

Trajectories of lived experiences of people living with Diabetes Mellitus in Africa: An evidence mapping of conceptual framework

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Abstract

Introduction: Diabetes Mellitus remains a major public health problem in Africa in the last two decades. A new conceptual framework for studying and understanding trajectories of experiences of people with diabetes mellitus in Africa is presented.

Objective: The paper examines all known factors influencing the trajectories of lived experiences of persons with diabetes and how these factors interact with each other at micro and macro levels.

Methods: A systematic mapping of peer reviewed literature (n=61) conducted in Africa and published between 01/01/1990 and 31/12/2020 was utilised.

Results: Using a conceptual framework, we synthesised the factors influencing trajectories of lived experiences of diabetes in Africa, grouped into six domains: diabetes risk factors, socio demographic characteristics, individual level experiences, household/family level experiences, community/society level experiences and national level experiences.

Conclusion: This framework can be used to test hypotheses about facilitators and barriers to health care seeking behaviour. As well as understand how trajectories of lived experience of diabetes might be influenced by policy or practice. Research based on understanding of trajectories is expected to improve diabetes patient's experiences and outcome in diabetes management and care in Africa.

to have died of diabetes in Africa. The fast rise observed in the prevalence and burden of diabetes (especially type 2 diabetes) in the Africa region have been attributed to major changes in lifestyle and rapid urbanisation of cities.⁴

Diabetes is a chronic condition with no specific cure that demands self-management regimen.⁵ However, the success in the care and management of diabetes in Africa has to do with patients' individual characteristics, beliefs and perception about the disease, support from patients' family, community, and health care system and health policies. Empirical evidence from the African setting suggests that people with living with diabetes experiences physical changes in their bodies, psychological and social changes to their identities after diagnosis.⁶ Again, medical adherence and non-adherence among diabetes patients also depends on their beliefs and lay representation of the illness,⁷⁻⁹ financial and social support from relatives and friends,¹⁰⁻¹² cost and type of treatment,¹³⁻¹⁵ health system issues¹⁶⁻¹⁸ and health policies and programmes.¹⁹ Within the African region, people with diabetes experience multiple, intersecting dimensions in the process of treating and managing the disease.²⁰ Drawing together these body of literature of the 'Lived Experiences' of people living with diabetes in Africa is to inform effective policy formulation and assist in identifying salient knowledge gaps is a significant effort. There is a lack of synthesis of the known time and context specific influences on trajectories of 'lived experiences' of people with diabetes within the African region. Previous, conceptual frameworks of diabetes experiences within the African context have only dealt with issue of medication adherence.²¹

The conceptual framework we proposed considers all possible factors influencing the 'lived experiences' of people living with diabetes mellitus in Africa. In this paper, we define 'lived experience' trajectory as the processes and transitions occurring from the time of diagnosis of diabetes through to care and management of diabetes.²² The term 'trajectory' was used because it incorporates the concept of time and process which is critical for understating the care and management of diabetes. Diabetes is distinct from other morbidities since

- It is chronic meaning once diagnosed, a person had to live with the diseases for the rest of his/her life
- There is disruption in the normal way of life in terms of change in dietary patterns
- Idiabetes management requires regular visit to the health centre and medication

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Introduction

Diabetes Mellitus remains a major public health problem in Africa in the last two decades.¹ By 2045, about 41.6 million people are estimated be living with diabetes in Africa up from 15.9 compared to million people in 2017.² In the Africa region, about 70% of people do not know they have diabetes as such the region has been classified as one with the highest percentage of undiagnosed people.³ In terms of cause of mortality, in 2017, 312,000 people were reported

- Diabetes leads to changes in the body
- Diabetes leads to psychological issues such as frustration, stress, worries, guilt and anxiety.

The main health related theory applied in understanding and explaining 'lived experience' of diabetes is the socio ecological model.²³ We argue that this theory has hardly been used to frame research on obtaining lived experiences on diabetes and the factors affecting the care and management of the illness also involves multiple levels.²⁴ The socio ecological models considered multiple levels (individual, community and structure) of influence on behaviour and reciprocal causation between behaviour and social environments, unlike determinant models that largely conceptualise healthcare decision making and use an individual level process.

Methods

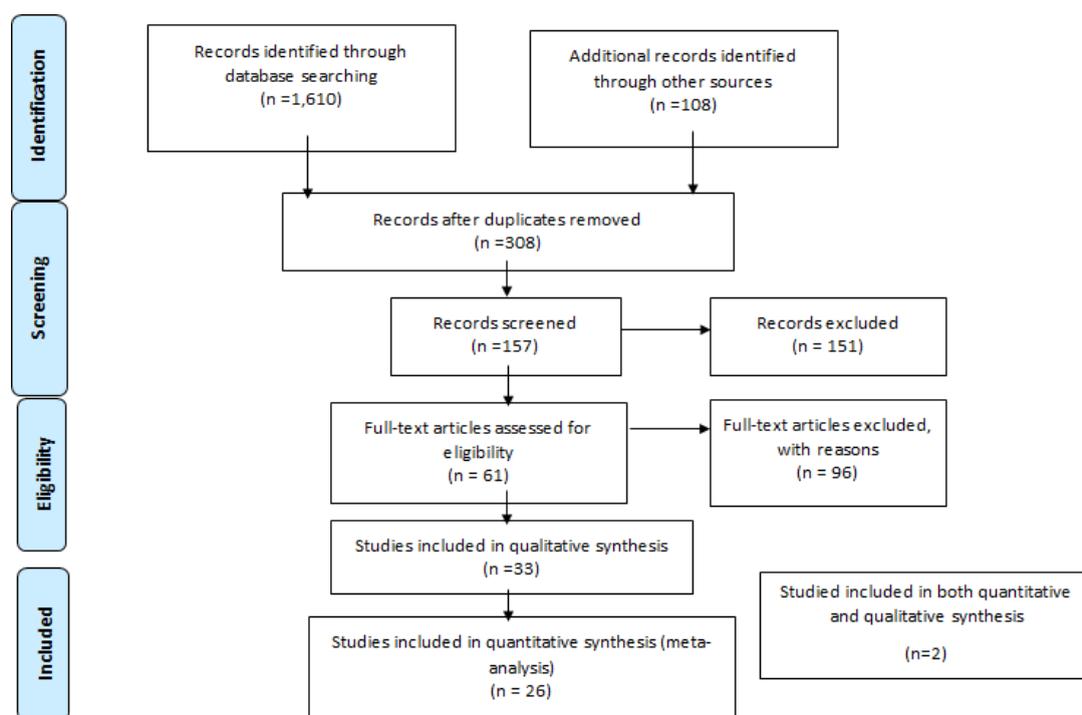
An inductive method was used to build this conceptual framework: initial drafting was based on research by experts and practice knowledge, as well as consequent orderly evidence plotting of peer reviewed literature.²⁵ Thematic analysis of issues reported in the studies from Western, Eastern, Northern and Southern Africa (n=61) were used to develop this framework.

To ensure that the conceptual framework was comprehensively captured, a systematic evidence mapping of En-

glish language peer reviewed literature of all documents on "lived experiences" on diabetes mellitus was conducted. Evidence mapping is considered an evidence synthesis methodology that is a modification of the systematic review; it is an orderly search of an extensive field that describes as broadly as possible all of the literature connecting to the subject matter without limiting to studies that assess the strength or direction of relationships.²⁶⁻²⁸ It methodologically recognises and creates a map of the literature and is progressively used in a range of social sciences.²⁹ Evidence mapping can be much more inclusive than a systematic review: our quality criteria were the studies should be published in a peer reviewed journal and conducted in the Africa region. Also, we did not exclude studies that used multiple references based on the same sample were included.³⁰ Data obtained from one study population might examine different issues of importance.

An electronic search was conducted (guided by PRISMA Flow Diagram) on relevant databases including PubMed, Scopus, Science Direct, EBSCO, MEDLINE and JSTOR. These electronic databases of peer reviewed literature were search for studies conducted in Africa and published in English between January 1990 and December 2020. These databases were selected because of their biomedical and social sciences research coverage. Amalgamations of relevant search terms were developed and tested for sensitivity. The final combination of search terms using

Figure 1: Systematic evidence mapping process (PRISMA 2009 Flow Diagram)



Boolean Operator were (lived experience* OR experience*) AND (Diabetes Mellitus* OR Diabetes*OR Gestational Diabetes* OR Type I diabetes OR Type 2 diabetes*). Figure 1 illustrates the process.

After duplicates were removed, all papers identified by the search were screened on their title and abstract to establish their inclusion.³¹ Papers were included if: conducted in Africa and published in full text in English in a peer reviewed

Review Article

journal between January 1990 and December 2020, and the abstract included factors contributing to the lived experience of diabetes. All non-peer reviewed papers (research articles, comments, book review, and letters) were not included.³² In circumstances where it was difficult to include or exclude papers based on their abstract or titles, the full text papers were screened. Papers were included if they were considered trajectories or influences on trajectories to the experiences of living with diabetes mellitus in Africa. Details of included articles are available (Appendix A: Data extraction and review summary). A comparison was made between each full text article and the draft conceptual framework. Components that were identified not to be adequately captured by the draft conceptual framework were merged in ensuing iterations. These included an additional component “experiences of diabetes” such as lay knowledge and beliefs about diabetes, risk factors associated with diabetes, cost of treatments and access to health care for diabetes management. All additions of concepts on diabetes to the conceptual framework were made as a team, based on our reading, expertise, and other discussions we had about the framework with experts during the development of the framework. We included 33 qualitative related studies, 26 quantitative studies and 2 mixed method (both quantitative and qualitative) on diabetes experiences in Africa.

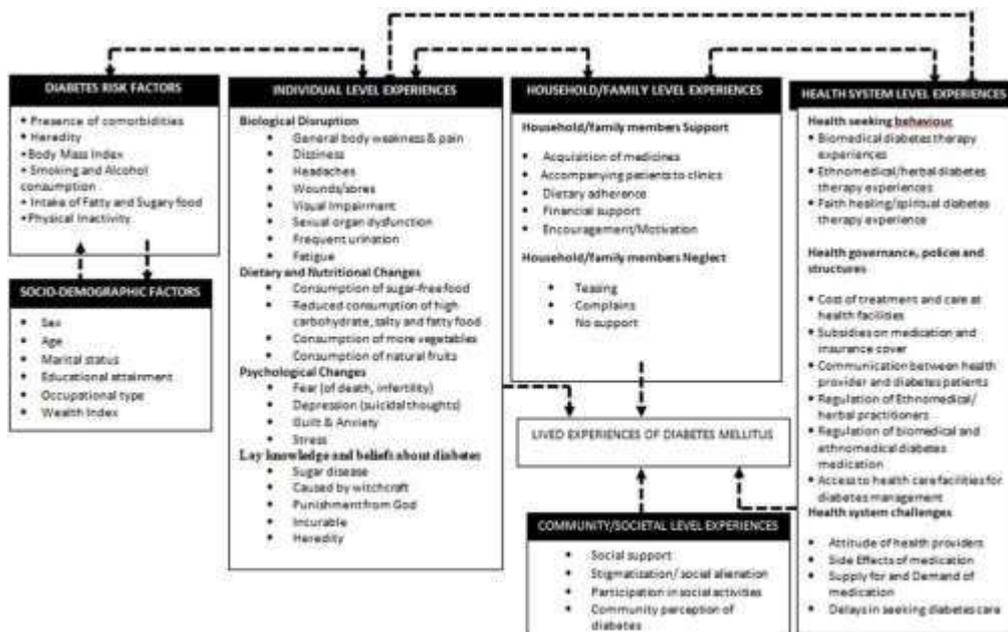
There were some limitations during our search methodology. Language, geography, and date limits meant that

the inclusion of additional language or years might have yielded extra information; however, our search for articles provided evidence from all African geographic regions, including studies done in non-English language but published in English. By focusing on publications on diabetes mellitus over three decades, our framework truly reflects a comprehensive summary of the field of experiences of diabetes mellitus evidence. We searched six databases, selected for their range; extra databases might include other evidence. Our search only included diabetes related terms (diabetes mellitus, type 1 diabetes, type 2 diabetes, gestational diabetes); our search will not have yielded papers that discuss other co-morbidities such as hypertension, stroke without making specific mentioned of diabetes.³³⁻³⁵ Our mapping method shows that the relative weight and rigour of evidence on the factors recognised remain unfamiliar. The final conceptual framework represents all aspects of trajectories of Lived Experiences of People with Diabetes Mellitus in Africa as evidenced by practice knowledge and in peer reviewed articles.

Conceptual framework of trajectories of lived experiences of people living with diabetes mellitus in Africa

A conceptual framework is defined as a set of ideas, presented in a structured means to assist in understanding a phenomenon. The conceptual framework Figure 2 represents “the subjects” to be studied with respect to trajec-

Figure 2: A conceptual framework for understanding trajectories of lived experience of people living with diabetes mellitus in Africa



jectories of lived experience of people living with diabetes mellitus.³⁶ It creates influences shaping these trajectories, grouped into six main levels of experiences to highlight the micro and macro context of living with diabetes mellitus:

- Individual level experiences: comprising socio demographic and economic characteristics of people living with diabetes, lay knowledge and beliefs about diabetes, changes in biological system, dietary and nutritional changes, and psychological changes

- Household/Family level experiences: involving support from household/family members and neglect of household family members towards people living with diabetes
- Community/Societal level experiences includes social support for people living with diabetes, community perception and definition of diabetes, stigmatisation, and diabetes patient's participation in social activities
- Health system level experiences: involved health seeking behavioural/therapeutic experiences, health governance, policies and structures and health system challenges affecting people living with diabetes
- Risk factors associated with diabetes mellitus comprises heredity, presence of other comorbidities, body mass index, physical inactivity, smoking and alcohol consumption, consumption of fatty and sugary foods and ageing.
- Socio demographic characteristics of people with diabetes include sex, age, educational attainment, marital status, occupational type, wealth index.

To fully comprehend the trajectories of living with diabetes and its impact, authors situated it within the micro and macro contexts; all six domains are interconnected.³⁷ For instance, a male/female (demographic) because of heredity (diabetes risk factors) is diagnose of diabetes could start experiencing changes in the body such as general body weakness and pain (biographical disruption), reduce the consumption of high carbohydrate, salty, sugary and fatty food (dietary and nutritional changes).³⁸ The person also goes through stress, anxiety, and depression (psychological changes) and this shapes the beliefs and knowledges about the disease. A diabetes patient also receives support/neglect from family/household members (household/family level experiences) and also support/neglect from the community or social environment (community/societal level experiences) and might influence their health seeking behaviour and care they receive from the health system (health system level experiences).³⁹ The framework is applicable especially with the African region, capturing concepts that are pertinent across space and time. For readability, our conceptual framework comprises brief phrases or simple words for each factor. This comprehensive visual overview is the contribution of our article to knowledge.⁴⁰ To illustrate its relevance across settings, we expound the conceptual using illustrations in the following sections.

We begin with how experiences at the individual level is influenced by socio demographic characteristics and risk factors influences their experiences at the individual, household/family, community, and health system levels when diagnosed with diabetes.⁴¹ Our evidence based illustration of each factor is preceded by points that provide further instances.

Diabetes risk factors

The presence of some risk factors such as presence of co-

morbidities, heredity of diabetes body mass index (BMI), smoking and alcohol consumption, intake of fatty and sugary food and physical inactivity have been highly associated with people with diabetes in Africa.⁴² Other risk factors identified in Africa include obesity and overweight, cigarette smoking,⁴³ Ageing,⁴⁴ and hypertension.⁴⁵

Socio demographic characteristics of persons with diabetes

The demographic and social characteristics of persons with diabetes mellitus plays a critical role in there lived experiences with the disease from diagnosis through to its management of the disease. Studies reviewed clearly show that in Africa, diabetes is more prevalent among females⁴⁶ relative to males.⁴⁷ Sex related differences in lifestyles may contribute to being diagnosed with diabetes mellitus. For instance, in some African countries, obesity or overweight (risk factor) are reported more in women compared to men. This may explain the higher diabetes prevalence among women.⁴⁸ Physical inactivity and low socioeconomic status among women in Africa are associated with higher prevalence of diabetes mellitus.⁴⁹ The lowest age one was diagnosed with diabetes in the region is 20 years and highest at 70 years.^{50,51} However, the average age at which diabetes is more prevalent is 50 years.⁵² The review of studies on diabetes in Africa reveal that it is more prevalent among the married⁵³ relative to the unmarried counterparts. These findings are contrary to two basic hypotheses that explain the beneficial effect of marriage on health. The first hypothesis states that healthier individuals tend to get married and remains married. The second hypothesis matches with post marriage effect: stress reduction and the adoption of healthy lifestyle.⁵⁴ Diabetes is most prevalent among educated individuals (secondary and tertiary levels) than the uneducated in Africa.⁵⁵ Higher education is often associated with higher income levels and unhealthy lifestyles and highly susceptible to diabetes mellitus.⁵⁶ High Prevalence of diabetes in Africa has been identified among people with sedentary work (involve mostly sitting or standing while working) compared to occupational types that involve being actively mobile.⁵⁷ High diabetes prevalence is also associated with people with high wealth index in Africa⁵⁸ relative to those in the low wealth index.⁵⁹

Individual level experiences of Diabetes Mellitus in Africa

The experiences of an individual after been diagnosed of diabetes are shaped by factors in their individual or intra personal context. We consider in this section the multiple events that individuals may experience after been diagnosed with diabetes. The trajectory starts with the individuals becoming aware of their health status, discovering a disruption in biological make up⁶⁰ changes in dietary and nutritional patterns⁶¹ and changes in psychological thoughts⁶² which are likely to shape the knowledge and beliefs about diabetes. These intrapersonal diabetes related experiences of individuals may differ depending

on their socio demographic and economic characteristics. Thus, these trajectories of events may not be linear; for example, a woman diagnosed of diabetes might not experience any changes in her body such as weight loss, might not change her dietary patterns and will not express any emotional thought such as worry and anger. The concept of biographical disruption, dietary and nutritional changes, psychological changes and individual lay knowledge and beliefs about diabetes are addressed in the subsequent sections.

Biographical disruption: Bury's⁶³ concept of biographical disruption refers to the disruption chronic illness causes to both the physical body and life trajectory of the sufferer and the meanings ascribed to such disruption. Studies in Africa have revealed that people with diabetes lived with range of experiences with regards to their bodies from general body weakness and pain,⁶⁴ dizziness,⁶⁵ headaches,⁶⁶ wounds⁶⁷ to visual impairment,⁶⁸ sexual organ dysfunction (erectile problem, virginal itching),⁶⁹ frequent urination⁷⁰ and fatigue.⁷¹ It has been reported that diabetic patients often evaluate their health status based on the severity and duration of the disease' disruption to their physical body. These individual experiences inform their illness actions to overcome these physical body disruptions to regain more stable and permanent strength and mobility. It is also argued that the severity of the disruption on the physical body may impact one's social identity within their family, community and society depending on their social status.⁷² This physical disruption has been reported to negatively impacts the personal agency of a diabetic patient's illness experience at two levels: inability to work effectively and to perform social roles.

Dietary and nutritional changes

Changes in dietary and nutritional patterns of persons with diabetes is found in some studies in Africa. Some of these changes comprises high consumption of sugar free food,³⁸ reduced consumption of high carbohydrate, salty and fatty food intake,⁵³ more consumption of vegetables,¹⁵ and consumption of natural fruits.³⁰ These studies argued that persons with diabetes find it difficult to adjust to newly recommended dietary preference by dieticians. Because they are used to the "normal" food they consume before being diagnose of diabetes. Diabetic patients are observed to consume more "home cooked" foods with low or no sugary additives, consumes less or no prepared packaged foods, sweet sweetened beverages and other processed foods. They also eat less of meat that have high concentration of fats, less of food that contain high carbohydrates and now put less salt in their food before they eat. Their soup and stew are now concentrated with more vegetables such as cabbage, carrots, cucumber, green leafy vegetables, and broccoli. Studies also revealed that persons with diabetes especially those with low socio economic status find it challenging to consume these vegetables on daily and regular basis.⁵⁷ With regards to fruit consumption, di-

abetic patients generally do not adhere to the recommended intake as prescribed by dieticians in Africa.⁵⁹ However, there are inconsistency with regards to the beliefs about the health effect of fruit consumption among persons with diabetes and their impact on blood sugar levels.⁷ Dietary changes, intervention and adherence is an important factor in the management of diabetes mellitus in Africa because of its implications on the blood sugar and glycaemic control. However, the cost of purchasing these items on regular is a challenge preventing strict adherence to the recommended dietary patterns within the African context.

Psychological changes

Being diagnosed of diabetes imposes a significant psychological and psychosocial burden on people with the disease. They undergo thought processes and express emotions on lifestyle and behavioural change considering their new health status. These psychological changes include stress, fear of death and infertility, depression (suicidal ideation), guilt, anxiety, worry, anger, frustration, and confusion.¹⁶ Studies have indicated that adverse emotional and psychosocial experiences of people living with diabetes significantly contribute to burden of the disease, physical deterioration, and mortality rates in Africa.⁶¹ Other studies argued that in the care and management of diabetes, psychosocial issues are often neglected by health professionals notwithstanding the fact that the emotional experiences and challenges of people with diabetes appear to be overwhelming for them.²¹ Psychosocial therapy is of importance in the care and management process for diabetic persons.

Lay knowledge and beliefs about diabetes

The lay knowledge and beliefs about diabetes are dependent on a diabetic individual's level of experience in Africa. Studies on lay knowledge and beliefs about diabetes in Africa have revealed that people with diabetes often refers to the disease as 'sugar disease'⁸ thus its causes are linked to the high consumption of sugary foods and drinks. Others also believe diabetes is a 'disease of the rich/wealthy'⁷ and intrinsically associated it with the kind of food (sugary and fatty) consumed by high income earners. Across the Africa region diabetic patients also ascribe supernatural and superstitious reasons to the diseases. They believe that diabetes is caused by witchcraft and punishment from God or deities because of an offence.²⁴ Heredity is also ascribed to the causes of the diabetes among studies done in Africa. Persons with the disease usually had knowledge about their family history of diabetes and this shaped their belief system of getting the disease at a particular age. This is because, per observation other family members had the disease at a particular age. Thus, they perceive that, irrespective of their lifestyle and behaviours, they will surely have the disease when they reach that particular age.⁵³ It is also documented in the African literature on diabetes that, the sources of knowledge through biomedical, ethnomedical and spiritual practitioners shape the knowledge

and beliefs systems surrounding diabetes and influence the health seeking behaviour for diabetes managements among persons with the disease in Africa.²⁹

Household/Family level experiences

This framework describes the household/family level experiences of diabetic persons in Africa. It illustrates how the intra-personal experiences of diabetes patients affect the inter-personal experiences with other members within the household or family. These interactions had implication for care and management of diabetes. Literature on diabetes especially among older population in Africa has revealed that, primary caregivers and other household/family members play significant role in the care and management of diabetes.²² Therefore, the lived experiences of persons with diabetes and their significant others is crucial in the management of the disease.

Household/family members support

Experience associated diabetes mellitus especially among the aged requires some active support such as involvement of partners, children, caregivers, and other family members in its management. Studies on family support for persons with diabetes in Africa found that household members provide various forms of assistance to diabetic patients.⁶⁴ These are acquisition of medicines, accompanying patients to health facilities, ensuring medical and dietary adherence, financial support, encouragement, and other forms of emotional support. Strong family support has been found to be a predictor of good quality of life among diabetes patients.⁶⁵ Family members usually eat the same healthy food that diabetes patient eat to identify and sympathize with them, laugh and walk with them. These forms of support have been observed to reduce the psychological burden of the disease.

Household/family members neglect

Living with diabetes can be a challenging experience not only to the patients but the entire family/household members. Studies on diabetes in Africa has indicated that people living with diabetes, their primary caregivers and other household members face day to day challenges with regards to dietary adherence, stress, medical adherence, drug purchase and other self-management practices.⁶⁶ There are disagreements often between diabetes patients and their family members when managing the disease. This may lead to total or partial neglect from family members. Studies have indicated that family members sometimes offer no financial or emotional support, such as complains about and teases people with diabetes.¹³ Family members who also serves as caregivers in the long run neglect persons with diabetes because of the burden of care and cost associated with it. Some cost details include disruption in family member's domestic routine and social activities, huge financial spending, and loss of productive hours.

Community/Societal level experiences

Community/societal perception of persons with diabetes disrupt their social identity. Thus, the social/community knowledge of diabetes such as the causes, symptoms and consequences of the disease determine the care and management of diabetes in Africa. Most African societies are generally communal in nature and studies have showed that persons with diabetes go through negative societal experiences such as stigmatisation, social isolation, inability to participate in social activities, negative social judgement, loss of friends and acquaintances.⁶⁷ Other studies on the other hand found that diabetes patients experience positive societal outcome such as social support, financial supports from friends, working colleagues, advice and motivation from peers and health professional.¹⁸

Health system level experiences

Living with diabetes involves a regular contact with the health care system in the management of the disease. Within this framework, the health system level experiences of diabetic patients are categorised into three namely

- Health seeking behaviour
- Health governance, policies, and structures
- Health system challenges.

Health seeking behaviour

Studies on diabetes care and management in Africa documented three major means through which persons with diabetes seek care and manage the diseases. These are biomedical therapeutic, ethnomedical (herbal) therapeutic and faith/spiritual therapeutic experiences.¹⁰ Studies further reported that while some adopt a pluralistic approach of combing the use of biomedical, ethnomedical and spiritual treatment for diabetes,²⁷ others only use one form of therapy for managing the disease.

Biomedical therapeutic experiences

Biomedical treatment sources serve as the first point of call to persons with diabetes. It starts from diagnosis of the disease to medical education and counselling by health professionals on living with the disease to routine medicine in take. Studies on biomedical treatment of diabetes in Africa indicate that many diabetes patients must take medication for the rest of their lives. This is to improve their insulin uptake to avoid the emergence of complications and sudden death.⁶⁸ However, non-adherence to medication is endemic among diabetes patients in Africa.²⁹ The knowledge diabetes patients have on the disease been drawn through direct interaction with biomedical professionals, reading biomedical books and experiencing biomedical treatment and its efficacy of its medicines. Biomedical treatment is considered by many diabetes patients in Africa very expensive considering the cost of medication and payment of other hospital bills on a regular basis. This offers an explanation to the concept of "non-adherence" to biomedical drug intake and seeking other alternative sources (herbal

and spiritual) of treatment to complement the biomedical drugs.⁶⁷

Ethnomedical therapeutic experiences

Research in the African region suggest that medical pluralism is pervasive and an essential component of non-communicable disease experiences²⁷ and there is evidence of persons with diabetes accessing pluralistic medical care.⁶⁷ Persons with diabetes often use ethnomedicines as a complement to biomedicines or as a complete replacement of biomedicine. Studies provided some plausible explanations for the use of ethnomedical therapy that both herbal and pharmaceutical drugs had similar plants origins, and in effect ethnomedical drugs has the same efficacy in controlling diabetes. Another explanation is that ethnomedical drugs are relatively less expensive and affordable than pharmaceutical drugs.²² The failed expectations of the rapid efficacy of biomedical drugs to control diabetes give many persons with diabetes to opt for herbal medicines. The motivation for the use of herbal medicine is based on the testament of earlier users, perceived potency, and ability to cure diabetes.²⁵

Faith healing/spiritual diabetes therapeutic experience

Studies on diabetes management and care in Africa highlighted the important role of religion and faith in God.⁵³ These studies have suggested that the lay knowledge and perception of causes of diabetes as witchcraft and punishment from God by persons with diabetes in Africa, influence their faith and belief in God for diabetes treatment and cure through prayers. While some diabetes patients combine biomedical therapy with spiritual therapy,⁶⁷ others solely depend on faith healing therapy.²⁰

Health governance, policies, structures and health system challenges

Cost of diabetes treatment and care at health facilities, subsidies on medication and insurance cover, communication between health provider and diabetes patients, regulation of ethnomedical practitioners and access to health care facilities for diabetes management play important role in the lived experiences of persons with diabetes in Africa. Studies on diabetes in Africa has revealed high cost of biomedical drugs (insulin), absence of health insurance cover of diabetes care,²⁴ inability of diabetes patients to afford consultation fees and laboratory services, high cost of transportation to nearby health facilities¹¹ are health system challenges persons with diabetes experiences. Other health care system challenges identified in the literature were the unavailability and shortage in supply of diabetes medication in remote health facilities¹⁵ and delay (long waiting hours) in treatment of diabetes at health facility, inability to afford diabetes monitoring devices (glucometer and glucose strips).¹¹ Literature on structural health challenges of diabetes care in Africa found misdiagnosis of diabetes, poor/negative attitude of health care provid-

ers¹⁸ and side effects of antidiabetic medication⁶⁹ as major bottlenecks persons with diabetes experience in seeking care.

Conclusion

We present a conceptual framework of trajectories of lived experience of people living with diabetes mellitus in Africa. This integrative framework helps develop understandings of diabetes related care trajectories and lived experiences of living with diabetes in a way that identifies distinct components while at the same time representing the integration of components operating at individual, household, community and national levels. Previous studies on trajectories of lived experience with diabetes have tended to focus on specific aspects of trajectories. In assembling for the first time, all identified explanatory factors that influence the trajectory of lived experience of persons with diabetes in Africa. Our framework can be used to test theories and generate hypotheses relevant to understanding diabetes care and management in Africa.

Our inductive approach to framework construction developed a conceptual framework from evidence. The conceptual framework builds on features of other models of health seeking behaviour. The six domains diabetes risk factors, socio demographic characteristics, individual level experiences, household/family level experiences, community/societal level experiences and health system level experiences have features like a socio ecological model. However, our conceptual framework differs from the simple socio ecological model for a reason that our framework additionally incorporates risk factors that are specific to diabetes experience. The start of diabetes trajectory begins with the presence of risk factors of the individual.

Our framework is built on systematic literature mapping. The systematic approach used is sufficiently robust and comprehensive to assert that the framework includes the known universal factors affecting the trajectories of lived experience of persons with diabetes in Africa. This framework could be modified to reflect future empirical and theoretical evidence generation.

Our conceptual framework marks an important step in how researchers might conceptualise and understand trajectories to diabetes experiences. By specifying and connecting influences, this framework can be used to inform the design of research and conduct analyses across contexts, methodologies, and epistemologies. Each component of our conceptual framework can be studied separately; and by considering the means through which each component may be affected by other components, to fully understand the trajectories of lived experiences of persons with diabetes mellitus in Africa. This framework situates the trajectory of diabetes experience highlighting the important role played by diabetes risk factors, and how that interacts with socio demographic characteristics of individuals, to individual, household, community and national level of experiences of people with diabetes in an at-

tempt to manage diabetes in Africa. This suggests testable hypotheses about how trajectories of lived experience of diabetes might be influenced by policy or practice.

This conceptual framework can be used to assess how, why and with what consequences, trajectories of lived experience of persons with diabetes are shaped. Every component of the framework allows for hypotheses testing about how trajectories of diabetes experiences might be impacted by changes to, for example the health system, policy environment or individual behaviour. Such interventions have the potential to affect diabetes related mortality outcomes.

Ethics approval and consent to participate

Not applicable in this context since it is a review paper

Consent for publication

Not applicable

Availability of data and materials

Please refer to supplementary file for review articles used.

Competing interest

None

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Authors' contributions

DK drafted the initial manuscript. RA and DK discussed the study and decided on the search strategy and wrote the methodology. DK, RA, MD and PD reviewed the manuscript. All authors have approved the final manuscript before publication.

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