

# A review of self-management of diabetes in Africa

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## Introduction

Diabetes is a chronic disease caused by a genetic or acquired deficiency in the production of insulin by the pancreas (type 1) or the ineffective use of insulin by the body cells (type 2).<sup>1</sup> It is characterised by high levels of blood glucose. Uncontrolled diabetes increases the risk of cardiovascular disease, stroke, nerve damage, foot ulcers leading to lower limb amputations, kidney failure, blindness, and premature death.<sup>2</sup> Diabetes requires lifestyle adjustments such as weight management, physical exercise, and appropriate diet, as well as use of medications to maintain normal glycaemia and reduce the risk of long-term complications.<sup>3</sup>

Due to the complex nature of diabetes management, and the need to alter everyday practice and choice to accommodate the disease, treatment rests primarily with the sufferers.<sup>4</sup> Self-management is a process in which individuals are actively involved in their disease management. This article seeks to explain the concept of self-management, and examine existing empirical literature on the self-management of diabetes in Africa. It will also highlight gaps in knowledge as well as implications for research.

## The burden of diabetes

Diabetes is one of the most prevalent chronic diseases affecting about 422 million adults worldwide.<sup>5,6</sup> Its overall prevalence quadrupled from 108 million in 1980 to 422 million in 2014,<sup>7</sup> and is expected to reach 642 million by 2040.<sup>6</sup> According to the International Diabetes Federation (IDF),<sup>8</sup> 14 million people had diabetes in Africa in 2015 and the figure is projected to reach 34 million by 2040. The above prediction shows a 142% surge in the prevalence of diabetes in Africa by 2040, compared with an expected 52% increase in the rest of the world. In Africa, 321 000 deaths were attributed to diabetes in 2015 and 79% of those deaths occurred in people under 60 years old.<sup>8</sup>

Type 2 diabetes, accounting for 90% of all cases of diabetes, has health, social, and psychological implications. It is the leading cause of non-traumatic amputations, blindness, and end-stage renal disease, and one of the principal causes of death from cardiovascular complications such as myocardial infarction.<sup>9,10</sup> Prolonged uncontrolled high blood glucose levels lead to damage to the heart, blood vessels, eyes, kidneys, and nerves leading to disability and premature death.<sup>5</sup> It doubles the risk of different types of cardiovascular diseases, such as coronary heart diseases and stroke.<sup>11</sup> It is also associated with many non-vascular diseases such as cancer, mental and nervous system disorders, infections, and liver disease.<sup>12</sup>

Diabetes like other chronic illnesses disrupts the physical, psychological, and social balance of an individual's life.<sup>13</sup> The disruption results from the physical limitations imposed on the affected individuals by the disease, as well as from the social and cultural implications of living with diabetes.<sup>14</sup> The need for modification of lifestyle such as a change in dietary patterns, maintaining blood glucose balance, and constant body watching/listening limits socialisation. The financial cost associated with diabetes also adds additional strain. Kralik et al<sup>15</sup> describe the chronic illness experience as living a restricted life, experiencing social isolation, and burdening others. Furthermore, complications of diabetes such as loss of sexual function, blindness, and loss of limb result in loss of sense of identity in individuals and change in social relationships.<sup>14,16</sup> Participants in the Diabetes Attitude Wishes and Needs (DAWN) study reported anxiety, fear, and worry about diabetes complications, depression, and a sense of hopelessness as challenges; they also reported being discriminated against in the work place.<sup>17</sup>

Diabetes has no cure, but is managed throughout the life of affected individuals with medications and lifestyle modification measures to maintain good glycaemic control, reduce the risk of complications, and improve the quality of life.<sup>5</sup> Funnell and Anderson explained that the chronic nature of diabetes, the complexity of its management, and the personal choices and daily decisions required in its management mean that just being adherent to medical advice is not enough for adequate management of the disease.<sup>18</sup> Many of the decisions and choices made in the daily management of the disease are done by affected individuals between hospital visits.

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Self-management is therefore promoted as the foundation of diabetes management.

## Self-management of diabetes

Self-management is the ability of an individual to manage the symptoms and consequences (physical, social, and lifestyle changes) of living with a chronic disease.<sup>19</sup> It is the ability of a person in conjunction with family, community and health professionals to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of a health condition.<sup>20</sup> In a qualitative metasynthesis of 101 studies, Schulman-Green et al<sup>21</sup> identified three major themes that represent processes of self management: focusing on illness needs (medical management); activating resources (identifying and benefiting from health, psychological, spiritual, social, and community resources); and living with chronic illness (processing emotions, adjusting to illness and the new self, integrating illness into daily life, and personal growth). Likewise, Corbin and Strauss, as cited in Schulman-Green et al,<sup>21</sup> described the work related to living with a chronic illness as illness-related work (medical management), everyday life work (maintaining, changing or creating new behaviours or roles), and biographical work (regaining altered sense of identity). Both findings describe three principal components of self-management as: taking care of ones' health and illness needs; learning new roles and learning to utilise resources to help one deal with day to day health, social and psychological consequences of living with chronic illness; and lastly learning to adjust to the new self by recognising and accepting the limitations imposed by the illness. Major tasks involved in diabetes self-management include healthy eating, being physically active, monitoring blood glucose, taking prescribed medications, good problem-solving skills, healthy coping skills, and risk-reduction behaviours.<sup>22</sup>

Studies have shown that self-management promotes adequate glycaemic control, reduces healthcare costs, prevents complications, and enhances quality of life.<sup>23-27</sup> However, the seemingly simple task of engaging in self-management is not without challenges. Poor self-management, resulting in high rates of diabetes-related morbidity and mortality among different ethnic groups as well as in developing countries, has been reported.<sup>8</sup> A systematic review, in which 80 studies were analysed to determine barriers to diabetes self-management, showed that negative attitude and beliefs about diabetes and its treatment, ignorance, differing cultural beliefs and values, financial resources, co-morbidities, and social support could facilitate or hinder self-management of diabetes.<sup>28</sup> This is the case in many developing countries.

A review of empirical studies on self-management of diabetes in Africa revealed that poor glycaemic control was recorded among more than 50% of persons living with diabetes across different settings.<sup>29-36</sup> Poverty, differing cultural and religious beliefs, and ignorance often

undermines self-management.<sup>29-31</sup> Poverty is recorded as a key factor that inhibits diabetes self-management.<sup>31, 32, 37</sup> In a cross-sectional study carried out at the University College Hospital Ibadan (the largest tertiary health institution in Nigeria) to explore the level of glycaemic control and adherence to diabetes self-management practices, only 44% of cohorts had adequate glycaemic control and 59% of participants were non-adherent to prescribed anti-diabetes drugs due to lack of finances.<sup>29</sup> Similarly, in another study to identify reasons for patients' non-adherence to prescribed oral hypoglycaemic medications in a 200-bed secondary healthcare facility in south-west Nigeria, more than two-thirds of respondents (82%) had never engaged in self-monitoring of blood glucose due to lack of affordability of equipment and lack of knowledge of its use. Also 35% of participants reported non-adherence to anti-diabetes drugs due to the high cost of medication.<sup>32</sup>

In addition, cultural beliefs and practices,<sup>30,31</sup> as well as family dynamics,<sup>30</sup> affect diabetes self-management in Africa. Family members have been known to play both a supportive and inhibitory roles in diabetes self-management, especially in the areas of meal planning and financial support. For instance, in many African households, meals are prepared centrally by the mother or sisters. This could affect diabetes self-management negatively in a situation where the person preparing the meals is not knowledgeable or inclined to accommodate the diabetic patient.

Differing health beliefs regarding causes of diabetes and expected treatment affect self-management. Researchers in Ghana<sup>38</sup> noted conflicting explanatory models of diabetes among persons living with diabetes in three urban communities in the country. Different understanding and beliefs regarding the causes and treatment of diabetes between healthcare professionals and patients often lead to conflicting expectations, poor self-management, and consequently poor disease outcomes.<sup>39</sup> For instance, the belief that diabetes is caused by supernatural causes may undermine care as patients may prefer to seek for solutions in prayer houses.

Other factors that affect self-management of diabetes among persons living in Africa include poor knowledge and practices of self-management,<sup>29,31,38,40</sup> little social support, and psychological distress.<sup>35,41</sup> Poor knowledge could result from low literacy levels or poor understanding, which could arise from lack of education by health professionals.<sup>42</sup> Many healthcare settings in Africa do not have structured diabetes self-management programmes – the only education given is done in the physician's office when there is an opportunity or obvious need.<sup>43,44</sup> People who are not educated may find it difficult to understand the pathophysiology of the disease as well as its management. Furthermore, ethnic differences in beliefs about diabetes and related management behaviours might inform initial disease conceptualisation, which might interfere with later understanding and acceptance of biomedical explanations.

## Gaps in knowledge and implications for research

All the empirical studies reviewed in this paper addressing self-management of diabetes in Africa from 2000 to 2015 were accessed from Medline and CINAHL. They focus on compliance to medical advice, which is only one aspect of self-management.<sup>21</sup> No study among those reviewed focused on partnership or collaboration between patients and healthcare professionals and none examined experiences of persons living with diabetes in Africa. Jackson et al observed that most persons living with diabetes in Nigeria rely on healthcare professionals to make decisions, set goals, and give instructions on what to do while they try to comply with the instructions.<sup>45</sup> Diabetes self-management requires cognitive, emotional, and behavioural skills to handle the complex decision making and self-management tasks involved in disease management.<sup>46</sup> The compliance model implied in the studies reviewed for this paper aligns with the medical prescriptive approach to care which evaluates the success of patients in managing their diabetes by their ability to adhere to a prescribed therapeutic regimen. This traditional compliance model does not enforce shared decision making or the independent thinking needed in diabetes self-management.<sup>47</sup> Diabetes self-management requires complex decision making to balance and maintain glycaemia; these decisions are made outside the physician's office and have a direct impact on disease outcomes. Therefore, the ability to make informed, healthy, and independent decisions and choices is paramount to successful self-management, and this cannot be achieved by simply adhering to a set of instructions.

The medical prescriptive approach to disease management has been judged ineffective in the management of chronic diseases.<sup>18,19,48,49</sup> A new model in which there is a partnership between healthcare professionals and persons with diabetes has been proposed for better disease outcomes.<sup>18,19</sup> In the partnering relationship, healthcare professionals provide self-management support that goes beyond providing information and includes helping patients to develop problem-solving skills, improve self-efficacy, and support application of knowledge in real-life situations.<sup>50</sup> Self-management support is a crucial aspect of diabetes management which must be provided at diagnosis and on a continuing basis.<sup>51,52</sup> The partnership and patient empowerment that result from this will help to increase the capacity of patients to think critically and make independent, informed decisions in their daily disease management for a better outcome.<sup>53</sup>

In addition, no study among those reviewed explored the experiences of individuals living with diabetes in Africa and how people with diabetes adjust and integrate diabetes self-management into their daily lives. Kneck and colleagues<sup>54</sup> argued that successful integration is necessary for achieving balance as well as adequate self-management, while control and decision making by others (healthcare professionals) objectifies the illness

(diabetes) and keep patients at the compliance level.

The idea of victim blaming shown in many studies on diabetes self-management in Africa will not provide a solution as people can only make an informed and healthy decision regarding their disease management when they are empowered through education and skills training. In view of the lack of understanding of diabetes and poor knowledge of self-management practices recorded in almost all the studies reviewed,<sup>43,44</sup> in addition to a lack of a national self-management education/support programme in many African countries, research should focus on examining the nature of partnership between people living with diabetes and healthcare professionals, as well as looking for ways to provide self-management support. Research should also be conducted to explore the experiences of people living with diabetes in Africa. Such studies will help to shed light on how contextual factors such as cultural beliefs, values, and practices influence the understanding and management of diabetes; as well as reveal possible reasons for poor glycaemic control and poor self-management.

## Conclusions

Diabetes is a chronic disease with dire physical, social, and psychological implications. Being a life-long disease with the need for lifestyle modifications, self-management is regarded as the foundation of its management. Major components of self-management include medical management, a partnership with healthcare professionals, and adjusting to life with chronic disease. Most of the research studies carried out in Africa focused on the medical prescriptive approach (medical management) to self-management. A look at the two other components of self-management would shed light on the reasons for the poor self-management of diabetes and poor glycaemic control prevalent in many African countries.

## Author declaration

Competing interests: none.

Any ethical issues involving humans or animals: none.

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