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Reframing applied disease stigma research: a multilevel analysis of diabetes stigma in Ghana.

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Reframing Applied Disease Stigma Research: A Multilevel Analysis of Diabetes Stigma in Ghana

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ABSTRACT

Research suggests that rural and urban Ghanaians living with uncontrolled diabetes—typified by extreme weight loss—experience HIV/AIDS-related stigma. This paper reports a multilevel analysis of this stigma within the broader context of diabetes handicap in two rural communities. Two key findings emerge. First, the content of stigma constitutes social representations of HIV/AIDS, and to internalized and projected collective attributions of protracted illness to witchcraft or sorcery. Thus the stigma experienced by people with uncontrolled diabetes is not specific to the disease category 'diabetes' and distant others affected by it. Second, extreme biophysical disruption, which precipitates misperceptions, stigma and/or discrimination, is both cause and consequence of financial destitution and psychosocial neglect. Both forms of handicap have deeper pre-stigma roots in poverty and the socio-psychological and cultural impact of long-term illness. Thus the actuality or threat of diabetes stigma has to be understood in terms of diabetes handicap, which in turn has to be understood as a product of shared responses to long-term illness in communities constantly negotiating financial, health and psychological insecurities. The scope for multifaceted/multilevel intervention is considered taking into account the biophysical and psychological impact of illness and the socio-psychological and structural realities of diabetes care in Ghana. Copyright © 2006 John Wiley & Sons, Ltd.

Key words: biographical disruption; diabetes handicap; emotions; Ghana; HIV/AIDS-related stigma; multifaceted/multilevel intervention

INTRODUCTION

It is estimated that 6.3% (i.e. 1 197 000) of adult Ghanaians (15–70 years) have Type 2 diabetes (Amoah, Owusu, & Adjei, 2002). Due to structural inequalities (Amoah et al.), high cost of care (NCD Control Program, 2001), and high rates of biomedical

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non-adherance and healer-shopping[1] (Adubofuor, Ofei, Mensah-Adubofour, & Owusu, 1993; de-Graft Aikins, 2005; Ofei, Forson, & Appia-Kusi, 1996), this population lives with or risks uncontrolled diabetes. Uncontrolled diabetes leads to a range of reported medical complications including vision impairment and blindness, gangrene, heart disease, renal damage and kidney failure (Adubofuor et al.; NCD Control Program). In 2005, the Director-General of the Ghana Health Service (GHS) declared Type 2 diabetes the fourth leading cause of death.

Despite formal recognition of its public health significance, diabetes care is poor. General, specialist and advocacy services are concentrated in southern urban areas. Therefore, rural groups, especially those living in the country's middle-belt and northern regions, face greater risk of uncontrolled diabetes and premature death. Previous research suggests that groups living with severe uncontrolled diabetes—typified by prolonged weight loss—experience, or express fear of experiencing, HIV/AIDS-related stigma due to widespread attribution of prolonged weight loss to HIV/AIDS (de-Graft Aikins, 2003).

Aims

This paper reports multilevel analysis of disease stigma experienced by people with diabetes in two rural Ghanaian towns within the context of diabetes handicap. It aims to respond to the current call for disease stigma research that bridges the gap between micro-social and macro-social analyses. An adjunct aim is to consider the scope for developing anti-stigma intervention as part of a participatory community diabetes project, presented in greater detail elsewhere (de-Graft Aikins, submitted for publication).

Conceptual background and framework

Three themes dominate current discussions on applied disease stigma research. First researchers stress a need for moving beyond the concept of stigma as a fixed attribute that links individuals to negative stereotypes towards reconceptualising stigma as an asymmetric social process that devalues relationships (Alonzo & Reynolds, 1995; Link & Phelan, 2001; Parker & Aggleton, 2003). Second, multilevel analysis of stigma is advocated. There is consensus that stigma research takes two oppositional and isolated paths. The micro-social approach, typified by (social) psychological work, examines stigma at individual and inter-individual levels. Researchers focus on problematic attitudes, beliefs, feelings and behaviours of stigmatizers towards the stigmatized and to a lesser extent experiences of stigmatized groups: emphasis is placed on addressing individual ignorance through education or facilitating coping strategies through counselling. The macro-social approach, typified by sociological work, is concerned with group (social/cultural) and structural level analyses. Researchers underscore entrenched socio-cultural and structural mechanisms of power and dominance that create social difference and the mediating context for stigma and stigmatizing practices: interventions that facilitate macro-social change such as rights-based (e.g. human, legal)

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[1]Seeking eclectic treatment within and between health systems (chiefly biomedical, ethnomedical and faith healing in Ghana) without prior referral.

responses and community mobilization are advocated. Critics call for a synthesis of both approaches to facilitate comprehensive examination of the complex roots and consequences of stigma. Finally researchers recognize the need for appropriate anti-stigma interventions. Deacon, Stephney, & Prosalendis (2005: xii) observe 'a gap between the relatively large body of research on what stigma is and the relatively small body of research on what to do about it'. Link and Phelan (p. 377) note that stigma 'exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them' (p. 377). As such 'multifaceted multilevel intervention' is required to address 'the many mechanisms that can lead to disadvantaged outcomes, and ...issues of both individual and structural discrimination' (p. 381).

Taking these recommendations as an essential starting point, this study applies to a social psychological approach that takes the individual–society interface as a unit of analysis. This mode of analysis, adopted within research domains of social representations and identity (Markova, 2003) and community participation (Campbell & Jovchelovitch, 2000), focuses on the inter-relationships between individual, inter-individual, group (social/cultural) and structural level phenomena. It is guided by two concepts: disease stigma (Deacon et al., 2005) and biographical disruption (Bury, 1982).

Disease stigma.   Deacon et al. (2005: 85) make a distinction between symbolic stigma (or stigma) and disease stigma. Stigma refers to 'value-based ideology that imposes moral judgements on others to affirm the ingroup's safe and moral identity'. Disease stigma constitutes 'negative social "baggage" associated with a disease that . . . is not justified by the medical effects of disease on the human body'. While both are inter-related, the latter fixes attention on the physical and social consequences of disease: this is crucial for understanding chronic disease experiences and handicap and the place of stigma within these.

Biographical disruption.   Chronic illness causes bodily disruption and reshapes the sufferer's life circumstances and social relationships. On the one hand, individuals have to deal with physical symptoms and *impairments* (abnormality in the structure and functioning of the body due to disease or trauma) and/or *disabilities* (restricted activity and/or inability to perform everyday tasks including self-care) (Radley, 1994). Bodily disruption 'shatters assumptions' (Crossley, 2000) about the integrity of one's body and physical capabilities, and of one's identity and future. On the other hand, individuals have to (re)negotiate social roles and responsibilities. Impairments and disabilities become focal points around which (often contradictory) *self and societal* perceptions, attitudes, emotions and responses revolve, and are reshaped. This carries potential for *handicap*. Defined as the social disadvantage associated with either impairment or disability, handicap is both socially and psychologically mediated.

Bury's (1982) medical sociological concept of biographical disruption captures the disruption chronic illness causes to both the physical body and life trajectory of the chronically ill and to ensuing complex responses by sufferers, significant and generalized others. Bury (1997: 124) notes that defining chronic illness as a disruptive event 'allows for its meaning to be situated in a temporal and life-course context'. Two types of meaning are distinguished. 'Meaning as consequence' refers to interpretations ascribed to everyday practices of negotiating treatment and support within one's lifeworld, community and the medical sphere. 'Meaning as significance' constitutes the 'more metaphysical under-standings in terms of an individual's personal meanings of life, death and the unknown'

(Conrad, 1990: 126). Both practical and symbolic meanings are mutually constitutive and embedded in shared, but heterogeneous, ideas circulating within society about the body, health, illness, life and death. As an analytical construct, biographical disruption fixes attention to: (1) diabetes experiences and handicap and (2) shifting meanings, social relationships and practices within which diabetes experiences and handicap unfold. This allows disease stigma to be examined within the widest context.

RESEARCH DESIGN

Research communities

Kintampo and Nkoranza districts are located in the Brong Ahafo Region in the country's middle-belt. Each district is made up of a nucleus—Kintampo town, Nkoranza town—and a satellite of villages. Majority of village dwellers are small-scale farmers; townsfolk are typically traders and skilled manual workers, although many farm as a second occupation. Educational status ranges from no formal education to university educated; men have higher literacy rates compared to women. The majority ethnic group is Bono, an Akan group; a minority are of Northern Ghana descent. Religious affiliations include Christian, Islamic and traditional religions.

While both districts have access to biomedical, ethnomedical and faith healing services, some differences in medical care and socio-economic support were observed at the time of initial research (2000–2001). First, Nkoranza's St Theresa's Hospital is a Catholic mission facility, while Kintampo General Hospital is a government run facility. Mission facilities have better resources and consistently out-perform state-run public facilities: for example, five doctors catered for Nkoranza's population of 145, 906, while Kintampo (population 145 000) was served by one doctor. Second, community members had access to the Nkoranza Community Insurance Scheme which provided full cover for hospital care. Third, a diabetes self-help group set up jointly by the hospital's matron and pioneer group members provided an active space for education and social support. Kintampo lacked these resources.

Data collection and analysis

Data were gathered through interviews, focus group discussions and two ethnographies (in Nkoranza) with 43 people with diabetes, 6 caregivers/significant others and 36 lay community members. Boxes 1 and 2 provide summaries of rationale for methods and key interview areas.

Participant recruitment underscored diversity across gender (42 women; 43 men), age (21–85), education (none to tertiary level) and socio-economic status (e.g. unemployed, farmers, civil servants). Additional criteria for people with diabetes included differences in diabetes status (duration and modes of treatment) and experience of co-existing conditions (e.g. hypertension and asthma).

Interviews and discussions were conducted in Bono-Twi, recorded (with permission), transcribed and translated. Transcripts were coded using the qualitative analysis package Atlas-ti. Coding aimed to capture the range of views—consensus, conflict, absence—on the outlined empirical categories.

Box 1: Method aims and target participant groups

Method	Target participant group	Aim
Individual interviews	People with diabetes	Elicit biographical accounts of diabetes experiences
Group interviews	People with diabetes	Elicit accounts and meanings of shared diabetes experience
	Lay community members	Explore socio-cultural knowledge of and responses to chronic illness and diabetes
Ethnographies (incorporating multiple interviews, conversations and participant observation)	People with diabetes; caregivers; significant others	Observe, discuss and document social interactions and practices that shaped these inter-subjective worlds

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Box 2: Key areas explored in individual, group interviews and ethnographies

Biographical and demographic data.
Knowledge of general health and illness, chronic illness and diabetes.
Knowledge and use of medical pluralistic medical systems.
Diabetes experiences: impact of diabetes on everyday experiences, social and medical relationships.
Illness practices: the influence of knowledge, experience, relationships and material resources on illness practices.
Community and caregiver responses to people with diabetes.

RESULTS

Results are presented in two parts. I will present an ethnographic study of a middle-aged woman ('Ruth') living with uncontrolled diabetes and extreme handicap in Nkoranza. Using Ruth's experience as backdrop, I will then explore the multifaceted dimensions of diabetes stigma and handicap in the two towns. A key for presentation of quotes is provided in Box 3.

Box 3: Key for quotes

Italicized words	Bono Twi if difficult to translate to English; English, if segment of Bono narrative is in English.
Underlined words	Emphasis or emotional stress placed on words or expressions.
((words))	Words in double parentheses describe and explain local terms and phrases.

. . .   Omission of sentence segment.
[. . .]   Omission of one entire sentence
K, Kintampo; N, Nkoranza; II, Individual Interview; GI, Group interview; E2, 2nd Ethnography PWD, person/people with diabetes; LI, lay individual

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Part one: An ethnographic study of diabetes experience in Nkoranza

Box 4: Ruth's experience of stigma and diabetes handicap

Ruth lived with severe uncontrolled diabetes and chronic physical impairments: loss of appetite, severe weight loss, joint pains and body sores. This had a pervasive impact on her life. She was unable to carry out the simplest everyday chores and had had to abandon her previous job as a food hawker. In the early years, she had financial support from her extended (paternal) family—but she was on insulin, which was expensive, and gradually financial support had been withdrawn. Three caregivers were identified: an older daughter, Adjoa (29), widowed, with three children, all of whom lived with Ruth; a son who lived locally, visited rarely, but made her yearly insurance contributions; and a niece, Cynthia (40), a teacher, who helped financially when she could. Other forms of financial and social support came from sympathetic hospital staff and self-help group members.

Ruth and her family attributed her diabetes to a mix of diet, lifestyle and spiritual causes.

> 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]

> 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]

> **Ruth**: . . .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.

> **DY**: 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.

> **DY**: 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.

> **DY**: 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.

Ruth's inability to treat her diabetes had led to acute weight loss. For a middle-aged woman who prior to getting diabetes and prior to abandoning regular treatment had had a healthy body image (i.e. buxom in Akan cultural terms), 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]

Shock turned to community speculation and gossip that Ruth may have contracted AIDS. This AIDS label had two inter-related consequences. First, Ruth experienced disruption to her social relationships: she was shunned by her friends, taunted in the streets by school children and lost customers.

> **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 bar owner. . . I passed through her bar for some water, she didn't give me.

DY: She didn't even give you water?

Ruth: Yes she didn't give me. Because I would drink from her cup.

When I sent food to the school to sell, the children wouldn't buy, because the teacher told them I have HIV/AIDS. [Ruth]

Second, her family became 'tainted' with this identity: they lived with 'courtesy stigma' (Goffman, 1963/1990). 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 an alleged AIDS sufferer.

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.

O: Something like what?

Adjoa: Some people thought she had got AIDS. This perception hung over her and made people stop buying her rice water.

Ruth's relationship with her significant others was fraught with emotionally charged misunderstandings. Most unfolded within the context of Ruth's extreme physical deterioration and community perceptions to this. Misunderstandings were most acute between Ruth and Adjoa. Ruth was convinced that her family had abandoned her because they perceived her as either an AIDS sufferer or a witch.

I gave birth to twelve children, but there are only nine left. [. . .]. 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]

Contrary to Ruth's convictions, Adjoa did not refer to her mother either as an AIDS sufferer or a witch. The family had initially believed and feared community rumours that Ruth had AIDS–her partner abandoned her as a result–but their fear had dissipated when her diabetes status was confirmed. None of Ruth's caregivers referred to her as a witch. Adjoa did not cook regularly for her mother, because she could not afford to feed her entire family regularly.

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]

Adjoa's narratives suggested that she did experience and project conflicting emotional responses onto her mother's condition and that these 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. Even as Adjoa recognized the extent of her mother's impairments, she glossed over her disabilities. Thus she criticized Ruth's inability to carry out her duties as a grandmother (e.g. taking on baby-sitting duties) and her culturally inappropriate response to her condition (emotional disintegration rather than stoicism at misfortune).

. . . 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. [Adjoa]

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. [. . .]. 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]

Thus, on the one hand, Adjoa stressed her intention to provide support, and 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.

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, then we can come back and bury her. But I have second thoughts and then decide to stay and take care of her. [Adjoa]

In the past, Ruth had 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 was predominantly medically inactive. She was hospitalized once, due to complications: hospital costs were covered by her insurance. She had no money to buy food and ate when she received donations from community members and friends. However, she adopted three regular strategies to address some of the disruptions caused by diabetes. First she took—often unsafe—herbal tonics to regain physical strength. This activity was dependent on financial donations from friends and family. Second, she prayed and attended church regularly for spiritual support. She also attended self-help group meetings for advice and support.

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, self-help group member]

Ruth's interview narratives were dominated by despair at the extent and severity of the impact of diabetes to her life. She frequently cried during interviews. She prayed for death to end to her chronic suffering. 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.

Recently, I even thought of committing suicide by poisoning myself. [. . .] [. . .] 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. [Ruth]

Part two: Placing diabetes stigma and handicap within a multi-dimensional context

Ruth's experience of diabetes stigma resonated with other participants' accounts in two ways. First, the content of the stigma she experienced constituted social representations of HIV/AIDS and her internalized collective attributions of protracted illness to witchcraft. Second, her experience of extreme biophysical disruption, which precipitated misperceptions of her health status, stigma and discrimination, was both cause and consequence of broader chronic disease handicap, namely financial destitution and psychosocial neglect. I will limit attention to these shared experiences.

The socio-cultural context of 'diabetes stigma'. The stigma experienced by people with uncontrolled diabetes in Nkoranza and Kintampo was not specific to the disease category 'diabetes' or distant others affected by it. In both towns, disease or illness was defined as disruption to unique states of physical–psychological balance, termed here 'body-self disruption' (Helman, 2000: 14). Individual, social and supernatural factors were implicated in body-self disruption. Individual factors included unhealthy lifestyles (e.g. drinking and smoking); social factors included (economically driven) toxic farming practices; supernatural factors included witchcraft, sorcery or devil's action. Some supernatural factors were mediated through proximal social relationships: elderly female relatives were more likely to be labelled as witches; while sorcerers could be men or women of any age, they too were likely to be close friends and relatives. At another level, diseases were categorized as either traditional or contemporary. Traditional diseases (e.g. epilepsy) had well established historical roots in Ghanaian culture and were likely to be attributed to supernatural causes. Contemporary conditions (e.g. most chronic conditions and HIV/AIDS) were products of contemporary living, and for some Westernization. Contemporary conditions were more likely to be attributed to individual and social factors and presented for diagnosis and treatment within the biomedical sphere. However, in reality, chronic disease by its very severe prognosis in poor communities simultaneously evoked supernatural causal theories. Therefore, practical social responses to the biophysical course of chronic illness invariably co-existed with speculation and/or attributions of witchcraft or sorcery. The contents of diabetes stigma were products of these processes.

The production of diabetes stigma. Lay and pre-diagnosis diabetes knowledge was poor: prevailing ideas encompassed basic biomedical accounts of diabetes (as a sugar disease) and socio-cultural attributions of personal responsibility[2] (see Box 5). Generally, diabetes evoked public sympathy: as a contemporary chronic disease, liable to beset anyone, and only treatable in the expensive biomedical sphere, its potential for financial and psychosocial disruption was widely recognized.

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[2]For an exploratory grading exercise, incorporated into group discussions, participants generated a list of chronic conditions (primarily asthma, cancer, sickle-cell disease, diabetes, hypertension, rheumatism and AIDS) and evaluated these in terms of threat to sufferers' lives and level of contagiousness on a scale of 1–10, 1 being least life-threatening/contagious, 10 being most life-threatening/contagious. Participants had greater knowledge of highly prevalent conditions such as hypertension and conditions prioritized in health campaigns such as HIV/AIDS. AIDS and epilepsy received consistently high scores: they were seen as both life-threatening and contagious. AIDS also received high ratings because it was linked to immoral behaviour. Diabetes, on the other hand, averaged low scores.

Box 5: Sources and contents of diabetes knowledge			
	Content (& elements)	Spread of views	Sources
1	Diet *Sugar, starch, fat*	All groups	Biomedical sphere; community communication networks
2	Lifestyle (personal responsibility) *Disease of the rich; consequence of poor individual lifestyle practices (drinking, smoking, etc)*	All groups	Biomedical sphere; cultural beliefs; community communication networks
3	Heredity	People with diabetes	Biomedical sphere
4	Physiology *'holes or growth' in the stomach; pancreatic malfunction; insulin irregularities*	People with diabetes, significant others	Biomedical sphere (clinical encounters, self-help group)
5	Toxic staples *Contaminated local crops, game and fish, through toxic farming, hunting and fishing*	People with diabetes, significant others	Observation of farming practices; community communication networks
6	Spiritual disruption *Sorcery, witchcraft, devil's action*	People with diabetes, significant others	Cultural beliefs; biomedical (nurses), ethnomedical, faith healing spheres; community communication networks

HIV/AIDS-related stigma emerged from the biophysical impact of diabetes. For some, poor pre-diagnosis knowledge led to delays in early diagnosis and treatment. For others, financial difficulties undermined commitment to sustained drug and diet management. These groups experienced extreme prolonged weight loss. Sudden and/or extreme prolonged weight loss was anchored in health promotional visual images of the emaciated HIV/AIDS sufferer.

> I grew very lean and in this town when you grow lean they think you have *AIDS*. [young female;PWD/FGD;N]
> 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;LI/FGD;N]

In both towns HIV/AIDS was viewed as life-threatening and contagious; it was also attributed to immoral behaviour (chiefly promiscuity). Fear of contagion and moral sanctions imposed degrees of social distancing, separation and other forms of discrimination. Thus, Ruth and other individuals with uncontrolled diabetes who were mislabelled as HIV/AIDS sufferers were ostracized, and abandoned by their partners or families. Women were more likely to be abandoned by their partners; family abandonment was usually a response to actual, anticipated or perceived 'courtesy stigma'. It is important to note (see next section), that these discriminatory practices were not due solely to HIV/AIDS-related stigma. However, many participants expressed fear of HIV/AIDS labelling. As most participants were poor, and struggled to maintain expensive drug and diet

management, uncontrolled diabetes was an ever-present threat. Fear surrounding HIV/AIDS-related stigma and its social implications led individuals to adopt strategies of social communication, most commonly secrecy, aimed at managing and controlling information about their changed identity. These strategies, some admitted, were counterproductive. Secrecy, for instance, maintained the invisible status of people with diabetes and the blurred boundaries between the uncontrolled phase of diabetes and manifest biophysical phase of HIV/AIDS.

HIV/AIDS-related stigma co-existed with the threat of witchcraft/sorcery stigma, as Ruth's experiences demonstrated. Witchcraft/sorcery attributions often began as rumours, or as healthcare advice (by nurses, ethnomedical practitioners and faith healers; see Box 5), but took socio-psychological shape in the private sphere.

> The disease . . . 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. [middle-aged, female;II; N]
> We thought it was a demonic disease because 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 its 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. [young female carer on her mother's amputation; E2; N]

Ruth, for instance, attributed her diabetes to her brother's sorcery and misinterpreted conflicted relations between herself and her daughter in terms of witchcraft attribution. Others projected witchcraft and sorcery attributions to malevolent, but familiar, others. These misplaced attributions generated family conflict and undermined caregivers' commitment to sustained support.

The expectation of being stigmatized has been defined as 'stigma consciousness' (Pinel, 1999, in Link and Phelan, 2001: 374): this process can lead to internalization of anticipated stigma or projection onto others. Researchers note that stigma consciousness can undermine relationships and life chances even in the absence of actual discrimination. Stigma consciousness in relation to HIV/AIDS or witchcraft/sorcery labelling clearly had such effect in Nkoranza and Kintampo.

Biographical disruption, diabetes stigma and handicap.   Diabetes disrupted six inter-related dimensions of everyday life: body-self, identity, economic circumstance, food practices, family relationships and social relationships. Disruptions evoked a range of emotionally mediated practical and symbolic responses (see Box 6). These crystallized round two forms of handicap: financial destitution and psychosocial neglect. Both were rooted in poverty and the physical, psychological and cultural impact of long-term illness. As such, they co-existed with, but preceded and transcended HIV/AIDS-related stigma.

Financial destitution.   Most participants struggled to pay for drug treatment,[3] diet management and travel to health centres. Many turned to family members for financial assistance. Prolonged financial dependence on family members led to intermittent, but, minor conflicts or, at the extreme end, permanent relationship breakdown. Women were more likely to be abandoned or divorced. A key outcome of loss of income or financial support was body-self disruption, and by extension other dimensions of biographical

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[3]For instance, a monthly supply of insulin cost between ¢60 000 and ¢90 000 (£6–£9 at time of study); this constituted 60% of the monthly income of minimum wage earners (on ¢5000 (50p) a day).

disruption. Thus diabetes stigma as a product of the physical consequences of financial destitution was embedded in poverty.

Psychosocial neglect. Psychosocial neglect emerged most visibly against the backdrop of HIV/AIDS-related stigma and financial destitution: courtesy stigma or prolonged financial dependency disrupted family relations and set the stage for psychosocial neglect. However, this handicap also had socio-psychological and cultural roots that preceded and transcended HIV/AIDS-related stigma and financial destitution. Biographical disruption evoked mixed—sometimes shared, often conflicting—emotions including fear, anxiety, anger, depression and hope (see Box 6). The targets, intensity and embodied functions of these relational emotions varied. For instance, mere anticipation of HIV/AIDS labelling and financial destitution could cause depression. Depression exacerbated stigma consciousness, social withdrawal and medical inaction. Internalization

Box 6: Biographical disruption and meanings evoked	
Disruption to:	Meanings (as consequence; significance)
Physical body *Minor symptoms (headaches and general weakness); major problems (visual impairment, extreme weight loss, sexual dysfunction, amputation); other chronic conditions (hypertension, arthritis, asthma)*	Fear of disability and death; fear and anxiety of HIV/AIDS labelling; commitment to (biomedical) management; hope for biomedical breakthroughs/cure
Identity *Extreme weight loss & HIV/AIDS related labelling; amputation, body-image change and restricted mobility; economic disruption and changes to social roles*	Depression (including self-reproach and projected anger); suicidal ideation; anger; medical inaction
Economic circumstance *Loss of earnings increased expenditure on treatment and travel costs*	Fear of complications, disability and death; depression; spiritual action (prayer, faith healing); passive/active cure-seeking
Food practices *Psychological (difficulty of giving up food one likes); economic (not being able to afford prescribed diets), social (negotiating dietary restrictions in public) and nutritional (eating poor quality staples)*	Frustration; secrecy; non-adherence to biomedical diet management
Family life *Minor disagreements from prolonged financial dependence or poor self-care; permanent relationship breakdowns (divorce, abandonment) from economic and psychosocial cost of care*	Depression (including self-reproach and projected anger); suicidal ideation; anger; blame; spiritual action
Community life *AIDS labelling; stigma, ostracism*	Self-isolation; depression; suicidal ideation; spiritual action

or projection of stigma consciousness (particularly of witchcraft/sorcery attribution) caused emotional conflict within lifeworlds; social withdrawal generated fear about a relative's will to live and the implications on their mental and physical health; medical inaction caused worry that a relative's complications might worsen or anger at their self-destructive behaviour. Depression itself contravened culturally appropriate ways of coping with misfortune. Second, caring for people with uncontrolled diabetes involved physical work. Carrying, bathing, feeding and other responsibilities restricted the social and working lives of caregivers. The emotional and physical demands of care suggested that both sufferers and primary caregivers lived with biographical disruption. Thus even in the absence of HIV/AIDS-related stigma or financial destitution, psychosocial neglect within lifeworlds was an inevitable risk.

DISCUSSION AND CONCLUSIONS

This study supports the current view that micro-social (individual/inter-individual) and macro-social (group/structural) research approaches, in isolation, fail to capture the multi-dimensional context and consequences of disease stigma. It also suggests, diabetes stigma operates within a broader context of disease handicap; sustainable anti-stigma interventions have to tackle both stigma and handicap. Selected examples will illustrate both arguments; implications for multifaceted multilevel intervention are considered alongside insights from a participatory community diabetes intervention project under development in Nkoranza district.

Diabetes stigma took two forms: representations of HIV/AIDS, and internalization and projection of witchcraft/sorcery attribution. Both often operated simultaneously at individual, inter-individual, group and structural levels.

HIV/AIDS-related stigma, on the one hand, lay in misattribution of the physical impact of uncontrolled diabetes to HIV/AIDS: this was a product of poor lay knowledge of diabetes, coupled with greater, though inaccurate, knowledge of HIV/AIDS drawn from health campaigns. Stigma consciousness generated individual strategies of coping that had potentially damaging effects on public and private support. On the other hand, as Link and Phelan's (2001) model of stigma mechanisms suggests, individuals concurrently experienced labelling (extreme weight loss as HIV/AIDS-related), stereotyping (of HIV/AIDS sufferers harbouring contagious disease), separation (of the moral healthy from the immoral ill), status loss (of abandoned and divorced women in particular) and discrimination (through ostracism) in public and private spheres. These mechanisms were rooted in socio-cultural and structural factors. For instance, HIV/AIDS-related stigma drew on 'negative social baggage' (Deacon et al., 2005) associated with extreme physical disruption caused and exacerbated by poverty, as well as embodied discourses around illness and morality. Women faced severe forms of discrimination which highlighted gender relations as key sites of pre-existing power struggles through which disease stigma was enacted. While the evidence that rural Ghanaians with uncontrolled diabetes live with the threat of HIV/AIDS labelling is new, the complex causes, course and impact of resultant disease stigma are widely reported in the HIV/AIDS-related stigma literature (Alonzo & Reynolds, 1995; Deacon et al., 2005; Ogden and Nyblade, 2005; Parker & Aggleton, 2003).

The inter-connection of psychological, social and cultural factors in witchcraft/sorcery attribution was also explicit. Attribution took shape partly in the public sphere through

rumour and during healthcare encounters, but was enacted primarily in the private sphere through psychological processes of internalization or projection. Stigma consciousness exacerbated emotional conflict within self, and between self and significant others: this placed family cohesion and psychosocial support at risk. Warranted or not, stigma consciousness operated against a concrete backdrop of persistent socio-psychological tensions and vulnerabilities within close relations. Reported by anthropologists (as the 'dark side of kinship' (Ciekawy & Geschiere, 1998)), psychologists (as 'enemyship' (Adams & Dzokoto, 2003)) and within studies on chronic disease in Africa (e.g. Harding & Higginson, 2004; Jilek-Aall, Jilek, Kaaya, Mkombachepa, & Hillary, 1997), this group process is legitimized through cultural beliefs and is noted to intensify in times of economic insecurity (Ciekawy & Geschiere; Field, 1960).[4] Crucially, it fixes attention to self and lifeworlds as fundamental sites of health risk and to vigilant monitoring of such risk; this presents challenges for dominant health science theories that situate risk in distant others and over-emphasize unconscious responses (e.g. Joffe, 1999).

The biophysical impact of diabetes preceded and transcended disease stigma. Systematic examination of biographical disruption demonstrated how body-self disruption generated psychological, emotional and social conflict even in the absence of both HIV/AIDS labelling and witchcraft/sorcery attribution. Such conflicts were as much implicated in discriminatory practices, as disease stigma. Thus anti-stigma intervention in both towns has to be developed within the broader context of disease handicap and focus on the interplay of biophysical, psychological, socio-cultural and structural dynamics.

Multifaceted multilevel intervention aims to address 'the many mechanisms that can lead to disadvantaged outcomes, and...issues of both individual and structural discrimination' (Link & Phelan, 2001: 381). Preliminary work on the Nkoranza project illuminates the challenge of translating this ideal into sustainable practice. Adopting the 'social psychology of participation' paradigm (Campbell & Jovchelovitch, 2000), the project aims to improve psychosocial and economic support for people with diabetes and caregivers, pluralistic healthcare and community diabetes knowledge, by facilitating productive alliances between people with diabetes, caregivers, lay communities, healthcare professionals in Nkoranza and external groups such as national health policymakers and 'development partners'.[5] The project suggests that improving education and psychosocial support is feasible; both can be mediated through existing productive alliances between Nkoranza's self-help group and biomedical facilitators. However, self-help group mobilization has been—and can be—undermined by the uncertain course of diabetes: members fall ill, plans and activities are postponed. Thus, everyday physical, psychological and social consequences of living with (potentially) debilitating illness are factored into process and outcome of participatory action.

Fundamentally, diabetes stigma and handicap are rooted in poverty and demand economic intervention. Ghana's health system, like many in sub-Saharan Africa, is under-funded, under-resourced, struggles to cope with the double burden of communicable and non-communicable disease and is unable to prioritize chronic disease intervention and

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[4]In this study, the link between economic insecurity and witchcraft/sorcery attribution was indirect (i.e. it could be inferred through the relationship between poverty and extreme biographical disruption). However, many participants attributed deteriorating collective health and social ethics (e.g. unscrupulous farmers, herbalists and faith healers) to economic insecurities.

[5]Donors or 'development partners' include DFID, USAID, DANIDA, WHO and the World Bank who together contribute just over 20% of the country's health budget (Ghana Health Service (GHS), 2005). An extra 12.61% of the budget comes from external loans, grants and HIPC funding (GHS).

policy. Economic interventions for the chronically ill are therefore complex ideals to negotiate and concretize. Two landmark structural solutions have emerged recently: a National Health Insurance Scheme in 2005 providing comprehensive cover for chronic illness and a Disability Bill in 2006 that stipulates free access to general and specialist medical care. Both are at testing phase and are unlikely, at present, to benefit individuals who cannot afford premium payments and/or those who live with ambiguous impairments and disabilities. Lessons can also be drawn from existing economic support schemes for communicable disease, such as service fee exemptions for tuberculosis and cholera (Health Research Unit, 2001). Ultimately a rights-based approach, such as the 14-year struggle which secured legislated rights for Ghanaians with disabilities, will be required to provide basic needs of affordable drugs and quality foods without which the poorest individuals with diabetes get trapped in a vicious cycle of biophysical disruption and chronic suffering.

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