All participants highlighted the issue of poor geographic access to biomedical services, particularly for rural dwellers. Geographic inaccessibility was generally blamed as the root cause of late presentation of diabetes cases. The argument went that early engagement of individuals with more accessible ethnomedical systems led to cases being presented to hospitals and clinics when conditions had deteriorated. In urban narratives the issue of oversubscribed and under-resourced public health facilities was raised. Participants discussed the lack of diabetes centres in the capital and the stress this placed not only on the one centre operating at the teaching hospital, but on less specialised public out-patients departments and private facilities.

Cultural inaccessibility revolved around two sub-themes. First, some noted that hierarchical structures within the biomedical system had a negative impact on relationships both with the public and with patients.

There are a lot of people who will come to a conventional doctor like me, they sit here and forget why they came in. People are intimidated by hospitals, especially our people. [doctor(GP)(Accra)]

Hierarchical structures were compounded by the technicality of biomedical language. Both nurses saw this as a problem inherent in doctors' practices. Furthermore, differences in social class undermined equal level discussion: at one level this led to the delegitimization of patients' beliefs and values; at another level it fed into a vicious cycle of poor education and low levels of public knowledge. Economic inaccessibility was described in terms of the high cost of biomedical treatment and the critical lack of institutionalised economic support for people with diabetes. This was cited as an overarching cause of patient non-compliance.

The cost of diabetes drugs and products is beyond the reach of even the well-paid individuals in our country. So that I have found people who in Ghana you would call 'rich' say "Doctor, I can't afford it anymore, I can't afford this drug anymore. Could you put me on something else?" and I can imagine how this frustration leads people to default on regular visit, default on their drugs and end up with complications. [doctor(specialist)(Accra)]

Burden of biomedical management regimes

Participants noted that the diabetes regime with its emphasis on sustained self-regulation and monitoring, placed enormous psychosocial burden on people with diabetes. The psychosocial burden of diet restriction was singled out as a critical factor in patient non-compliance, next to cost of care.

You may not know what you have done and your sugars are flying up and another time sugars are down and today you don't have to eat this, you don't have to drink this, at social gathering you are not happy so diabetes is actually a difficult disease. [Nurse(Accra)]

The second aspect was the iatrogenic effects of diabetic drugs and physical complications arising from administering daily insulin injections. Participants noted that problematic side effects often led to some patients discontinuing drug treatment or abandoning biomedical care altogether.

We know ourselves that some medications will have complications like hypoglycaemic episodes. [doctor(Nkoranza)]

There are particular problems with daily injections, there are people who have abscesses by trying to give themselves injections everyday of their lives. [doctor(GP)(Accra)]

Shifting definition of diabetes

The biomedical definition of diabetes was viewed as problematic. The majority of participants noted that the technical definition of diabetes shifted with each endocrinological advance. Therefore the idea that one developed diabetes because of low blood-sugar levels no longer held true. Diabetes could just as equally arise from very low blood-glucose levels or from fluctuations in blood-sugar levels. This, participants noted, posed problems for diagnosis and treatment.

We realise that people we are saying are diabetic probably have had diabetes for about ten years and these people, at the time they had diabetes, had normal sugars so the new definition or the paradigm of diabetes is basically still shifting or has moved from high glucose to irregularity in the metabolism of glucose so low sugar does not necessarily mean no diabetes. So you could still have low sugars but you'll still have an irregularity in metabolism of your sugars and that can give diabetes well before your sugar goes high (enough) to be recognised. By that time, you already have complications. [doctor (houseman)(Accra)]

External factors impacting biomedical diabetes care

Problematic patient beliefs and practices

Three main arguments were made. The first line of argument - posited by all except the private GP – centred on the link between illiteracy and inability to understand technical biomedical explanations of diabetes. Illiteracy and poor education were perceived as the main cause of ‘patient ignorance’. Patient ignorance was in turn held up as both cause and consequence of poor doctor-patient communication practice.

It is difficult to explain some of these diseases in common language for people to grasp and if you have a situation where the person is also not educated then it becomes even more difficult to explain to the person what is happening. [doctor(housemen)(Accra)]

The private GP disagreed with this dominant viewpoint. He argued that poor knowledge of diabetes was a product of poor doctor-patient communication, which in turn was rooted in cultural and economic inaccessibility.

If you take your time to explain to the patient the reason and say that this why you have a chronic disease and you need to keep an eye on it the average - and medicine is common sense - the average person has some knowledge of what you're talking about and they comply.[doctor(GP)(Accra)]

The second line of argument, made by all participants, was the inability of patients to comprehend and/or come to terms with the chronic nature of the condition. All participants made reference to the psycho-emotional impact of diagnosis on their patients: patients expressed considerable concern, and emotional distress, at the economic and physical implications of living with diabetes. Second, participants asserted that chronically ill individuals invariably drew on traditional spiritual causal theories to make sense of their diagnosis and subsequent experiences. Third, the majority of people with chronic illness were unable to deal with the psychosocial and economic burden of living with diabetes. The inability of people with diabetes to come to terms with their diabetes status, fed into healer-shopping. Participants noted that in a quest for cheaper treatment, to prevent complications or to find a cure, individuals adopted eclectic treatment choices.

What I've noticed is that people tend to have multiple doctors and they get multiple advice on diabetes and from all shades of professionals: traditional healers, general practitioners, and specialists who have nothing to do with diabetes and know nothing about it so it's a very complex situation.

[doctor(specialist)(Accra)]

Fundamentally the phenomenon of healer-shopping was attributed to a lack of patients' belief in biomedical treatment goals. Here, a strong link was made between social class and choice of treatment sequence in the process of healer shopping. For the elite the first port of call was the doctor. But as illness progressed and hopes for a cure within the biomedical setting diminished, individuals would turn to ethnomedical and religious systems.

A lot of people see the traditional healer as a last resort and that tends to be a behaviour pattern that I see to be associated with the elite. They in the initial phase are a bit ashamed to go to a traditional healer as a start. But when they have tried your treatment for hypertension, your treatment for diabetes, your treatment for everything and they can't see a stop to all that and they see the cost mounting, they invariably try. [doctor(specialist)(Accra)]

The opposite process was posited for poor, uneducated individuals and especially rural dwellers. However most participants qualified this assertion by noting that this practice could be as much about a search for a cure rooted in similar belief systems as it could be about greater accessibility of ethnomedical systems in rural parts of the country.

For those who have no access to conventional health centres, I believe that they tend to see a traditional healer first. Again this is part of their lives, they've grown up with it so they see nothing as a start and they tend to see us when all has failed and that is the pattern we see in a teaching hospital where I work in. [doctor(specialist)(Accra)]

The final point centred on the impact of diabetes complications on social identity. Participants noted that for some patients, physical and social identities were intricately linked; the desire to maintain a normal body-image (strong, able-bodied and mobile) often overrode the necessity of dealing appropriately with serious complications.

In many situations the hospital can't do anything about it because of that delay. You can't salvage that limb anymore. You've got to chop it away and when you chop it away, for somebody living in the village, it changes his social status and that's what they cannot take. As they've said many times to me, "I'd rather die with my two legs on than to die with one. I'd rather be buried with two legs than with one" [doctor (Accra)]

Problematic ethnomedical practice

Ethnomedical diabetes care was viewed negatively. Much of the critique has to be contextualised within broader out-group assessment, described in Chapter Five, however two key problems were singled out as having particular implications on diabetes treatment: poor ethics and poor quality drugs. Ethnomedical professionals' claim to cure diabetes was viewed as highly unethical. Some doctors argued that ethnomedical practitioners misappropriated biomedical knowledge to gain professional credibility in the public sphere.

The traditional healers do not advertise treatment for hypercholesteroline. Yeah they don't advertise treatment for hypercholesteroline for the simple reason that they don't hear a lot spoken about it. But let me get up today and get on the air and let me sort of set up an association for lipid disorders and so on and so forth and the traditional healers will find a remedy for it and say that it is curable.

[doctor(specialist)(Accra)]

Such unethical practice created false hope for individuals living with incurable disease and undermined the goals of biomedical care. For example some individuals presented diabetes at later complicated stages of the condition due to early engagement with ethnomedical practitioners, while others abandoned biomedical care to engage unsuccessfully with ethnomedical systems after biomedicine had failed to cure them.

The second problem concerned the harmful effects of non-standardised ethnomedical drugs. All participants stressed their belief in the pharmacological properties of indigenous plants and herbs with some acknowledging the existence of diabetes-specific ethnomedical drugs, such as that developed at the Mampong Centre. It is worth noting that the centre doctor highlighted the efficacy of diabetes drugs produced at the centre, with a caution that these drugs were only effective for NIDDM. However none endorsed the efficacy of non-standardised ethnomedical drugs. Some noted that patients who returned to biomedical care after unsuccessful consultation with ethnomedical systems, presented complications directly linked to iatrogenic effects of ethnomedical drugs.

We see a lot of patients who are taking herbal medicine prescribed by some of these healers who end up with kidney failures and liver failures, some bleed from their GIT (gastrointestinal tract) because these things irritate the mucosa. [doctor(houseman)(Accra)]

Biomedical perspectives on improving diabetes care

Three recommendations were made: improving structural deficiencies, quality of communicative practices and addressing exploitation of ethnomedical intellectual property.

Participants argued for more diabetes centres, mandatory diabetes testing, free diabetes care and research funding into the psychosocial determinants of diabetes. Urban doctors emphasised the need to train private and public sector biomedical staff with no technical expertise in diabetes care.

The first challenge was to improve quality of interpersonal relationships within the context of clinical consultations. Participants acknowledged a critical need to validate patient beliefs and improve quality of communication and information provided during patient consultations. Secondly participants stressed the need to improve quality of public health education; education of ethnomedical professionals was subsumed into broader goals. Two solutions were presented to improve ethnomedical practice. The first was to standardise ethnomedical drugs.

We still have to search for what effects herbal drugs have on the other organs of the body in a long term. And if we are able to satisfy our curiosity, we will even advice our patients to go use herbal drugs.[Nurse(Nkoranza)]

I believe in it and I want to see it standardised.[doctor(GP)(Accra)]

The second solution involved educating ethnomedical practitioners on practical aspects of diabetes care, such as symptom recognition, dealing with complications and knowing when to refer patients to biomedical practitioners.

I would focus on foot problems for instance and teach these traditional healers what the discoloration of the foot means. I'll teach them where to find the pulses. I'll teach them how to test for sensation. I'll let them know what the danger signs are so if you see these danger signs, speak to somebody.
[doctor(specialist)(Accra)]

Some participants stressed that the improvement of ethnomedical practice would require granting legal recognition to ethnomedical intellectual property. They noted that the code of

secrecy within the ethnomedical sphere, and collective reluctance to engage in the collaborative health process was largely due to misappropriation of ethnomedical intellectual property by the formal healthcare system. They stressed that in order to restore the faith of ethnomedical practitioners in the motives and goals of the collaborative health process, ethnomedical practitioners had to be legally and financially compensated for sharing knowledge beneficial to public health.

The handling of the traditional healers had been that they are not compensated financially so they resort to keeping their knowledge to themselves. But if they are compensated, then they can open up and this will be better for the nation. [doctor(Accra)]

Providing the understanding is there between doctors and herbalists, providing both are ready to learn from each other, I think it will be helpful for all of us. [Nurse(Nkoranza)]

9.2.2. Ethnomedical diabetes treatment practices and goals and mediating factors

Ethnomedical treatment practices and goals

The ethnomedical treatment process incorporated diagnosis, treatment and systematic assessment of treatment outcomes. The goal of treatment was to provide a cure for the condition.

Diagnosis involved taking down patients' histories and of observing symptoms and in some cases confirming the diabetes status from hospital records. The bio-tech rural herbalists incorporated blood-glucose tests into their diagnostic procedure. The traditional religious healers carried out spiritual investigations if conditions were suspected to have spiritual underpinnings. The rural healer sought answers from deities with particular expertise in treating chronic conditions, while the urban healer prescribed diagnostic medications that elicited particular physical symptoms that confirmed or negated a diabetic state. There was some ambiguity in both accounts about the characteristics of the deities consulted and the diagnostic herbs used.

Ethnomedical treatment of diabetes comprised herbal drug treatment and diet restrictions. The dominant form of diet restriction involved a ban on sugary foods. Some

professionals drew on traditional diet management approaches, rooted in knowledge of nutritional value of staple foods.

Years ago, when our elders were eating I used to watch them; and I realized that when our mothers were cooking they used a lot of plantain and a little bit of cassava. Even today what I have often advised my diabetic patients is to eat a lot of plantain.” [traditional-religious-healer(Nkoranza)]

For the traditional religious healers spiritual treatment was carried out alongside pharmacological treatment, if a case was suspected to have spiritual underpinnings. Both healers stressed that physical and spiritual causes were interlinked; therefore successful treatment was dependent on attending to both dimensions.

The curative properties of ethnomedical medications were stressed. The majority claimed that their drugs restored blood-glucose levels to normal range, while the urban bio-tech group stressed their drugs healed the pancreas. An interesting point made by the bio-tech was that poor physiological knowledge did not necessarily undermine the efficacy of their drugs. They argued that although professionals could not provide a comprehensive explanation of the physiological underpinnings of diabetes, they could still cure the condition by applying their wealth of ethno-pharmacological knowledge.

The knowledge we have has been passed through long [long] ages, through trial and error. So if somebody says this medicine cures diabetes, he may not know what diabetes is, but apply it and you will find it cures it.” [biotech herbalist(Accra)]

What we do is give medication to heal the pancreas, to begin to function. So when the pancreas is functioning, we don't know where the pancreas is, but when it begins to function it restores the sugar. [bio-tech herbalist(Accra)]

The definition of 'cure' used within ethnomedical accounts was synonymous with 'controlled management' within biomedical discourse. Thus a positive confirmation of cure was sustained absence of physical symptoms such as tiredness, frequent urination and weight loss. Despite the strong assertions made regarding the curative properties of their drugs, professionals pointed out

that diabetes was generally a difficult condition to cure, especially when presented in the late stages.

When diabetes is presented early, you can cure it faster but if it is brought in late, it will take a long time to cure. That is the problem we have. [biotech-herbalist(Accra)]

Diabetes is very difficult to cure and you might get to a point and think you have cured it, but that might not be the case. [biotech-herbalist(Nkoranza)]

Ethnomedical assessment of in-group knowledge and practice

Positive ethnomedical in-group assessment

Positive assessments centred mainly on the efficacy and curative properties of drugs. Participants referred to 'drug purity' and 'drug strength', and the ability of drugs to cure with minimal side effects.

We brew the herbs and ask you to take it in this form, unlike biomedicine where certain things have been taken away from the original herbs. Nothing is added or taken away with ours, so it is more potent. [biotech-herbalist(Nkoranza)]

Two urban bio-tech herbalists defended the emphasis on ethnomedical drug 'purity' and 'strength' by drawing from biochemical theories circulating the Ghanaian scientific community, which highlighted the multifaceted efficacy of unrefined ethnomedical drugs.

Doctors are always challenging our claim that one herbal drug can cure many different conditions. But even Professor [X], the biochemist at Legon ((the University of Ghana in Accra)) has stated that herbal drugs in their natural state have different properties, which can act on different parts of the body. [biotech-herbalist(Accra)]

Negative ethnomedical in-group assessments

The dominant theme highlighted by all except two urban bio-tech practitioners, was that ethnomedical drugs were slow acting, compared to pharmaceutical drugs. While this did not undermine the fundamental efficacy of the drugs, participants expressed awareness that the slow acting nature of the drugs led to people discontinuing treatment. They stressed that patients had

to approach the treatment process with patience and a fundamental belief in the efficacy of herbal drugs.

External factors impacting on ethnomedical care

Problematic patient beliefs and practices

Two problems were outlined. First, participants noted that patients often consulted at late stages of the illness.

They take too long before coming to see you. If they come early we can cure them, but they always delay coming here and it takes a long time before we can cure them. That is the problem. [biotech-herbalist(Nkoranza)]

The practice of late presentation was linked to early unsuccessful engagement with biomedical systems and also to problematic attribution of chronic illness to spiritual causes. There was strong professional consensus, as noted earlier, that while lay individuals attributed chronic illnesses to spiritual causes, not all chronic illnesses had spiritual underpinnings. Diabetes, they noted, was caused largely by biological factors and demanded biological treatment. However they emphasised that individuals who subscribed to spiritual causal theories were unlikely to comply with pharmacological treatments.

The second problem was non-compliance. The dominant professional experience was that of clients failing to return for follow-up consultations. Like biomedical professionals, ethnomedical professionals regarded non-compliance as a critical barrier to treatment success. Rural professionals made sense of non-compliance in terms of 'laziness'. Drawing on an economic model of illness action, they argued that since ethnomedical care was relatively inexpensive and largely structured around a flexible payment system, individuals who did not follow-up treatment lacked a basic drive to improve their health.

Let's say a patient owes some arrears in payment, if they come and tell us they don't have any money, we will continue giving them drugs until the arrears are paid off, so if they don't come for treatment then it is due to sheer laziness and not financial problems. [biotech-herbalist(Nkoranza)]

Problematic biomedical practices

Two problematic biomedical practices were outlined. First, patients' early engagement with biomedical systems was viewed as problematic. This was linked to the general difficulty of curing diabetes at late stages.

Most patients come here as a last resort. Some go from hospital to hospital until they are fed up before they come here. [traditional-religious-healer(Nkoranza)]

The second problem related to the inability of biomedical professionals to cure diabetes. Rural professionals noted that individuals were often 'sent home to die' by hospitals. The rural traditional religious healer raised the issue of invasive biomedical therapies and side effects of drugs, both of which were perceived as factors in patient non-compliance and abandonment of biomedical care.

Problematic faith healing practices

Traditional religious healers noted that faith healers only dealt with spiritual dimensions of illness and did not incorporate pharmacological treatment. They had had experiences of treating individuals who attended prayer camps in search for cures, in the first instance, but ended up seeking traditional religious treatment because they had developed complications.

When some people get sick, they think somebody wants to kill them spiritually so they end up in the church for prayers to be said for them. But in the church they are not given any drugs, they only pour water and lavender on their heads; meanwhile the problem is not spiritual. So the patient will be moving in circles until the disease becomes acute then they find their way here, and when you are not successful in treating them then they point fingers at you. [traditional-religious-healer(Nkoranza)]

Ethnomedical perspectives on improving diabetes care

Ethnomedical practitioners noted that lay knowledge of diabetes was poor and needed to be improved. While this group made no explicit self-critical comments regarding the adequacy of their knowledge of diabetes (or indeed of their practice as a whole), they stressed their openness to biomedical approaches. Politicised practitioners stressed that while biomedicine provided a

welcome resource, it ought not displace traditional ethnomedical knowledge systems and practices. Secondly, professionals expressed willingness to present drugs for standardisation. There was general consensus that the standardisation of ethnomedical drugs would be beneficial for public health. Pharmaceutical misappropriation of ethnomedical knowledge constituted a dominant theme around which politicised practitioners discussed issues of standardisation. These discussions, like biomedical discussions, highlighted the importance of building trust between biomedical and ethnomedical groups, as a necessary prerequisite for the standardisation process.

If I tell you a particular plant cures diabetes, you could research and develop what that plant contains and you could use it. But the man who has given the knowledge is not given anything. These researchers have become exploiters. Now no herbalist will tell them everything. [biotech-herbalist(Accra)]

9.2.3. Faith healers treatment practices, goals and mediating factors

Faith healers' treatment process involved spiritual healing and assessment of healing outcome informed largely by clients' subjective accounts of recovery. The goal of faith healing was to cure diabetes.

There was no physiological diagnostic component to faith healing. Physiological dimensions of illness were peripheral to faith healing practice, since the majority of individuals who consulted religious healers for treatment did so for the sole purpose of obtaining spiritual healing for an already diagnosed condition. The majority of healers made reference to individuals consulting faith healers because they were 'at the end of their tether'.

We don't have any methods of confirming diabetes. Usually people would have confirmed that they had diabetes before coming here. [faith-healer(Kintampo)]

People come and they say at this point of the illness only God can help me. If I don't turn to God I'll probably die. [faith-healer(Nkoranza)]

Faith healers focused on spiritual diagnosis. This was informed by the chronic nature of the condition and the inefficacy of pharmacological treatment. Thus a particular case of diabetes would be diagnosed as spiritual if an individual had exhausted the broad range of pharmacological treatments and still suffered great physical or spiritual discomfort. There was also a sense in all the narratives that the process of making a spiritual diagnosis was facilitated by God or by 'divine' knowledge. There were repeated references in all narratives to "*nyame yi kyere*" (the power of God to reveal the nature of the problem.)

Wisdom is from God. As I have given my life to the living God, there are certain things revealed to me. There are certain times I pray and I have access to things I haven't come across before. [faith-healer(Accra)]

The treatment process involved two components: fasting and 'deliverance'. Fasting aimed at strengthening the spiritual focus of the individual and also facilitated the efficacy of deliverance. The emphasis placed on the spiritual importance of fasting meant that faith healers often overruled the dietary concerns of their clients. This had important implications for people with diabetes.

Sometimes people will say 'I have diabetes so I'm not allowed to fast'. Sometimes we will listen, other times we will say 'try it at 10am', then we'll say 'try it at three' and before they realise it they would have fasted till six pm. Having gone through this process they need no one to tell them that they feel better. Some even say 'I can't believe I have been able to fast till 6pm.' Many rejoice, dancing and singing. [faith-healer(Nkoranza)]

Deliverance involved intense praying, by faith healers, aimed at ejecting the spiritual causal agents from the body of the person with diabetes.

RFH: So a person with diabetes will be called to the front and we start praying for them. As I pray you see that the spirit or the power behind the illness starts to shake this person. It might cause them to fall. When they fall I move towards them. Sometimes the spirit will say 'if you are trying to deliver this person from me, I will hit his head against the coconut tree and kill him right now'. Sometimes if you don't rush towards them immediately when they fall, the spirit will say 'I will hit his head on the ground and kill him.'

Ama: Is the spirit talking at this point?

RFH: Yes, you see what I mean. When that happens I am dealing with the spirit directly while the elders and helpers are protecting the person physically, so we can complete the work without him coming to physical harm. In the meantime I'm crying 'Jesus, Jesus, use your fire, use the holy ghost' and I'm praying and speaking in tongues. You'll see that the spirit flies out and the person goes quiet. When they get up they say they feel no pain in their body. Then they can resume doing the things they were prevented from doing.

The success of the healing process was judged by the extent to which the physical symptoms of diabetes were eliminated. This was ascertained in the case of 'resident clients'⁴ by their ability to return to normal life (by eating restricted foods without exhibiting complications for example) or for 'non-resident clients' a subjective report of a return to normal life. In some cases individuals were sent back to their doctors for assessment of their diabetic status. Despite strong claims to the power of spiritual healing, healers provided vague details on success rates. The discrepancy between claims and observable results were explained within the framework of faith – a strong belief in the ability of God to effect permanent healing eventually.

We haven't cured everyone but God will do it eventually. However most people say they have noticed a difference in their lives. [faith-healer(Nkoranza)]

Faith healers' assessment of in-group knowledge and practice

Faith healers' assessment of in-group knowledge and practice was largely positive. No negative self-critiques were made. The nature of the positive assessments made legitimised, to some extent, the lack of negative assessment within this group. The positive assessments centred on three themes: faith in God; the exclusive focus on spiritual conditions and a shared religious belief system between healer and individuals seeking spiritual healing. Firstly, the practice of healing was fundamentally rooted in Christian faith and scripture. For all healers this faith allowed no room for negative critique even in instances where the healing process did not result in the desired outcome. Ultimate answers to all life's problems, they stressed, lay in the spiritual and religious realm.

⁴ All rural faith healers had prayer camps adjoined to their churches, which acted both as sources of sanctuary and healing centres. My use of 'residents' and 'non-residents' is to distinguish between people with diabetes who spent prolonged periods at the camp and those who did not.

Secondly, no claims were made to curing the physical dimension of disease, rather all healers stressed that faith healing focused on the spiritual dimension of illness. There was a strong sense that faith healers played a valuable adjunct role to biomedical and ethnomedical practice. For the majority, faith healing often constituted the critical first step to the curative process in the sense that the faith healer removed the root spiritual cause thus allowing the biomedical and/or ethnomedical practitioner to cure the physical component.

In cases of infertility for example a women might be sent to a doctor but as the doctor works on the problem we pray for the woman, as they work, we work. [faith-healer(Nkoranza)]

Thirdly lay knowledge of faith healer 'expertise' in solving spiritual problems was the drawing force for healing consultations. Healers noted that the majority of individuals who consulted religious healers for treatment did so with full knowledge and acceptance of the principles underpinning the practice of faith healing.

People come through faith and also through observation of the successes of our church. [faith-healer(Kintampo)]

Conflating these factors – a clear 'professional objective' underpinned by strong Christian faith, no evident engagement (or need to engage) in cross-professional competition and perhaps crucially a high degree of overlap between treatment goals of treatment goals of practitioner and client - there was perhaps little need for critical reflexivity within this group.

Faith healers' perspectives on improving diabetes care

Some participants noted that changing harmful diets could prevent diabetes; the majority endorsed faith healing and prayer as critical adjunct to hospital and herbalist treatment. Beyond this no further ideas were expressed on improving diabetes care.

SYNTHESIS

This synthesis focuses on three key areas. First, dynamics underpinning production and access to shared and contested knowledge on diabetes within the medical sphere will be outlined. Second, professional perspectives of diabetes experiences and illness action: areas of overlap and absence between professional groups and people with diabetes will be highlighted. In the final section, I discuss professional alliances and conflicts and identify possible ways of minimizing conflicts and strengthening alliances to facilitate the collaborative health process.

Diabetes knowledge

There was a clear demarcation between groups whose professional identities were based on dealing with physical/pharmacological aspects of diabetes and those dealing partially or exclusively with spiritual aspects of diabetes. These identities shaped interest in and use of five eclectically sourced causal themes circulating within the pluralistic medical sphere: dietary imbalance, lifestyle, heredity, physiology and spiritual disruption.

For biomedical and bio-tech herbalist groups, public legitimacy of biomedical knowledge drove knowledge production, access and use. Because contemporary conditions were understood and deemed better treated within a biomedical framework, bio-tech ethnomedical practitioners drew on scientific and scientized knowledge to increase professional credibility and legitimacy in the public sphere. Crucially, ethnomedical groups drew on biomedical knowledge in symbolic rather than technical ways: the curative effects of ethnomedical drugs, the majority asserted, worked independent of applied physiological knowledge. Further, both groups engaged in discussions regarding the importance of spiritual causal theories to people with diabetes, although these theories were not drawn on for everyday professional practices.

Traditional religious healers and faith healers drew on similar spiritual causal theories and principles for treatment. Traditional religious healers, who applied a dual physical-spiritual framework to the diagnosis and treatment of diabetes, drew further from biomedical knowledge

to enhance professional success. Faith healers focused exclusively on spiritual dimensions of diabetes and thus held no professional interest in biomedical knowledge. Thus, while traditional religious healers draw on similar casual themes to other ethnomedical professionals, there were considerable absences in faith healers' accounts compared to the three groups.

Professional perspectives on biographical disruption

The economic burden of living with diabetes appeared in all professional group narratives, as a key disruptive aspect of diabetes experience. High cost of biomedical treatment was a key theme around which all three groups discussed their strengths and limitations. Biomedical groups acknowledged the high cost of biomedical treatment and its impact on compliance and self-care. Ethnomedical groups emphasized their strengths in terms of offering cheaper and more flexible alternatives. Faith healers described their strengths in terms of offering spiritual solace and solutions for individuals in spiritual distress. Beyond this only biomedical groups discussed further disruptive aspects of diabetes experiences.

Biomedical professionals drew attention to the physical and psychosocial burden of biomedical drug/diet management routines. Some urban participants discussed disruptive physical impact of diabetes on social identities and possible anxieties evoked by people living with uncontrolled diabetes. Finally, rural participants drew attention to the possibility of family disruptions stemming from economic burden of diabetes. These latter discussions were, like lay narratives, placed within the context of care-giving norms operating within poor rural communities. Two key biographical disruption themes were absent however: disruption to food practices and social support.

Professional perspectives on illness action

All three groups expressed some knowledge of coping strategies and styles adopted by people with diabetes. The focus and content of knowledge varied, as did the level of reflexivity with which professionals assessed their role in the illness action process. Biomedical and ethnomedical groups placed emphasis on drug and diet management as well as broader lifestyle

changes. Some factors undermining successful engagement in these practices, such as biomedical drugs costs, side effects of ethnomedical drugs and the psychosocial burden of diet management and lifestyle change appeared in biomedical narratives. Ethnomedical groups emphasized their particular strengths – drug efficacy and affordability – but made no comment on issues of drug side effects and treatment complications. Prayer was a central issue for faith healers, although they focused on mediated prayer within the church context, with comparable neglect of the role of private prayer, the dominant spiritual strategy adopted by the majority of people with diabetes. Further, no comment was made on complications arising from faith healing practices.

All three groups overemphasized cure seeking as the dominant coping style adopted by people with diabetes. Distinctions were not made between passive and active cure-seeking. With the exception of biomedical groups, who demonstrated greater understanding of the role of psychosocial and family disruption on coping strategies and styles, the majority of participants attributed cure-seeking to the influence of spiritual causal theories, or to economic disruption. A noteworthy absence was the lack of comment on inaction as a coping style, given that this was underpinned by extreme socio-economic disruption.

Professional collaboration: issues and solutions

The inter-group professional rivalries centre on pharmacological and spiritual expertise; this suggests there will have to be different criteria for facilitating collaboration between the three groups. I will therefore focus on the biomedical-ethnomedical relationship and then turn to the traditional religious – faith healer relationship. I will then focus on the problem of absence within biomedical discourse on faith healing practices, and highlight the particular problem this poses for diabetes intervention and health policy more generally.

Biomedical and ethnomedical collaboration

Diagnostic and pharmacological expertise were highly valued within the public sphere, constituted key criteria informing treatment choices of people with diabetes and - by association - the key sites around which conflicts between biomedical and ethnomedical groups revolved. Ethnomedical groups misappropriated biomedical technical knowledge as a symbolic tool to maximise professional legitimacy and credibility in a competitive pluralistic medical sphere. Biomedical groups appropriated ethnomedical intellectual property within the collaborative health process without due recognition and financial compensation; this compounded the marginalisation of ethnomedicine in the healthcare arena and undermined knowledge sharing between the groups.

Two ways forward were suggested by both groups. First, both stressed the importance of legal and financial compensation for ethnomedical knowledge use. This, both groups argued, would facilitate greater trust and improve the process of ethnomedical drug standardisation. Second, consensual emphasis was placed on educating ethnomedical groups on physiological profile of diabetes and target-specific diabetes treatment. As both challenges were raised in participants' discussions, external mediation has some chance of success. A third way forward, which is inferred from broader narratives, centres on biomedical-ethnomedical referrals. Both groups share more consensual than conflicting concepts about health and illness and treatment processes in general. While the debate on biomedical management versus ethnomedical cure might seem irresolvable at cursory glance, a deeper analysis of the ways in which both groups of practitioners make sense of the process and quality of treatment highlights consensual themes, which can facilitate collaboration in this third area. Consensual themes on treatment process, illness action, the recognition of distinct areas of professional strengths and weaknesses, and the emphasis placed on education, suggest practical alliances can be struck. Such alliances may depend on addressing the broader issues of knowledge misappropriation and professional mistrust.

Traditional religious healers and faith healers: professional identities and scope for collaboration

Professional conflicts were strongest between traditional religious healers and faith healers. However, there was a split between the remaining ethnomedical groups with the politicised sub-group aligned to traditional religious healer perspectives, and the apolitical sub-group to faith healer perspectives. This in-group, across-group conflict was structured along the lines of Christian faith vs traditional Ghanaian religious faith. Two areas of conflict emerged: first in terms of legitimacy of religious identity, second remit of professional expertise. The apolitical ethnomedical group, along with faith healers delegitimised traditional religious religion. The political ethnomedical group, alongside traditional religious healers, made a strong case for the appropriateness and effectiveness of holistic traditional religious practices. Despite this strong belief in efficacy of treatment there was reflexive awareness, within the traditional religious group specifically, of the public clash between traditional religious and Christian values and the impact of this on their diminishing professional worth in the medical pluralistic sphere.

The scope for collaboration between traditional religious practitioners and faith healers is difficult to envision within the context of current information. Collaboration, in the strict sense of two systems working together through referral systems, will be difficult to forge, given the highly emotive and public divisions. Given a social context that is strongly Christianised, competition between the two swings in favour of the faith healing system in terms of uptake of services, a dynamic which traditional religious healers are strongly aware of. Yet as lay narratives highlight, the private legitimacy given to traditional religious healers, and the covert use of their services, coupled with the empirical failures of faith healing, suggest that faith healers are unlikely to fully undercut the role of traditional religious healers.

Biomedical practitioners and faith healers: absent themes and implications on health policy

Fundamentally the role of faith healers as legitimate professional competitors, not only of traditional religious healers, but also of biomedical practitioners, must come to the fore in health policy discussions. Faith healers held the least knowledge of diabetes did not carry out diagnosis or offer pharmacological treatment. They advocated and endorsed problematic

pharmacological practices that both biomedical and ethnomedical practitioners criticised, such as dual use of ethnomedical and biomedical treatment. Furthermore their spiritual treatment practices incorporate elements (such as fasting, reverting to a normal diet) that could cause diabetic complications. Yet they held out a cure through Christian faith, claimed to manage high rates of compliance and to be expert at curing diabetes. For those who experience their social realities through an evangelical Christian framework and access faith healing treatments the (long) wait for a cure compounded with clear lack of treatment assessment and problematic advice could result in serious complications. These issues emerged strongly in the narratives of lay health groups and people with diabetes and require more open debate in the professional arena.

OVERVIEW OF CHAPTER TEN

This discussion chapter ties together key empirical, theoretical, and analytical strands of the thesis. Drawing on the theoretical framework, the first part outlines the ways in which cognitive-emotional polyphasia as an analytical framework, facilitated identification of cultural norms shaping discourses and embodied action on health and illness. This sets the stage for outlining, in part two, the three sets of social representations of diabetes identified in analysis: (1) the social representation of diabetes as a life-changing or life-threatening disease; (2) the social representation of diabetes as a 'sugar disease' and (3) the social representation of diabetes as a spiritual disease. In part three, possibilities for participatory intervention are outlined, drawing on research results and broader readings of local, regional and international health policy discussions.

CHAPTER TEN

SOCIAL REPRESENTATIONS OF DIABETES IN GHANA: RECONSTRUCTING SELF, SOCIETY, AND CULTURE

In Chapter Three I outlined two key ways in which the expanded concept of cognitive-emotional polyphasia would facilitate identification of social representations of diabetes in Ghana (see Chapter Three, section 3.3.2). First, I argued that the concept would allow systematic examination of heterogeneous socio-cultural knowledge on health, illness and diabetes. Second, viewing cognitive-emotional polyphasia as simultaneously embodied and discursive, I argued it would facilitate the examination of group and individual identity and agency in the social representations process.

I begin the chapter by discussing socio-cultural knowledge on health and illness and its production through cultural, social and psychological processes. This sets the stage for outlining the nature and functions of social representations of diabetes and possibilities for transformation.

10.1. COGNITIVE-EMOTIONAL POLYPHASIA AND ANALYSIS OF A DYNAMIC ORGANISM-ENVIRONMENT-CULTURE SYSTEM

Narratives of people with diabetes, lay healthy individuals and health professionals highlighted the heterogeneous and dynamic nature of socio-cultural knowledge. Normative ideas about health and illness were shaped by cultural, religious, political, scientific and scientized modalities of knowledge which were produced through inter- and intra-group processes with elements drawn from a variety of shared sources within and outside the Ghanaian socio-cultural context. Emotions underpinned discourses, lived experiences and social interactions. Some identified emotions were rooted in public life and underpinned particular social practices (such as witchcraft activity), illuminated culturally sanctioned modes of responding to misfortune and illness (the stoic sufferer) and the nature of inter and intra-group relations (health professional

rivalries). Other emotions were rooted in subjective illness experiences. These cognitive-emotional processes shaped cultural, social and individual thinking and actions around health, illness, diabetes and medical pluralism.

Two key findings emerged on the role of culture in knowledge production. First, analyses showed that while culture shaped everyday life, it was simultaneously shaped - through the mediation of inter-cultural interaction and exchange - by external cultural forces. The religious character of Ghanaian culture was imagined through the lens of a colonial past⁵. This set up deep ideological and psychological conflicts about the nature and source of the supernatural, its role in misfortune and illness, and the legitimacy of expert mediators. Contemporary Ghanaian ethnomedicine was not confined within socio-cultural boundaries. Like other regional indigenous systems, its strengths (ethno-pharmacological knowledge) and weaknesses (lack of clinical expertise) have become valuable commodity for cross-national, inter-continental pharmaceutical research and development. In Chapters Two and Three, the role of African ethnomedical practitioners as re-inventors of medical tradition was highlighted. This was evident within the Ghanaian context. Cultural re-invention, like that reported elsewhere, was underpinned simultaneously by inter-cultural (global pharmaceutical practices) and by intra-cultural (biomedical and ethnomedical rivalries) processes. On the one hand, ethnomedical professionals viewed the strengths as a cultural legacy, which deserved fierce protection and conservation from global pharmaceutical interest. On the other hand the weaknesses that undermined their professional legitimacy within the public sphere were addressed through appropriation of rival biomedical practices.

Secondly, Ghanaian culture did not constrain group and individual life: groups and individuals negotiated, reformulated or bypassed core elements of cultural norms according to the material and physical demands of everyday life. The re-invention of medical tradition by sub-groups of ethnomedical professionals to strengthen legitimacy in the healthcare arena

⁵ This phenomenon of post-colonial cultural imagining/ re-imagining and reconstruction through the eyes and practices of 'colonial masters' has been reported in Jovchelovitch's (1997) work on the social representations of the Brazilian public sphere and constitutes a central aspect of post-colonial theoretical discussions (cf. Ahluwalia, 2001).

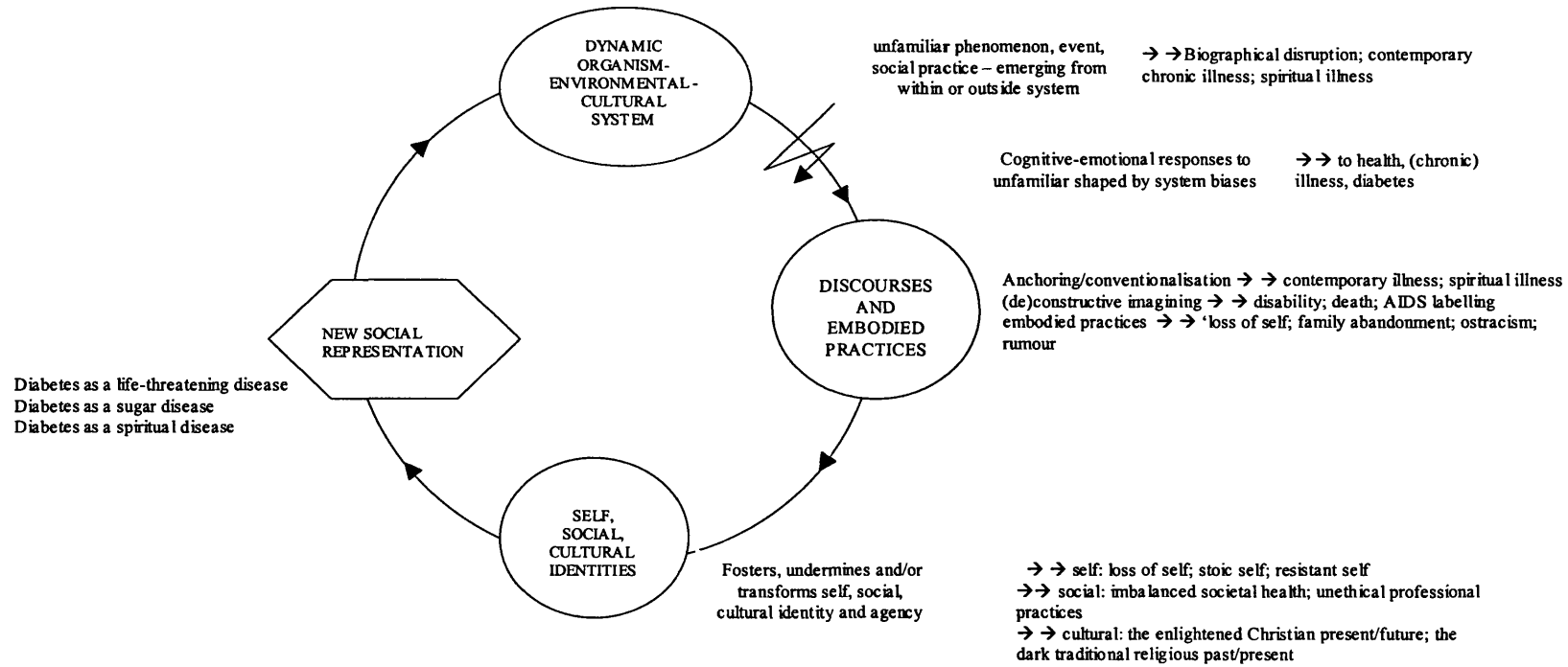
provided a clear example. Farmers flouting ethical codes in response to economic necessities constituted another dominant rural example. Discourses on chronic illnesses and diabetes experiences also highlighted the ways responses to body-self disruption overrode culturally sanctioned modes of illness action. The stoic self had transformed into the suicidal self in rural settings where the economic burden of chronic illness seemed to have changed attitudes to death⁶. Some people with diabetes did not “sell their illness to find a cure”, as the popular proverb endorsed, but held secrets from significant others as a self-protection strategy.

Both findings illuminated the ways in which the unfamiliar, which set the context for the development of social representations, could emerge from within and outside socio-cultural boundaries.

Figure 10.1 depicts three sets of social representations, which emerge at the levels of self, society and culture. This schematic outline and the discussion that follows underscore the importance of conceptualising social representations as socio-psychological phenomena that shape “related but different” (Moscovici, 1988:228) discourses and practices at different levels of social organisation.

⁶ Anthropological work on Akan culture highlights the ways in which a changing socio-economic landscape has caused deep shifts in Akan cultural definitions of ‘good death’ and ‘bad death’ (van der Geest, 2004). While suicide, by any age group, was deemed ‘bad death’ in the pre-colonial era, and carried great stigma, contemporary views accommodate the psychological impact of poverty and illness. This lessens the public shame of taking one’s life, and positions the practice within an ambiguous space between ‘good’ and ‘bad’ death - not quite mourned with ostentation, but not completely hidden from public view or banished from public thinking.

Figure 10.1. Social representations of diabetes in Ghana at levels of self, society and culture: a schematic depiction



10.2. SOCIAL REPRESENTATIONS OF DIABETES

10.2.1. Social representations at the level of self: diabetes as a life-changing/ life-threatening disease

The social representation of diabetes as a ‘life-changing disease’ or a ‘life-threatening disease’, was constructed within three social spheres: life-worlds of people with diabetes, within shared worlds of people with diabetes and the biomedical sphere. The unfamiliarity of body-self disruption constituted the key site around which discourses and embodied action revolved. There were clear areas of consensus, conflicts and absences.

In terms of diabetes knowledge, dietary, lifestyle, heredity, and practical physiological causes were drawn on and discussed in similar ways across all three spheres. The attribution of diabetes to toxic staples was prominent in the narratives of life-worlds and shared worlds, but absent in biomedical narratives. The attribution of diabetes to spiritual disruption was characterised by broader discursive practices around spiritual causal theories: it received glancing references by some participants as out-there theories and for others constituted valid identity-defining theories demanding practical attention.

Some aspects of biographical disruption were common across the three spheres. On the one hand, body-self disruption was common to all people with diabetes and constituted a key focus of biomedical discourses. Also common was the ways in which the psycho-emotional impact of body-self disruption for people with diabetes and those in their life-worlds, took on different, often conflicting interpretations and interactions. Disruption to food practices was also a dominant lived experience, with some dimensions recognised by biomedical groups. On the other hand, while disruption to personal and social identity was a common experience, severity varied depending on type of diabetes, socio-economic status and geographical location. For example, the most severe form of identity disruption – weight loss, AIDS labelling and ostracism – was experienced predominantly in the rural areas. This appeared to be underpinned by a combination of low-income status, close social networks and pervasive public images of

the emaciated AIDS sufferer. For some, this constituted the site around which conflicts within the life-world emerge.

Chapters Six, and Seven, highlighted the ways consensus, conflicts and absences on knowledge and experiences shaped illness practices. While the majority of people with diabetes, their caregivers and biomedical professionals advocated biomedical management as the ideal coping style, the severity of biographical disruption led to contradictory coping styles – passive cure-seeking for the majority, and active cure-seeking and inaction for a minority of low-income and mostly rural people with diabetes. These ‘contradictory’ coping styles often constituted rational responses in the face of psychological, social and material disruption. At the heart lay the cognitive-emotional tensions between people with diabetes and those they associated with. The productive and disruptive functions of these tensions varied depending on the nature of social circumstances and relationships.

Tensions that emerged between people with diabetes and their broader communities – fear of AIDS labelling and ostracism on the one hand, fear of AIDS suffers on the other - were largely based on misperceptions generated through absences in diabetes knowledge, rather than delegitimation of the ‘disease’ diabetes and people living with diabetes. Diabetes, in its public characterisation as *esikyere yare* (a sugar disease), generated sympathy, rather than fear, because of its association with the high cost of chronic illness care. Moreover when juxtaposed with other prevalent conditions such as hypertension, epilepsy and AIDS, it was viewed as a low-risk condition, unlikely to cause serious complications or social stigma. These tensions were therefore amenable to change, as will be discussed shortly.

Cognitive-emotional tensions between people with diabetes and biomedical professionals stemmed from gaps between social logic and medical logic. These silences were rooted within poor communicative practices between clients and professionals. These were, in turn, shaped by a variety of factors, including structural deficiencies, class differences and professional rivalries. These tensions were largely reflective of broader health professional-lay relationships. Lay treatment choices were framed by cultural emphasis on the value of body-self knowledge, on physiological and pharmacological specificity and on systematic assessment of

treatment outcomes. The degree of biographical disruption on self and significant others, determined the extent to which this pragmatic approach shaped empowered treatment choices within a complex pluralistic medical sphere.

Cognitive-emotional tensions were most disruptive within life-worlds: at the heart of these tensions was the impact of body-self disruption on self- and family identities. The impact was multi-dimensional. Body-self disruption for the person with diabetes led to greater dependency on caregivers for socio-economic, physical and emotional support, and/or to loss of self and participation in social life. Care-givers were faced with life-restricting economic and physical burdens, compounded in cases where body-self disruption was extreme, by the psychological and emotional burden of living with tainted family identities and responding to unpredictable psychological and emotional changes in their relatives. This finding mirrors critical health work, which highlight the ways emotional conflict within life-worlds is often bi-directional and underpinned by the uncertainty chronic illness evokes for sufferers and carers (Charmaz, 1983, 1991; Crossley, 2000).

Finally, shared worlds of people with diabetes, most visibly organised through self-help groups, produced the least cognitive-emotional tensions. In Nkoranza, for example, consensual experiences, coupled with shared awareness of the socio-psychological impact and consequences of diabetes shaped a supportive environment that transcended support provided within life-worlds. The unique benefits of self-help group support have been noted in the critical health literature (Greenhalgh & Collard, 2001; Krause, 2003).

10.2.2. Social representations at the level of society: diabetes as a sugar disease

The social representation of “diabetes as a sugar disease” was shared in the public domain, and drawn on by all groups. As aspects drawn on within life-worlds and shared worlds of people with diabetes have been discussed, the focus here is on lay and health professional groups. The dominant discourses and embodied action revolved round the unfamiliarity of contemporary chronic illnesses. Lay groups shared similar discourses and embodied action. Health professional discourses and practices were conflicted.

The majority of lay and medical groups discussed the dietary and heredity causes of diabetes in similar ways. Practical physiological dimensions appeared in the narratives of educated lay groups, and biomedical and ethnomedical groups. Finally, the spiritual dimensions constituted out-there theories for the majority of lay and biomedical groups, were legitimised by some ethnomedical groups, and for faith healers and traditional religious healers constituted a dominant focus for professional expertise. Differences in access and use of knowledge shaped particular practices in the public sphere.

Diabetes was commonly viewed as a physical disease caused by high-sugar diets. Beyond this diabetes was indistinguishable from other contemporary chronic illnesses in terms of psychosocial and socio-economic impact. Sympathy was expressed for envisaged economic disruption faced by people with diabetes. Biomedicine was deemed best diagnostic and treatment choice, although expensive. Ethnomedicine was endorsed as a viable affordable alternative.

The legitimacy granted to biomedical knowledge and practice in diabetes care shaped lay advice on drug and diet management. However key absences in knowledge within the public domain, particularly on the complex physiological profile of diabetes and issues of ethnomedical drug efficacy, compromised social support. Furthermore absences compromised diabetes prevention practices within lay healthy groups. These absences were by-products of unequal knowledge production and professional rivalries within the pluralistic medical sphere.

Biomedical professionals underestimated the complexity and sophistication of lay theories of health and illness. Consequently, they disseminated simplified versions of practical biomedical knowledge on dietary, heredity and physiological causes of diabetes. These absences underpinned AIDS labelling in rural communities, on the one hand, and on the other hand undermined diabetes prevention practices among lay healthy individuals.

The absences were further compounded by distortions and misappropriation of biomedical knowledge from ethnomedical groups. Ethnomedical professionals exploited shared knowledge on the high cost of biomedical drugs to push forward strong media driven agenda as affordable alternatives to biomedicine. Because non-standardised ethnomedical drugs caused

complications for the majority of people with diabetes, ethnomedical discursive practices had crucial implications on quality and continuity of self-care. Faith healers did not draw on, or misappropriate biomedical knowledge. However, their publicly legitimised status as providers of spiritual support and solutions, coupled with key absences in their knowledge of the physiological and pharmacological dimensions of diabetes had problematic implications for diabetes illness action. Lay people drew on media disseminated and word-of-mouth knowledge on faith healer practices to provide potentially damaging advice on spiritual treatment for people with diabetes.

10.2.3. Social representations at the level of culture: diabetes as a spiritually caused disease

The social representation of diabetes as a 'spiritually caused disease' was a contemporary version of a collective representation, which centred on the nature of the supernatural and its role in misfortune and illness. It constituted three sets of theories.

First, the spiritual dimensions of diabetes were discussed in terms of 'out-there' theories circulating the lay sphere, accessible to all but not personally endorsed. This view appeared in narratives of biomedical, non-political herbalists, urban lay groups, was consensual and focused on generalized evil as causal route. Rural people with diabetes drew on this social representation as a secondary theory: sorcery, moral transgression, and witchcraft were dominant causal routes cited in these discussions. Finally, for traditional religious healers and faith healers who were active producers of this representation, the broad range of spiritual causes of illness - generalised evil, traditional religious deity action, witchcraft, and sorcery - were deemed valid causal routes requiring professional diagnosis and treatment.

These theories shaped different discursive practices. No discernible actions appeared within accounts of those drawing on out-there theories although, health professional groups engaged in some discussion about the importance of legitimising spiritual beliefs held by people with diabetes to improve rapport and compliance. For some rural people with diabetes, diagnosis was sought within the traditional religious and faith healing spheres when symptoms first appeared;

however once a biomedical diagnosis is made spiritual treatment was restricted to faith healer services and private prayer. Individuals assessing both spheres for diabetes treatment experienced poor results or complications – the majority of participants express a strong preference for private prayer. However low-income people with uncontrolled diabetes, and little to no social support, were likely to access the faith healing sphere for spiritual treatment and support.

The cognitive-emotional tensions underpinning this social representation generated diverse outcomes. Public discourses on the supernatural underpinnings of illness tapped into the complex socio-psychological space mediating cultural and religious identity. The professional rivalries between faith healers and traditional religious healers, for example, were shaped not only by pragmatic professional concerns, but also by deep-seated ideological conflicts about legitimate cultural and religious identities. The discursive practices stemming from these conflicts highlighted distinct outcomes for different groups. Faith healers who represented and advocated mainstream evangelical Christianity were closed to traditional religion, despite showing as much knowledge of its core tenets as other social groups. Traditional religious healers, who represented traditional religion and drew on its core tenets for their professional livelihood, espoused religious pluralism. This openness was not directed only to other religious beliefs and practices, but also to other medical practices. Within lay groups, public denouncement of traditional religion conflicted with private use of traditional religious services; this was further complicated by moral shortcomings and empirical failures of faith healers. Given the complex interlinking of this social representation with cultural and religious identity and its strong emotional underpinnings, I speculated it was unlikely that the services of the publicly marginalized traditional religion healer would be fully undercut by the popular role of the evangelical Christian faith healer.

10.3. TRANSFORMING SOCIAL REPRESENTATIONS OF DIABETES: PRODUCTIVE ALLIANCES AND PARTICIPATORY ACTION

In Table 10.1 I present a summary of needs for people with diabetes and ways forward proposed by research participants. There is a clear hierarchy of needs for people with diabetes, aspects of which dovetail into broader needs for public health and pluralistic medical practices. The overriding and urgent concern for people with diabetes is the availability and cost of biomedical care and recommended foods. The greatest challenge lies in addressing the needs of low-income people on insulin.

The second major concern is the prolonged psychological and emotional disruption experienced by groups living without adequate social, economic and medical support. Here, the problem of AIDS labelling and ostracism require particular attention. Fear and/or experience of AIDS labelling and ostracism evoked loss of self and loss of participation in social and family life for these marginalised groups. At its most extreme, this mix of factors led to illness inaction.

Finally, the lack of support for care-givers requires attention: caregivers and significant others experience a variety of social, economic and psychological disruptions to their lives which impacts on their identities, quality of life and ability to support their relatives.

Diabetes education emerged as the dominant need for lay healthy individuals. Poor diabetes knowledge did not only impact on quality of communicative and social practices between lay groups and people with diabetes, it indirectly fed into neglected issues on nutrition, heredity, lifestyle that constituted diabetes risk factors for lay healthy people.

Table 10.1. List of needs for improving diabetes care

Social Group	Participants' views on improving diabetes care	Additional areas emerging in analysis
People with diabetes (shared worlds) & Caregivers	Addressing high cost of drug treatment Addressing cost of recommended foods and availability of quality staples Improving public education Improving practical biomedical information Addressing biomedical misappropriation of ethnomedical intellectual property and issues of standardisation Availability of tester kits	Material support (for low-income unemployed groups) Psychosocial support (for both people with diabetes and caregivers)
Lay health groups	Biomedical compliance Addressing high cost of drug treatment Use of standardized ethnomedical drugs Improving public education	Addressing issues of AIDS labeling and ostracism Addressing diabetes prevention among lay groups
Biomedical groups	Addressing structural barriers to biomedical services Addressing poor communicative practices Addressing public education (lay and ethnomedical) Addressing biomedical misappropriation of ethnomedical intellectual property and issues of standardisation	Bridging the gap between medical and social logic (education of biomedical groups) Addressing professional disinterest in faith healer practices
Ethnomedical groups	Improving public education (lay and ethnomedical knowledge) Addressing biomedical misappropriation of ethnomedical intellectual property and issues of standardisation	Addressing ethnomedical misappropriation of biomedical knowledge and practices Addressing unethical ethnomedical practices
Faith healers	Addressing poor dietary practices Biomedical compliance	Addressing harmful faith healer practices Addressing faith healer disinterest in biomedical perspectives on diabetes

Within the pluralistic medical sphere, three key problems required critical attention. First, structural deficiencies in the health system required attention: unequal distribution of services, lack of quality diabetes equipment and high cost of care had a significant impact on biomedical professionals' ability to provide quality diabetes care. Closely linked was the impact of poor biomedical communicative practices, which were partly attributable to structural deficiencies and partly to class differences. Secondly, professional conflicts and rivalries between biomedical and ethnomedical groups generated crucial absences and misunderstandings in the public sphere that undermined positive illness action. The mutual professional disinterest between biomedical and faith healer groups was a third area of concern. Problematic faith healing practices were underpinned by absences in practical biomedical knowledge.

Some of the outlined needs can be addressed through productive alliances between the research groups. Other needs will require productive alliances between the research groups and external (local and international) partners. I turn to a discussion of both processes.

10.3.1. Feasible participatory action: productive alliances between life-worlds and the pluralistic medical sphere

Education

Productive alliances between people with diabetes and biomedical groups on the one hand and between biomedical, ethnomedical and faith healer groups on the other can address three areas of knowledge deficiency.

First, biomedical knowledge and public health knowledge can be improved through stronger communication links between people with diabetes and biomedical professionals. Issues surrounding practical physiological knowledge, the severity of physical disruption and its impact on social identities, and the complex dimensions of disrupted food practices and nutritional imbalance, which do not feature in biomedical discourses, should form the basis not only of clinical care, as well as public health education. Existing communication channels, such as clinical encounters and self-help group meetings, can be used for this purpose. It is worth

noting that, the qualitative differences in care between Nkoranza and Accra, both with self-help groups and specialist diabetes centers, and Kintampo, which exists without organized support systems, suggests that education of biomedical professionals could be more successful if channeled through self-help group networks. Self-help group activism within healthcare (Krause, 2003; Nettleton, 1995) and community development (Valente et al, 1997), have been shown to be highly successful.

Improved biomedical knowledge can be incorporated into broader diabetes campaigns for lay healthy individuals. AIDS labeling and ostracism has a significant impact on rural lives and causes concern for urban people with diabetes. This problem is absent in biomedical narratives and requires incorporation in health campaigns. Evidence from recent community intervention work in the region (cf. Jilek-Aall et al, 1997; Killewo et al., 1997) suggests that community education can improve social responses and support given to individuals living with stigmatised conditions. This is an area that could also benefit from self-help group input. Work on AIDS (Joffe, 1995,1996) and on chronic conditions with ambiguous physiological profiles (Krause, 2002,2003), highlight the positive impact sufferers have on public attitudes through media campaigning.

Secondly, although educated urban groups show greater knowledge of practical physiological and pharmacological dimensions of diabetes, all groups fail to engage in issues around risk factors for lay healthy individuals. Diabetes education will have to explicitly incorporate practical information on key areas of absence in lay healthy narratives. As the majority of lay groups drew knowledge from the national and local media, this could constitute the key medium for public education.

While exchanges between self-help groups and biomedical professionals will not require external mediation, a key consideration for public health education will be funding. During fieldwork, the Ghana Diabetes Association, which is responsible for diabetes education nationwide, operated with a yearly budget of ₵4,000,000 (£400 at time of research, just over £300 at time of writing). This suggests that while it is possible to facilitate productive alliances

between these groups, it is unlikely to yield long-term changes unless alternative avenues of funding are actively sought.

Knowledge sharing between the professional groups can be improved in two key ways. First, biomedical and ethnomedical groups express awareness of the roots of professional antagonism and rivalries and offer similar solutions. Ethnomedical groups express willingness to improve diabetes knowledge and basic clinical practice, while biomedical groups acknowledge the importance of building trust as a fundamental basis for improving professional relationships. The current policy emphasis on the collaborative health process provides a supportive structural context within which biomedical and ethnomedical alliances can be strengthened.

Second, the biomedical system, as the legal conduit for public health education and health policy development, will need to engage with the health work of faith healers. Faith healing ministries have regional and national bodies, which co-ordinate activities of churches and faith healing camps. These regulatory bodies could provide the space for policy and public health debate and development. This process, like public health education is likely to require funding that lies beyond the financial capabilities of the Ghana Diabetes Association.

Psychosocial support

There are fewer than 50 psychologists working in Ghana. Most work in the area of mental and occupational health, and are situated in southern towns. The provision of psychosocial support is unlikely to be facilitated by this professional group. Existing self-help groups on the other hand may constitute useful resources for psychosocial support, as the work of self-help groups in diabetes support in other deprived social contexts suggest (Krause, 2003; Greenhalgh et al, 2001). In Nkoranza, the self-help group played an active role in providing social and emotional support for members and their families. It also liaised with doctors and nurses on key issues of management and self-care and therefore provided a valuable educational service. In Accra, the self-help group operated as an educational service. This group like Nkoranza's liaised with biomedical professionals and thus constituted a site for professional-client interaction. These

ongoing activities by both groups could be explicitly harnessed for psychosocial work, particularly in the underserved area of caregiver support. They could also be drawn on as practical guides for the development of self-help groups in Kintampo. Given the disruptive nature of diabetes, particularly among the rural poor, critical attention will have to be paid to the physical and emotional capabilities of self-help group members. Also important will be the financial aspects of providing long-term psychosocial support for needy members and caregivers.

10.3.2. Speculative participatory action: ‘hypothetical’ alliances between researched groups and external (local and international) partners

While education and psychosocial support are crucial to improving the quality of life for people with diabetes and their caregivers, their most urgent needs - good quality affordable drugs and food – require external mediation. Two sets of productive alliances have been identified involving people with diabetes (and self-help groups), biomedical groups, local policy makers, as well as groups external to the public healthcare system and local policy makers.

Community insurance schemes

Community insurance schemes have gathered considerable attention within current HIPC inspired health service initiatives in Ghana (see Chapter One, section 1.1). Within this context, the Nkoranza community health insurance scheme could play a key role for people with diabetes in Nkoranza and neighbouring communities. At present this scheme covers hospital admission and treatment, which is beneficial to low-income people with uncontrolled diabetes who require intermittent hospital care. It is possible that such a scheme could broaden its remit to cover a percentage of drug costs (K. Bona, personal communication, 2001; Atim, 1999). However, further exploratory work is necessary to implement useful expansion for rural groups.

At present, the majority of urban insurance schemes cater for civil service and private sector employees; this excludes the unemployed or those working in the informal sector. Recent discussions highlight the popularity and success of informal collective saving schemes among

low-income urban groups (Atim, 1999). As in the rural context, the application of these informal schemes to the improvement of diabetes care will require further empirical exploration.

Local and international policy intervention

Ultimately, the urgent problem of drug and food costs will require local and international policy intervention. In Chapter One, I drew attention to documented structural problems undermining diabetes care (Amoah et al, 2000). Among these was a lack of a diabetes advisory service, no guidelines for diabetes care, no tax exemption for diabetic medications, erratic supply of essential diabetes products at health facilities and a general deficiency in facilities and resources. These problems were compounded by the lack of a formal national policy and poorly trained diabetes health care professionals (Amoah et al, 2000). The Ghana Diabetes Project was set up to address these critical issues in diabetes care. While it has been successful in gathering epidemiological data on prevalence rates and national attitudes to diabetes, it is yet to apply its findings to the improvement of professional and self-care (F. Ofei, personal communication, 2001). Its failures can, in part, be attributed to the well-documented and much discussed limitations of the top-down participatory approach, and also, to its ambitious collaborative profile and practical goals. Alliances between large multi-disciplinary academic and industry groups have been shown to be fraught with conflicting knowledge and power interests that undermine shared project goals (Kelly & Van Vlaenderen, 1996; Campbell, 2003).

Emerging work in Latin America suggests that participatory work on marginalized health areas like diabetes show greater promise when they are low-scale, actively involve people with illness and their health professionals and when these groups are provided with an empowered platform for income generation (Krause, 2003). AIDS work in Africa and Asia also suggests that long-term health projects have better chances of success if international donors by-pass state and local institution mediation and engage directly with people in need (Campbell, 2004; Cornish, 2004). The provision of drugs and the improvement of professional practices in Ghana might benefit from these approaches. The ethnomedical drug standardization process may also benefit

from these approaches. Its intricate links with international health policy debates and directives on the legalisation of African ethnomedicine (DeJong, 1991; Tsey, 1997; Prakash, 2003) suggest that making standardized drugs available to people with diabetes, will require productive alliances between multi-sectoral and local-international policy partners.

Links made between toxic staples and diabetes deserve further exploration. This area has received no attention within local literature. However, broader themes on the general decline of agricultural practices are shared by recent nutrition work, which attributes rising levels of poor nutrition and health in low-income countries to the growth of the global food market (Drenowski and Popkin, 1997; Lang, 1999). Local research on the negative impact of the informal food vendor sector on societal health also support concerns expressed by participants (Mensah et al, 2002). This suggests that diet interventions will have to focus not only on increased and affordable food supply, but also crucially engage in issues of local agricultural production. This process lies outside the remit of health systems and will require committed multi-sectoral policy approaches. The participatory framework for the improvement of biomedical and ethnomedical drug treatment may be applicable for diet management and broader public nutritional health.

CONCLUSIONS

This thesis sought to develop a critical social psychological approach that bridged the gap between the cultural and individualistic approaches to diabetes care in Ghana. It also sought to apply its findings to the development of practical interventions in diabetes care that drew on existing professional and life-world resources. It expanded the conceptual framework of social representations theory by incorporating perspectives from critical health psychology, socio-cultural theories of emotion and applied social psychology. This facilitated a systematic examination of the cognitive-emotional nature of socio-cultural knowledge production, and the psychological, socio-cultural and material mediation of diabetes experiences and illness action. Social representations of diabetes were identified through this process, as well as the scope for practical long-term intervention. Here, I conclude with a discussion of the strengths of the conceptual approach of the thesis within the context of its stated goals, as well as highlight its limitations and possible areas of further research. I place these closing comments within the broader context of chronic illness in Africa.

MOVING BEYOND CURRENT CULTURAL APPROACHES TO CHRONIC ILLNESS

Three assumptions guide current cultural approaches to the chronic illness problem in Africa. Researchers begin with the premise that the majority of societies conceptualise illnesses under three distinct categories: natural, social and supernatural. Medical systems are deemed to have specialist areas across this spectrum: biomedicine is generally conferred expertise in the treatment of naturally caused conditions, while most indigenous medical systems are deemed expert in the treatment of supernaturally caused conditions. Causal categories are perceived to be shared between lay people and indigenous health systems and to shape illness action in linear ways: individuals living with naturally caused illnesses will seek treatment within medical systems expert in the treatment of naturally caused illnesses; those living with conditions deemed supernaturally caused will seek treatment within ethnomedical systems

designed to diagnose and treat supernatural dimensions of disease. As chronic illnesses are widely attributed to supernatural causes, the dominant assumption is that ethnomedical services are the first and sometimes only port of call for people with chronic illness. Within this framework poor illness practices and self-care are attributed to faulty cultural beliefs and poor ethnomedical practices and interventions centre on addressing cultural beliefs as a means of improving public awareness and understandings of biomedical constructions of chronic conditions, as well as compliance and self-care.

These key assumptions are challenged by this thesis. First, the findings suggest that it is problematic to impose distinct natural, social and supernatural categories on illness causation. These categories exist, but are drawn on interchangeably. Whereas concepts of diabetes, within dominant cultural work, would be viewed purely in terms of supernatural causal attribution, analysis here highlights the ways in which participant groups conceptualised diabetes simultaneously in terms of processes of natural causation (dietary imbalance, poor lifestyle practices, heredity), inter-individual action (sorcery) and supernatural agency (generalised evil, witchcraft). More importantly by working through the modalities and contents of knowledge of health, illness and diabetes, results indicate that concepts of natural, social and supernatural causation are not shaped solely by cultural or traditional knowledge, or drawn from cultural sources. Shared meanings on health and illness generally and diabetes specifically are drawn interchangeably from cultural, religious (traditional and Christian), political, scientific (technical biomedical), scientized (practical biomedical), emotional knowledge modalities. These modalities are in turn constructed through intra-cultural and cross-cultural discursive and embodied practices.

Two key findings on socio-cultural knowledge production emerged in analyses. Contrary to the emphasis on the centrality of spiritual causal theories to chronic illness, spiritual causal theories constituted peripheral secondary theories of diabetes, while physical and psychological underpinnings of illness received greater emphasis. More crucially, while spiritual causal theories remained a strongly identifiable collective representation, its role in the

lives of lay people and health professionals was conflicting. I showed how the social representation of diabetes as a spiritual disease captured the complex interface between changing cultural and religious identities and underpinned ideological and psychological conflict surrounding illness practices.

In terms of lay engagement with pluralistic medical systems, findings mirrored alternative cultural work, which argues that African pluralistic medical systems are conceptualized and drawn on as a co-existence of alternatives.

Biomedicine was highly valued in the Ghanaian public sphere for its expert diagnostic and treatment practices. This legitimacy was partly mediated by similarities between Ghanaian cultural concepts and key practical biomedical constructs. Concurrently, ethnomedicine was valued within the public sphere for its treatment successes. While traditional religious healers and faith healers faced conflicting public endorsements, both groups offered services that were accessed - overtly or covertly - by a broad range of groups. From the opposite end, all medical systems were subjected to public critique on technical and ethical dimensions of professional care. These critiques and ensuing tensions evoked during complex illness episodes shaped empowered lay choices within an unpredictable pluralistic healthcare system.

Put together, these results imply that problematic illness practices, such as non-compliance, healer shopping and dual use, cannot be directly attributed to 'faulty' cultural beliefs, epistemological conflict with biomedicine or a shared value system with ethnomedicine. It is more useful to view illness action in terms of complex socio-psychological responses to biographical disruption. More generally, it is important to view pluralistic medical systems in Ghana, in terms of a co-existence of alternatives, rather than a hierarchy of alternatives. As alternative cultural studies demonstrate, this co-existence is underpinned simultaneously by cultural openness to alien cultural systems and to intra-cultural critique.

MOVING BEYOND REGIONAL MEDICAL PSYCHOLOGY APPROACHES

In Chapter Two I drew attention to key limitations within regional health psychology approaches to chronic illness care. The KABP studies overemphasised the biophysical dimensions of illness and neglected psychosocial underpinnings. The psychosocial work highlighted the mutual inter-relationship between physical, emotional and socio-economic dimensions of chronic illness, but had three key shortcomings. It provided scant information on the ways in which the chronically ill responded to the burden of illness within the low-income context. It failed to engage with the internal dynamics and reciprocal relationships within life-worlds. Finally, while it provided recommendations on psychosocial intervention there was no discussion on how interventions could be developed, implemented and maintained within the context of limited economic, technical and structural resources. Critical health work provided useful conceptual frameworks for addressing these absences, however they lacked adaptable guides for intervention work in low-income settings like Ghana. Key absences highlighted in the mainstream, psychosocial and critical health fields have been addressed within the social representations framework adopted by the thesis.

KABP approaches are criticised for overemphasising the biophysical dimensions of illness and biomedical compliance to the detriment of complex socio-psychological experiences and social logic. However there are aspects of these key KABP concerns that are theoretically and empirically important. First, body-self disruption constitutes the recurring focal point around which all other disruptive life events revolve – it cannot be treated as incidental to the illness experience. Secondly, results highlighted the importance of practical biomedical knowledge in Ghanaian public life, as well as the lives of people with diabetes. The majority of people with diabetes, their significant others and lay healthy individuals, for example, endorsed biomedical management as the ideal coping style.

Within the Ghanaian context, however, two crucial issues emerged concerning diabetes experiences and illness action that required a broader analytical framework than that offered by the KABP approach. The first issue concerned the gap between medical logic and social logic and its impact on illness action and health promotion. The second concerned the complex interplay between psychological, socio-cultural, and material dimensions of diabetes experiences.

Systematic assessment of the modalities of knowledge produced and drawn on by people with diabetes, lay health individuals and health professionals highlighted three problematic dimensions of knowledge exchange and use between biomedical and lay groups. First, a clear distinction emerged between the functions of practical (scientized) and technical (scientific) biomedical knowledge for illness action. Practical biomedical knowledge was central to everyday illness practices, technical knowledge was peripheral. However, poor biomedical communicative practices undermined adequate dissemination of practical biomedical knowledge within the public sphere. The vacuum created was filled by ethnomedical and faith healer perspectives, as well as lay use of second-hand health information. A minority of educated participants accessed technical knowledge. In the absence of comprehensive information about diabetes, for example, circulating ideas of other conditions were drawn on to make sense of diabetes symptoms. This led, notably, to AIDS labelling and ostracism of people living with uncontrolled diabetes. The social representation of diabetes as a sugar disease emerged through a combination of inadequate biomedical discursive practices, professional rivalries with ethnomedical groups, professional disinterest in faith healer practices and broader disengagement with health risk factors dominating lay discourse.

The third social representation – of diabetes as a life-changing or life-threatening disease – captured the complex interrelationship between the psychological, socio-cultural and material context of diabetes experience. Core to this was body-self and emotional disruption. While levels of material and social support set clear divisions between people living with controlled diabetes and those living with increasing uncontrolled diabetes, or between people coping well

with diabetes and those who were not, body-self and emotional disruption was common to all diabetes experiences. Interview narratives highlighted the ways emotional responses to body-self disruption underpinned passive cure-seeking not only among low-income groups unable to afford biomedical care, but also among wealthy people with diabetes. Ethnographies demonstrated the ways body-self and emotional disruption undermined the quality of life for both people with diabetes and their caregivers. For the person with diabetes this led to greater dependency on caregivers for socio-economic, physical and emotional support. Caregivers were faced with life-restricting economic, physical and psycho-emotional burdens.

These processes were intricately linked and mutually influential. The factors underpinning illness inaction and its consequences for sufferers and caregivers demonstrated this clearly. The dynamics of illness inaction also demonstrated that material support, for low-income groups, constituted a fundamental non-negotiable need. Without material support “meanings as significance” (Bury, 1982), ceased to embody abstract questions about one’s life, death and the unknown, but lived certainties about one’s (often prayed for) impending mortality.

IMPROVING DIABETES CARE IN GHANA: CRITICAL CONSIDERATIONS

A hierarchy of needs for people with diabetes, as well as lay healthy individuals and pluralistic medical groups were identified. Availability of affordable drugs and good quality food, and psychosocial support constituted crucial needs for people with diabetes. Dovetailing into broader issues of quality and continuity of care for people with diabetes was the need for lay and professional education and attention to structural deficiencies.

Synthesis highlighted participatory work that could be carried out through ‘productive alliances’ between people with diabetes and biomedical groups in the areas of professional and public education, and psychosocial support. The critical mediating role of self-help groups was underscored in this process. However urgent requirements such as affordable drugs and quality food could not be feasibly addressed within the context of current information. Without drugs

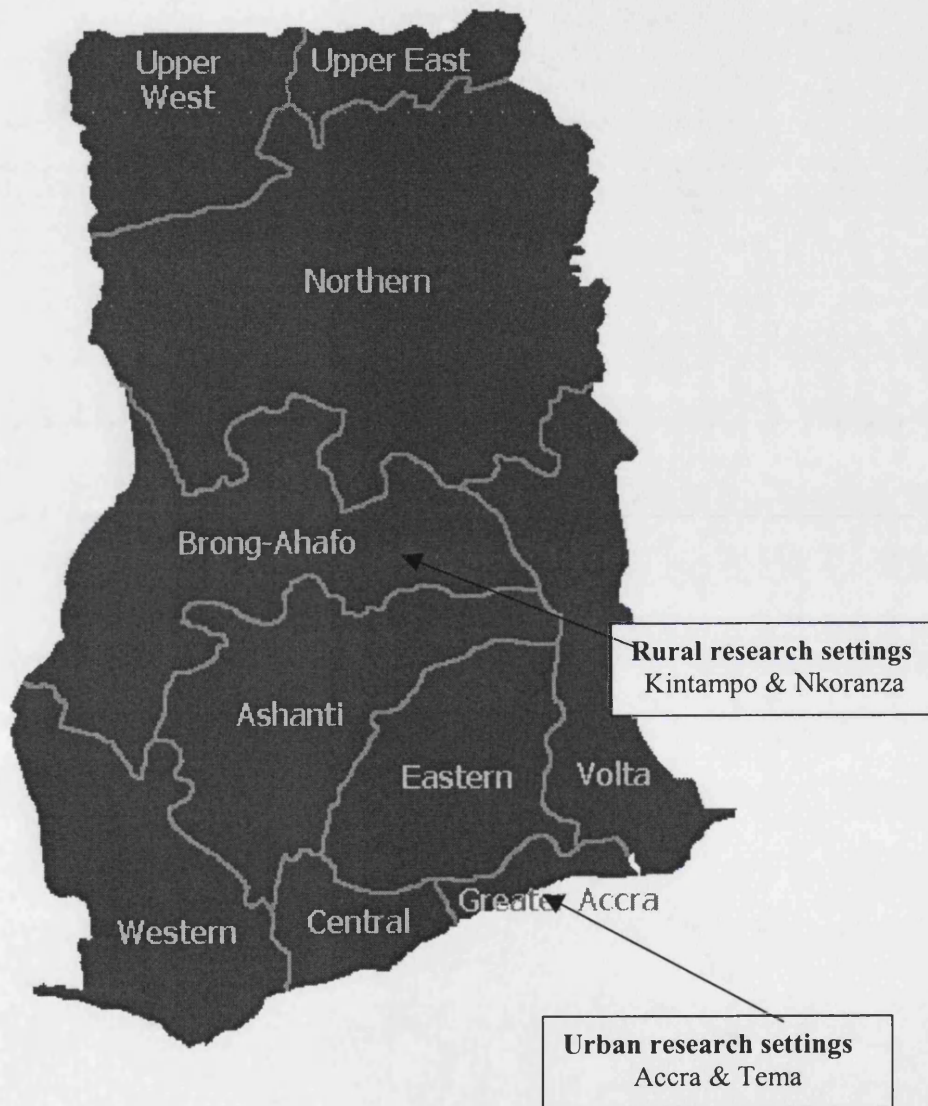
and healthy diets, low-income (mainly rural) people with diabetes face the risk of uncontrolled diabetes and the threat of disability and death.

This finding highlights the tough barriers that face development and implementation of long-term health intervention projects within economically deprived healthcare systems. Social psychological perspectives on participation in low-income countries stress that to improve life circumstances of socially excluded or marginalised groups, critical attention has to be paid to the integrated ways in which social identities, different versions of local knowledge and material and symbolic power relations mediate community determinants of health (Campbell and Jovchelovitch, 2000; de Freitas, 2000; Guareschi and Jovchelovitch, 2004). The importance of empowering local groups is strongly advocated in participatory work with chronic illness and other long-term conditions: this body of work suggests that national and international donor participation that bypasses state and institutional facilitation and engage directly with people in need, has the best chance of long-term success (Krause, 2003; Cornish, 2004). The ways in which these ideas can be incorporated in future work have been discussed. To improve quality and continuity of diabetes care in Ghana these critical socio-psychological and material requirements must frame the context within which conceptual, policy, and intervention development take place.

APPENDICES

**APPENDIX A: MAPS OF GHANA SHOWING DEMARCATIONS OF
REGIONS, ETHNIC/LANGUAGE GROUPS AND RESEARCH SETTINGS**

GHANA: MAP OF ADMINISTRATIVE DIVISIONS



GHANA: DISTRIBUTION OF ETHNIC GROUPS/ LANGUAGES



In the shaded territory mainly Akan is spoken.

APPENDIX B: INTERVIEW GUIDES

Appendix B1: Interview Guide – Expert Informants

1. Background

1.1. Professional history

Prompts: Position in organisation/facility, length of service, speciality/area of expertise.

2. Diabetes [all participants]

2.1. General health concerns at national/regional/district level (what diseases cause the most/least concern, which health problems are assuming importance?)

2.2. The problem of diabetes at national/regional/district level?

Prompts: explore prevalence issues, public health education, illness seeking practices.

2.3. The management of diabetes and complications of diabetes at national (regional, district, facility) level?

2.4. Public perceptions and attitudes towards diabetes?

2.5.. Public perceptions and attitudes towards chronic illness in general?

2.6. General patterns for people seeking medical help?

2.7 How accessible is health care generally and for diabetic individuals specifically?

Prompt: urban/rural, across type of facility.

3. Roles of different organizations and relationship to diabetes care

3.1. GHS: health research/policy

3.2. TAMD/CSRIPM/GNATH: ethnomedicine and medical pluralism

3.3. GDA: clinical management, psychosocial support, public education.

Appendix B2: Individual and Group Interview Guide – People with diabetes

Introduction: – Identity and role of interviewer, general aims of research and role of participant in the process, issues of confidentiality, data access and ownership.

1. General Life History

1.1. Could you tell me a little bit about yourself?

Prompts: Age

Educational status

Economic status (occupation)

Family profile (marital status, number of children and/or extended family members in household)

Explore social dynamics (social activities, friends, other status)

2. Diabetes

2.1. I would like us to discuss your diabetes. Can you recount how the illness started?

Prompts: How did you first notice that ‘something was wrong’?

How did you discover it was diabetes?

Did you know about diabetes prior to your getting the illness?

Why do you think you got diabetes?

What causes diabetes?

Do you think diabetes is infectious/contagious? Why? / Why not?

Which group of people are most likely to get diabetes and why?

2.2. At which stage of your illness did you seek medical treatment?

Prompts: If at late stage, what were reasons for waiting?

What concerns or expectations did you have with respect to the illness and its treatment?

Who/what influenced your decision to seek medical treatment?

2.3. Did you try alternative forms of treatment before you sought medical treatment?

Prompts: What/who influenced the decision to try alternative forms of treatment?

What sorts of treatments did you try?

Were these treatments successful or unsuccessful?

2.4 What was your immediate reaction when you were diagnosed with diabetes?

Prompts: Were you worried? Did you believe the diagnosis?

How did you feel about the life long nature of the illness?

2.5. How do you feel about your diabetes now?

Prompts: Have you adjusted to the condition?

How do you cope with medical label?
How do you cope with managing regimens?
How have you adapted to the physical discomfort of the illness?
What is like to make routine visits for medical care?
Do you feel adequate health services are available to you
How do health professionals and others perceive or treat you?

2.6. Let's talk a bit now about your support system.

Prompts: Does your family know you have diabetes? What has been their response?

Do your friends know you have diabetes? What has been their response to this?

Does your employer know you have diabetes? What has been their response to this?

Do you have a support system (family friends who help you manage your diabetes)

What kinds of ideas or beliefs do people around you (in your neighbourhood / village / town) have about your illness?

2.7. How has diabetes made an impact on your everyday life?

Prompts: Has the illness affected your diet?

Has the illness affected your social life?

Has diabetes affected your economic situation?

Have you had to make lifestyle changes?

Have you experienced any other problems as a result of your diabetes?

How often do you think about your illness?

What strategies do you use to simply 'get by' on a daily basis?

2.8. Do you think diabetes is a life threatening illness?

Prompts: What are some of the complications that could result from diabetes?

Which of these complications do you think are most threatening to your health?

Can these complications be prevented and how?

Have you had any complications yet?

2.9. Let's now focus on prevention. How can one avoid getting diabetes?

Prompts: What advice would you give to others to prevent getting diabetes?

Do you think or believe you could have avoided getting diabetes?

What would you have changed in your life if you had had the chance?

2.10. Could we talk a bit about your experience of diabetes treatment? What kind/kinds of treatment do you use for your diabetes?

Prompts: Do you use biomedical treatment?

Do you use herbal medications?

Do you use spiritual treatment (church, traditional religious healer)?

What about other home and/or traditional remedies?

2.11. If you were advising a friend to seek treatment for diabetes what would you advise them to do?

Prompt: Explore reasons for any order of treatment chosen.

3. Chronic illness

3.1. How would you define chronic illness? (explore causes)

3.2. What types of chronic illness do you know? Can you describe any of these illnesses?

Prompt: with names – hypertension, asthma, arthritis, epilepsy, sickle cell, cancer, etc.

(When list is obtained conduct sorting exercise to grade most severe – least severe illness, on a scale of 1 to 10, 1 being least severe, 10 being most severe)

Explore: why illnesses have been graded the way they have been.

3.3. Do you live with any of these illnesses?

3.4. Where would you place diabetes (on the grading scale) in relation to your experience of diabetes and other conditions you live with (or conditions you know about)?

3.5. What group of people are most likely to get chronic illness and why?

3.6. Can chronic illness be cured? (Explore reasons)

3.7. What is the best treatment for chronic illness? (Explore opinion of traditional vs biomedicine in treating chronic illness or spiritual/psychological/physical forms of treatment)

3.8. What kinds of ideas or beliefs do people around you (in your neighbourhood / village / town) have about chronic illness?

4. Medical Pluralism

4.1. Which one of these treatment methods would you use if you were ill?

- (1) Mobile herbalist with cure-all medicines
- (2) Specialist traditional healer group practice using modern methods
- (3) Traditional religious healer
- (4) Medical centre which uses scientifically tested herbal drugs (e.g Mampong Centre)
- (5) Health post or clinic or hospital
- (6) Foreign versions of traditional medicine (Chinese herbal, acupuncture, chiropractic)
- (7) Religious/spiritual healing (prayer camp, regular church, private prayer)
- (8) Home remedies (bitter leaf, bitters, other)

(Explore reasons given for choices – what influences choices? Type of illness? Treatment offered? A mixture of both? Which preferred? Which trusted? Which have benefits? Which don't.)

5. Perceptions of health and illness

5.1. Generally how would you define health?

5.2. Would you say you were in good or bad health generally? What are your major problems (apart from diabetes)?

5.3. What do you normally do to keep healthy or to avoid being ill in everyday life?

Prompts: food as prevention and treatment

Smoking, exercise, medical check-ups

Holistic health/lifestyle

5.4. What would you define as illness?

5.5. What would you say causes illness?

Prompts: Physical, Psychological, Spiritual factors / examples.

5.6. Can one do anything at all to prevent illness?

6. Other issues raised by participants or highlighted during discussion / Question and Answer session/ Wrap up, Thank yous and remuneration.

Appendix B3: Individual Interview Guide – Family members and close associates of diabetes sufferers

Introduction: – Identity and role of interviewer, general aims of research and role of participant in the process, issues of confidentiality, data access and ownership.

1. General Life History

1.1. Could you tell me a little bit about yourself?

Prompts: Age; Educational status; Economic status (occupation) etc

2. Diabetes

2.1. I would like us to discuss your (relative's/friend's) diabetes. Can you recount how the illness started?

Prompts: How did you first notice that something was wrong?

Why do you think your relative got diabetes?

Which group of people are most likely to get diabetes and why?

2.2. At which stage of your (relative's/friend's) illness did he/she seek medical treatment?

2.3. What or who influenced the decision to seek medical treatment?

2.4. Did your (relative) try alternative forms of treatment before he/she sought medical treatment?

Prompts: What/who influenced the decision to try alternative forms of treatment?

What sorts of treatments did he/she try?

Were these treatments successful or unsuccessful?

2.5 How did you feel when your (relative) was diagnosed with diabetes?

Prompts: Were you worried? Did you believe the diagnosis? Why? / Why not?

How did you feel about the life long nature of the illness?

2.6. How do you feel about your (relative's) diabetes now?

Prompts: Have you adjusted to the condition/situation or not? Why?

Is there a support system for your relative? (explore – carers and their roles)

How do you feel about the lifelong nature of the illness now?

2.7. How has your relative's diabetes made an impact on your everyday life?

Prompts: Has the illness affected your family?

Has the illness affected your social life?

Has diabetes affected your economic situation?

Have you had to make lifestyle changes?

Have you experienced any other problems (health, career etc) as a result of your relative's diabetes?

2.8. How do you cope as your relative's carer?

Prompts: Economic, physical, emotional dimensions. Do you cope well or not? Explore reasons.

Relationship with healthcare providers.

2.9. Do you think diabetes is a life threatening illness?

Prompts: In what ways is it so?

What are some of the complications that could result from diabetes?

Which of these complications do you think are most threatening to your relative's health?

Can these complications be prevented and how?

Has your relative had any complications yet?

2.10. Let's now focus on prevention. How can one avoid getting diabetes?

Prompts: What advice would you give to others to prevent getting diabetes?

Do you think or believe your relative could have avoided getting diabetes?

2.11. Could we talk a bit about your relative's current experience of diabetes treatment? What kind/kinds of treatment does he/she use for his/her diabetes?

Prompts: Do he/she use biomedical treatment?

Do he/she use herbal medications?

Do he/she use spiritual treatment (church, traditional religion)?

What about other home and/or traditional remedies?

What are his/her/your reasons for using alternative medicine?

2.12. Could you talk about your relative's experience of using these forms of treatment?

Prompts: What kind or kinds of treatment have been effective for controlling his/her diabetes?

What kind or kinds of treatment does he/she prefer? Why?

What kind or kinds of treatment do you prefer?

List of positives and/or negatives of each form of treatment.

2.13. If you were advising a friend to seek treatment for diabetes what would you advise them to do?

Prompt: Explore reasons for any order of treatment chosen.

2.14. What kinds of ideas or beliefs do people around you (in your neighbourhood / village / town) have about diabetes?

2.15. Does this affect the way you and your relative handle his/her experience of diabetes?

3. Chronic illness – General

3.1 How would you define chronic illness?

3.2 What types of chronic illness do you know? Can you describe any of these illnesses?

Prompt: with names – hypertension, asthma, arthritis, epilepsy, sickle cell, cancer, etc.

(When list is obtained conduct sorting exercise to grade most severe – least severe illness, on a scale of 1 to 10, 1 being least severe, 10 being most severe)

Explore: why illnesses have been graded the way they have been.

3.3 Where would you place diabetes on this scale?

3.4 Are any of these illnesses contagious? (are chronic illnesses in general contagious?)

3.5 What causes chronic illness?

3.6 What group of people are most likely to get chronic illness and why?

3.7 Can chronic illness be cured? (Explore reasons)

3.8. What is the best treatment for chronic illness? (use categories generated in Q4 to explore treatment options.)

3.9. Apart from your relative with diabetes do you have another relative or friend who lives with a chronic illness? (Have you cared for someone else with a chronic illness)? Which illness does your relative/friend have? (Explore experiences of those who respond yes)

3.10. What kinds of ideas or beliefs do people around you (in your neighbourhood / village / town) have about chronic illness?

4. Medical pluralism

4.1. Which one of these doctors or healers or centres or treatment methods would you try if you were ill?

- (1) advertising traditional healer with a cure for every illness
- (2) a specialist traditional healer group practice using modern methods
- (3) a fetish shrine
- (4) a medical centre which uses scientifically tested herbal drugs
- (5) a health post or clinic or hospital
- (6) foreign versions of traditional medicine (Chinese herbal, acupuncture, chiropractic)
- (7) religious/spiritual healing (prayer camp, regular church, private prayer)
- (8) Home remedies (bitter leaf, bitters, other)

(Explore reasons given for choices – what influences choices? Type of illness? Treatment offered? A mixture of both? Which preferred? Which trusted? Which have benefits? Which don't.)

5. Perceptions of health and illness

5.1. How would you define health?

5.2. Would you say you were in good or bad health generally? What are your major problems?

5.3. What do you normally do to keep healthy or to avoid being ill in everyday life?

Prompts: food as prevention and treatment

Smoking, exercise, medical check-ups

Holistic health/lifestyle

5.4. How would you define illness?

5.5. What would you say causes illness?

Prompts: Physical, Psychological, Spiritual factors / examples.

5.6. Can one do anything at all to prevent illness?

5.7. What do you do when you fall ill?

Prompts: Explore knowledge of different kinds of illness (acute/chronic/other)

Reaction / response to illness according to severity/ perceived aetiology

Health seeking practices / behaviour

Healing

5.8. In general would you say that people are healthier now than in your parents' time (a generation ago)? Why/why not?

6. Closing/ General Issues as raised by participant / Question and answer

Appendix B4: Group Interview Guide – Lay individuals

Introduction: – Identity and role of interviewer, general aims of research and role of participant in the process, issues of confidentiality, data access and ownership.

1. General Life History

(focus on name, age and hometown/residence of each participant)

Other demographic details (educational status, occupation, family profile) filled in forms at the end of discussion.

2. Health Beliefs and Related Practices

2.1. Generally how would you define health?

2.2. Would you say you were in good or bad health generally? What are your major problems?

2.3. What do you normally do to keep healthy or to avoid being ill in everyday life?

Prompts: food as prevention and treatment; smoking, exercise, medical check-up;

2.4. How would you define as illness?

2.5. What would you say causes illness?

Prompts: Physical, Psychological, Spiritual factors - examples.

2.6. Can one do anything at all to prevent illness?

2.7. Generally, what do you do when you fall ill?

Prompts: Explore knowledge of different kinds of illness (acute/chronic/other)

Reaction / response to illness according to severity/ perceived aetiology

Health seeking practices / behaviour

2.8. In general would you say that people are healthier now than in your parents' time (a generation ago)? Why/why not?

3. Medical pluralism

3.1. Which one of these health practitioners, centres or treatment methods would you access if you were ill?

(1) advertising traditional healer with a cure for every illness

(2) a specialist traditional healer group practice using modern methods

(3) a traditional religious practice

(4) a medical centre which uses scientifically tested herbal drugs

(5) a health post or clinic or hospital

- (6) foreign versions of traditional medicine (Chinese herbal, acupuncture, chiropractic)
- (7) religious/spiritual healing (prayer camp, regular church, private prayer)
- (8) Home remedies (bitter leaf, bitters, other)

(Explore reasons given for choices – what influences choices? Type of illness? Treatment offered? A mixture of both? Which preferred? Which trusted? Which have benefits? Which don't.)

4. Health services experiences and public health education

4.1. When you are ill, do you feel you have adequate health services available to you?

Prompts: Accessibility (geographical, economic)

Health professional (doctor/nurse/traditional healer) – patient relationship

4.2. Where / who do you obtain your health related information from?

Prompts: Family/friends

Health professionals

Media (papers, radio, tv)

Other sources

5. Vignette (on diabetes – based on common diabetes education themes)

(We will recite a story after which we shall ask questions based on the contents. If any of you do not hear or understand parts of it, please let us know and we will reread/recite it)

V1

There is a woman/man who lives down the road from you. She/he has always been a hard worker, she/he goes to the farm regularly and sells foodstuffs and provisions outside her house when she is not at the farm /works as a tailor when he is not at the farm. Lately she/he has lost a lot of weight and complains of being tired all the time. She/he confides in you and says she/he is always thirsty and keeps drinking huge amounts of water. She/he has also been urinating a lot, waking up as much as five times a night to urinate. She/he has observed that ants gather round her/his urine when she/he urinates outside. But what she/he is worried about most is her/his eyesight. She/he can only see things that are very close to her/him; far away things or people at a far distance seem to be a blur. She/he doesn't know what to do, because nobody in her/his family has experienced these sorts of problems.

Q1. What is the problem of the person described here?

Q2. Do you know somebody who has such problems?

Q3. What would you do if a member of your family had a problem like this?

Q4. What would your neighbours think about your family?

Q5. What treatment would you advice?

6. Chronic illness

6.1. How would you define chronic illness? What causes chronic illness?

6.2. What types of chronic illness do you know? Can you describe any of these illnesses?

Prompt: with names – hypertension, asthma, arthritis, epilepsy, sickle cell, cancer, etc.

(When list is obtained conduct sorting exercise to grade most severe – least severe illness, on a scale of 1 to 10, 1 being least severe, 10 being most severe)

Explore: why illnesses have been graded the way they have been.

6.3. Are any of these illnesses contagious? (are chronic illnesses in general contagious?)

6.4. What group of people are most likely to get chronic illness and why?

6.5. Can chronic illness be cured? (Explore reasons)

6.6. What is the best treatment for chronic illness? (use categories in Q.3 to explore treatment options)

6.7. Do you have a friend or relative who lives with a chronic illness? (Have you cared for someone with a chronic illness)? Which illness does your relative/friend have? (Explore experiences of those who respond yes)

6.8. What kinds of ideas or beliefs do people around you (in your neighbourhood / village / town) have about chronic illness?

7. General Issues as raised by participants /Question and Answer session / Wrap up.

Appendix B5: Interview Guide – Health Professionals

Introduction – Identity and role of interviewer, general aims of research and role of participant in the process, issues of confidentiality, data access and ownership.

1. General History

Can you tell me a little about yourself?

Can you tell me a little about your work history / specialities?

2. Perceptions of health and illness

2.1. Generally how would you define health?

2.2. What can one do to keep healthy or avoid being ill in everyday life?

2.3. How would you define illness?

2.4. What would you say causes illness?

2.5. Can one do anything at all to prevent illness?

2.6. How do you treat conditions that are presented to your practice?

3. Diabetes

3.1. Can we discuss diabetes in general terms? What is diabetes?

3.2. Let's talk about prevention. Can diabetes / complications of diabetes be prevented?

3.3. Do you have any special training in diabetes treatment and management?

3.4. Could you describe the characteristics of patients who usually suffer from diabetes?

3.5. Could you tell me about how patients present with diabetes for the first time?

3.6. Can you tell me about the reaction of patients when they are first diagnosed with diabetes?

3.7. Can we talk about how you deal with cases? How would you treat a 'typical' diabetes case?

3.8. Would you say you were successful at treating diabetes?

3.9. What are the factors that enhance successful treatment?

3.10. What are the factors that undermine successful treatment?

3.11. How do you deal with problems like non-compliance? What are the underlying reasons for non-compliance?

4. Perceptions of in-group practice and out-group practice

4.1. What is your opinion of ethnomedicine/biomedicine/faith healing?

4.2. What are the differences and/or similarities between ethnomedicine/biomedicine/faith healing?

4.4. Can you think of any conditions best treated within ethnomedicine/biomedicine/faith healing?

4.5. What are the benefits of using ethnomedicine / biomedicine/faith healing?

4.6. Are there other professional or personal health options for lay people and people with diabetes. (Explore using 8 categories generated for lay people and people with diabetes)

APPENDIX C: PARTICIPANT PROFILES

Table 1. Group interviews with people with diabetes

Table 1a. Demographic details of rural and urban male groups (N=22)

	Participant	Age	Educational status	Occupation
KINTAMPO	01	69	Secondary	Retired MOH employee
	02	63	Primary	Retired army serviceman
	03	62	Primary	Retired tailor/active farmer
	04	60	Tertiary	Retired teacher/businessman
	05	51	None	Farmer
	06	28	Secondary	Policeman
	07	26	Secondary	Shoemaker
NKORANZA	01	85	None	Farmer
	02	71	Primary	Rtd Public health worker
	03	71	None	Farmer
	04	70	None	Farmer
	05	64	None	Farmer
	06	62	Primary	Rt'd purchasing clerk
	07	60	Tertiary	Rtd teacher
	08	51	None	Farmer
ACCRA SETTING	01	69	None	Retired (former job unspecified)
	02	65	Tertiary	Retired civil servant
	03	54	Tertiary	Business man
	04	53	Secondary	Farmer
	05	45	Secondary	Bank Clerk
	06	41	Secondary	Mechanic
	07	39	Tertiary	Civil servant

Table 1b. Demographic details of rural and urban female diabetes group (N=22)

	Participant	Age	Educational status	Occupation
KINTAMPO	01	55	None	Farmer
	02	55	Secondary	Petty trader
	03	50	Primary	Market trader
	04	42	Primary	Market trader
	05	41	Secondary	Soap maker
NKORANZA	01	65	None	Trader
	02	60	None	Unemployed
	03	60	None	Trader
	04	60	None	Farmer
	05	60	None	Farmer
	06	60	None	Farmer
	07	54	Primary	Trader
	08	56	None	Farmer
	09	42	Primary	Unemployed
ACCRA SETTING	01	65	Secondary	Business woman
	02	64	Secondary	Retired
	03	60	Primary	Market trader
	04	56	Tertiary	Teacher
	05	56	Secondary	Baker
	06	45	Secondary	Business woman
	07	42	Tertiary	Civil servant
	08	39	Primary school	Market trader

Table 2. Rural and urban individual interviews with people with diabetes (N=20)

Table 2a. Demographic details of urban and rural male interviewees (N=11)

		Participant	Age	Educational status	Occupation
RURAL SETTING	Kint. setting	01	56	Secondary	Farmer
		02	35	Secondary	Farmer
	Nk. setting	03	28	Secondary	Farmer
		04	46	Secondary	Receptionist
URBAN SETTING	ACCRA	01	65	Tertiary (post doc)	Economist
		02	64	Tertiary (post grad)	Accountant
		03	63	Tertiary	Rt'd civil servant
		04	56	Tertiary	Company owner
		05	31	Secondary	Driver
	TEMA	06	76	Tertiary	Retired diplomat
		07	73	Tertiary (post doc)	Retired biochemist

Table 2b. Demographic details of rural and urban female interviewees (N=9)

		Participant	Age	Educational status	Occupation
RURAL SETTING	KINTA MPO	01	73	None	Farmer
		02	64	None	Farmer
	NKORANZA	03	74	None	Retired farmer
		04	45	None	Unemployed
		05	21	Secondary (vocational)	Student
		06	30s	Primary	Baker
URBAN SETTING	ACCRA	01	64	Primary	None
		02	35	Secondary	Businesswoman
	TEMA	03	65	Tertiary	Rt'd teacher / trader

Table 3. Demographic details of ethnography participants (N14)

Life-world	Participant profile
URBAN: John [diabetes duration: 8yrs]	John , 56; secondary educated; retired servicemen; Diane , wife; 60; secondary educated; retired bank clerk; primary carer Hannah , daughter; 30; university educated; teacher; carer; Patricia , Diane’s sister; 50s; education/employment status unspecified Charles , son; early 20s ; secondary educated ; apprentice ‘technician’ ; carer Patrick , family friend; 30s; lay preacher
RURAL GROUP 1: Maame Efua [diabetes duration: 8yrs]	Maame-Efua, 70yrs; no formal education; [retired trader/bar owner] Alice; daughter, 32; secondary educated; hairdresser; primary carer Grace; daughter; late 30s; college/university educated; teacher; carer
RURAL GROUP 2: Ruth [diabetes duration: 6yrs]	Ruth, 50yrs; no formal education; food hawker. Adjoa, daughter, 29, trader; primary carer Cynthia, cousin, 40; teacher; occasional carer George ; family friend, 50s; self-help group secretary Jane; neighbour; 50s; unemployed; self-help group member

Table 4. Group Interviews with healthy lay individuals

Table 4a. Demographic detail of rural and urban young lay groups (N=23)

	Participant	Gender	Age	Educational status	Occupation
KINTAMPO	01	Female	35	Secondary	Farmer
	02	Male	35	Secondary	Farmer
	03	Male	32	Secondary	Farmer
	04	Male	30	Secondary	Mason
	05	Female	29	Primary	Seamstress
	06	Male	28	Secondary	Farmer
	07	Female	22	Secondary	Farmer
NKORANZA	01	Male	28	None	Electrician
	02	Male	26	Junior secondary	Driver
	03	female	26	Junior secondary	Carpenter
	04	Female	25	Junior secondary	Tailor
	05	Male	25	Junior secondary	Trader
	06	Female	25	Secondary	Market trader
	07	Male	25	Senior secondary	Trader
	08	Male	24	Secondary	Trader
	09	Female	23	Junior secondary	Hairdresser
ACCRA	01	Male	27	Tertiary	Teacher
	02	Male	27	Tertiary	Teacher
	03	Female	24	Tertiary	Teacher
	04	Male	24	Tertiary	Postgrad Student
	05	Female	23	Tertiary	Business
	06	Male	22	Tertiary	Undergrad. Student
	07	Female	20	Secondary	Customer relations officer

Table 4b. Demographic details of rural and urban middle-aged group (N= 28)

	Participant	Gender	Age	Educational status	Occupation
KINTAMPO	01	Male	60	Secondary	Farmer
	02	Male	53	Secondary	Farmer
	03	Male	52	Tertiary	Teacher
	04	Female	51	Tertiary	Teacher
	05	Female	50	Primary	Trader
	06	Male	45	Primary	Mechanic
	07	Female	45	None	Petty trader
	08	Female	44	None	Farmer
	09	Male	40	Secondary	MOA supervisor
NKORANZA	01	Male	63	Secondary	Retired
	02	Female	60	None	Farmer
	03	Female	56	None	Farmer
	04	Male	55	None	Mason
	05	Male	54	Secondary	Farmer
	06	Male	46	Tertiary	Teacher
	07	Female	45	Secondary	Seamstress
	08	Male	45	None	Farmer
	09	Female	45	Secondary	Trader
	10	Male	45	Secondary	Painter
	11	Male	43	Secondary	Farmer
ACCRA	01	Male	64	Tertiary	Banker
	02	Female	64	Secondary	Business woman
	03	Female	62	Tertiary	Civil servant
	04	Male	59	Tertiary	Accountant
	05	Male	58	Secondary	Business man
	06	Female	54	Tertiary	Teacher
	07	Male	50	Secondary	Store supervisor
	08	Female	49	Secondary	Artisan

Table 5. Demographic details of expert informants and health professionals

Table 5a. Demographic details of expert informants (N=11)

Setting	Areas of Expertise			
	National / Regional Healthcare	'Collaborative health model'	Ethnomedicine	Diabetes care
Urban	UEI1, deputy head, Ghana Health Service, doctor, male, 50s	UEI2, deputy head, TAMD, sociologist, male, 40s	UEI4, president, GNATH, practising herbalist, male, 50s	UEI6, head of GDA, consultant endocrinologist, male, 40s
		UEI3, deputy head CSRIPM, biochemist, male, 40s	UEI5, secretary, GNATH, practising herbalist, male, 60s	UEI7, secretary of the GDA (Accra Branch), male, 70s
Rural	REI1, Regional health services administrator practising hospital doctor, male, 40s	N/A	REI3, secretary BA regional branch of GNATH.	RE4, secretary, Nkoranza branch of GDA, male, 50s
	REI2, Secretary, Nkoranza health insurance scheme, civil servant, male, 40s			

Table 5b. Demographic details of health practitioners (N=23)

Settings	Biomedical Practitioners		Ethnomedical Practitioners		
	Doctors	Nurses	Modernised practitioners	Traditional practitioners	Faith healers
URBAN [Accra]	UD01, male consultant, KBTH, 40s.	UN01, female Matron, KBTH, 40s.	UH01, male herbalist, 50s	UH03, male herbalist, 60s	UFH01, male faith healer, 30s
	UD02, male houseman, KBTH, 30s.		UH02, male herbalist, 60s		
	UD03, male GP, CSRIPM, 60s.		UH04, male herbalist, 40s		
	UD04, male GP, private practice, 50s.				
RURAL [Nkoranza [Kintampo]	RD01, male medical administrator, St Theresa's, 40s.	RN01, female Matron, St Theresa's, 40s.	RH01, male herbalist, 50s	RH04, male fetish priest of inherited shrine, 30s	RFH01, male, 30s
			RH02, male herbalist, 40s		RFH02, male, 50s
	RD02, male medical administrator, KGH, 40s		RH03, male herbalist, 40s		RFH03, male, 30s
		RH04, male herbalist, 30s		RFH04, male 30s	RFH05, male 30s

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