

Mental health in diabetes management: A qualitative study

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Abstract

The realization of Sustainable Development Goal 3 (Target 3.4) is hindered by the high cost of treatment and budget cuts in health services provision in sub-Saharan Africa. Available research in diabetes self-management scarcely emphasizes mental health yet it is an important predictor of self-management. As part of a broader study, this qualitative arm sought to explore psychological challenges associated with diabetes self-management. The sample of 12 respondents comprised people living with diabetes, health professionals, community health workers and caregivers in Kenya. Semi-structured in-depth interviews were used for data collection. Data were coded manually. The themes of stigma and mental distress were found in analysis. Research, design and implementation of support models that incorporate elements of self-empowerment and patients' psychological needs are recommended.

Keywords: Type 2 Diabetes; stigma; mental health; psychological needs; peer and social network support

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1. Introduction

By design, health systems focus more on clinical markers of success to the detriment of social dimensions of disease (Hushie, 2019). Consequently, patients' mental health needs are often not considered yet diagnosis and management of any acute disease is accompanied by other non-clinical consequences. The diagnosis and management of chronic diseases is accompanied by strong affective reactions (shock, disbelief, fear, anger, sadness, hopelessness), anxiety and a range of psychological defenses including denial and frustration (Masupe et al., 2022; Suglo & Evans, 2020). Emotions play indirect causal roles, interact with other prevailing factors or are the outcomes of disease management (Gonzalez & Tanenbaum, 2016). More specifically, Type 2 diabetes affects both patients and caregivers' emotional wellbeing through multiple emotions including fears (of loss of control over life, disease complications, drug side effects and pain through injections) (Piotie et al., 2020; Janes & Titchener, 2014); worry; despair, feelings of self-blame; shame and embarrassment, among others. Patients may also be afraid of being a burden to family and the accompanying physiological and psychological complications including hypoglycemia and low sex drive (Hushie, 2019); and suffer from the pill burden, self-blame, loss of worth, embarrassment at self-managing in public and cognitive deficits (e.g., forgetting) that accentuate the fear of diabetes (Piotie et al., 2020; Schabert et al., 2013). These emotional reactions to diagnosis impede acceptance of diagnosis and medication adherence (Suglo & Evans, 2020; Feifer & Tansman, 1999; Martinez et al., 2018).

Some research indicates that diabetes patients experience stigma via stereotype threat that is triggered by societal expressions of disgust and ridicule towards obese people or those self-managing in public (Link & Phelan, 2001). This fear of negative appraisal leads to self-stigmatization, reinforces the "sick" stereotype that socially isolates patients and is associated with non-disclosure (Mogre et al., 2019). Social embarrassment has been reported regarding food choices (Abdulrehman et al., 2016) which prevents freely associating in other social activities (Mphwanthe et al., 2020). Stigma can also be viewed from the perspective of power dynamics i.e., loss of control; and attitudes of blame and feelings of fear and disgust (Schabert et al., 2013). Additionally, feelings of draining meagre family resources increase self-blame, with implications for self-management and disclosure to social networks. In addition to negative affective reactions, patients and caregivers suffer diabetes distress that is triggered by multiple factors including stigma and social exclusion, difficulties in self-management, disruption in self-image arising from body marks from injecting, carrying glucometer, weight gain; self-blame for the disease and fear of pain (from injecting) (Oluchina & Karanja, 2022).

Successful diabetes management requires a realization of the need to add an explicit psychological component. First, since patients are responsible for self-management, they should be involved in relevant decision making from diagnosis through self-management (Anderson et al., 2000). Secondly, patients require coping skills via role playing, shared decision making and structured self-management education to improve self-confidence, wellbeing and metabolic control (Doherty, 2022); and group therapy to improve assertiveness, reduce isolation and improve feelings of validation (Feifer & Tansman, 1999). To reduce stigma, Schabert et al. suggest the need to target the health problem itself, the source of stigma and social policy.

From the foregoing it is evident that psychological factors such as anxiety, depression, fear of hypoglycemia and diabetes distress negatively affect self-management. Whereas a broad body of knowledge on psychological barriers to diabetes self-management exists in developed countries, limited qualitative data is available in sub-Saharan Africa. This study sought to fill that gap by answering one pertinent question: What psychological challenges are faced by diabetes patients in self-management?.

2. Methods and materials

2.1. Ethical considerations

Ethical approval was obtained from the Kenya Medical Research Institute (KEMRI) Protocol No. 4295.

2.2. Research design, setting and sample

This qualitative study used in-depth interviews to understand participants' lived experiences. The purposive sample (n = 12) was drawn from a large referral hospital and three other public healthcare facilities in Kenya. The sample consisted of people living with diabetes, family caregivers, medical professionals and community health workers (Table 1).

Table 1.
Characteristics of sample

Participant No.	Age (Years)	Gender	Designation
1	40-45	Female	Clinical officer
2	30-35	Female	Clinical officer
3	35-40	Female	Clinical officer
4	25-30	Female	Clinical officer
5	35-40	Female	Community health worker
6	35-40	Female	Community health worker
7	35-40	Female	Caregiver
8	45-50	Male	Person living with diabetes
9	70-75	Female	Person living with diabetes
10	20-25	Male	Person living with diabetes
11	20-25	Male	Person living with diabetes
12	40-45	Female	Person living with diabetes

2.3. Data collection procedure

An interview guide was developed a priori from a broad review of literature. Interviews were conducted face-to-face in healthcare facilities in November and December between November and December, 2021 and lasted up to one hour. Both Kiswahili and English were used in interviews. Health professionals and community health workers identified and referred people living with diabetes to the study.

2.4. Data analysis

Translation and transcription followed data collection. The six steps of coding and thematic analysis were used (Braun & Clarke, 2006) without any software. Transcripts were read through many times while taking notes that were used to create initial codes. These codes were matched with verbatim data extracts. Trained research assistants verified each other's codes. Codes were then joined into themes in line with the core research question. Reporting was done following the Standards for Reporting Qualitative Research (O'Brien et al., 2014).

3. Results

We interviewed a total of 12 respondents (female = 9, age range 20-75 years) comprised of people living with diabetes (n = 5), health professionals (n = 4), community health workers (n = 2) and caregivers (n = 1). Stigma and mental distress emerged from the qualitative analysis as distinct themes.

Theme 1: Stigma

Sub-theme 1: Self-stigma

Participants agreed that the lifelong nature of diabetes placed undue strain on their mental resources and alienated them from self- and others. The burden of disease bred feelings of

dependence on family members, friends and medical professionals for medication and sustenance. This often resulted in feelings of loss of worth and helplessness, especially among previously healthy (strong) breadwinners. One male living with diabetes said that:

“The family raises issues with the food I need to eat. I just feel that I am a burden to everyone at home.” (P11)

Men living with diabetes found it difficult to disclose their status to family, community health workers and medical professionals because of the drop in sex drive associated with the disease. This is due to the fear of being demeaned for inability to satisfy their spouses sexually or having other men take advantage of their situation. In the words of a community health worker:

“Where the husband has diabetes and the wife not...and the husband is unable to satisfy the wife.... they both receive counselling...that the wife needs to be patient with the husband until a time when she can be satisfied.” (P5)

Sub-theme 2: Societal stigma

Participants reported that diabetes was accompanied by lay beliefs about diabetes as a disease of the rich, due to witchcraft or incestuous family relations. This resulted in rejection. A medical professional reported that:

“One child was abandoned here (health facility) by the parents because they had no history of diabetes in their family.” (P4)

Painful changes to the body including weight gain/loss, body sores and swelling of feet that accompanied diabetes were misinterpreted as signs of HIV/AIDS, witchcraft or incest. One participant said that:

“I lost a lot of weight until people knew I was very sick. My clothes were unable to fit me because I lost a lot of weight. People were suspicious but my husband assured them that I did not have the disease (HIV).” (P12)

This was corroborated by a male participant living with diabetes who said that:

“You get labelled as a HIV person and they use their eyes to judge you.” (P8).

Theme 2: Mental distress

Sub-theme 1: Lifelong stressor

Participants agreed that living with diabetes was a daily stressor. In the words of a health professional:

“Living with diabetes is not an easy thing...starting from acceptance that I have diabetes and will live with it forever is a heavy thing.” (P1)

The lifelong burden of taking medicine was also reported as a continuous stressor among diabetes patients, a position that was echoed by other participants. One health professional said that:

“Some of them eventually give up because taking medicine for a lifetime is not easy.” (P2).

Sub-theme 2: Disclosure

Due to the irrational interpretation of diabetes symptoms, participants reported reluctance to visit hospitals. Such visits were interpreted by social networks as evidence of HIV+ status. For instance, one participant living with diabetes said that:

“They think that you are having another illness (HIV) but hiding it and claiming it is diabetes.” (P9)

Further, male heads of households rarely disclosed their condition to family members. This is because of the feelings of depreciation of self-worth that accompany disclosure, especially if the person was the family breadwinner or head of the family. One male participant living with diabetes reported that:

"In my household, only my wife knows of my status...I cannot tell anyone else...she is the one who can keep my secrets." (P8)

4. Discussion

The findings provide evidence of the need to understand the role of stigma in Type 2 diabetes self-management. Stigma reported in this sample results from lack of knowledge and irrational beliefs surrounding diabetes and accentuated by HIV-related comparisons e.g., due to loss of weight. The net result is diminished disclosure and medication nonadherence.

Often, lifestyle changes including clinic attendance and medication are externally imposed and reflect readjustments in power dynamics between patients and family or health professionals since the imposed conditionalities are non-negotiable. This dependence on external regulation is mentally demanding in cultures where men have traditionally played the 'provider' role.

Non-disclosure among men may therefore be interpreted as the final attempt at retaining a sense of self-worth after loss of good health, livelihood (especially blue-collar workers) and decision-making (on when to take medication, attend clinics, dietary preferences, sex, etc.). Previous work has reiterated the need for interventions that focus on patients' feelings of control (Funnell & Anderson, 2004). This finding leads to the question of who makes decisions concerning specific behaviours important to critical care (Vassilev et al., 2014) and the extent to which those decisions are related to the satisfaction of psychological needs (Peyrot et al., 2007).

The diagnosis and development of diabetes renders patients unable to contribute equally to the social capital pool. Hence, previously strong breadwinners become "useless" in the eyes of the family/society. Findings show that non-reciprocal relationships evoke negative feelings about receiving help. Men bear the biggest burden due to close associations between 'ownership' (of sexual virility, livelihood, physical strength) and self-worth. Findings therefore question the extent to which social networks cater for the needs of people living with non-communicable diseases. Specifically, economically weak social networks that bear the disease burden consequently suffer fatigue and complete failure to ensure access to health. The failure of the immediate family to readjust to or provide for new dietary requirements as found in previous research is a good example (Absetz et al., 2020).

5. Limitations

First, the non-probabilistic sampling methods used in the study limit the generalizability of findings. Secondly, persons living with diabetes may not have disclosed full information because some aspects of the interview may have been viewed as too personal.

6. Conclusion

This study sought to understand the psychological barriers to effective diabetes self-management. From the findings, we conclude that stigma is a barrier with varied antecedents that require a multidimensional approach at intervention. Secondly, it is important to question whether prevailing support models focus on the satisfaction of mental health needs. Towards that end, Psychology can contribute to the study of behavioural aspects of diabetes as a key element of diabetes self-management.

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