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Chapter

Family-Centered Diabetes Care for Better Glycemic Outcomes of Outpatients in Rural Areas

Mabitsela Hezekiel Mphasha and Tebogo Maria Mothiba

Abstract

Most of diabetes care of outpatients takes place at their families. Family members who may have inadequate or lack diabetes knowledge are expected to offer home care, predisposing patients to poor outcomes and associated health problems. To review and discuss literature related to family-centered diabetes care. Comprehensive Literature Review was used to collect data by reviewing literature related to family centered diabetes care. Literature review involved evaluating discoveries of other researchers. The results of literature review showed that family-centered care is essential for better diabetes outcomes and preventing new cases. So far, family-centered care was successful in children's diabetes care and may be beneficial for older outpatients. Family-centered diabetes care improves knowledge of both patients and families, minimize prevalence and improve diabetes outcomes of outpatients.

Keywords: family centered diabetes care, diabetes, family, outpatients, literature review

1. Introduction

The International Diabetes Federation (IDF) [1], pointed out that rising cases of Diabetes Mellitus (DM) are a threat to the public health sector and seventh leading cause of death in South Africa [2]. In Africa, South Africa (SA) is the fifth country with the highest population of diabetes patients which is estimated at 2.6 million and more than 1.5 million people with undiagnosed diabetes mellitus [3], specifically, Type-2 Diabetes Mellitus (T2DM), remains more common where 2 million persons have been diagnosed with T2DM in SA [4]. Diabetes has recently been found to be a high risk Non-Communicable Diseases (NCDs) linked to COVID deaths worldwide. Central to DM prevalence is obesity which is a leading predisposing factor to all NCDs.

Family members of diabetes patients are already at risk of developing the disease due to family history. Physical and mental health of family members may be negatively affected while taking care of diabetes patient, leading to compromised patient care [5]. Hence the introduction of Family Centered Care (FCC) to lessen the negative consequences of caregiving for individuals diagnosed with DM. Rural areas such as Limpopo Province in SA, have been progressively urbanized, which has led to adoption of unhealthy lifestyles such as physical inactivity and bad eating habits, resulting in rising prevalence of obesity which contribute to poor diabetes outcomes and complications [6].

So far, family-centered diabetes care has been successful and produced better diabetes outcomes in children, who are helped by family members to carry certain relevant tasks related to self-care practices [7]. Less focus has been given to older people who are mostly affected by diabetes [3]. Therefore, this book chapter is intended on closing the gap by advocating for the family-centered diabetes care among older outpatients at rural areas.

2. Diabetes burden

Approximately 9% of people worldwide have diabetes and that 90% of the diabetic cases are Type 2 Diabetes Mellitus (T2DM) cases [8]. Over 80% of diabetes cases are those living in developing countries [9]. Type-2 diabetes is rising in Africa and threatening public health sector particularly because it is predisposing factor to various NCDs including diabetes, and its prevalence is anticipated to increase by 110% over the next two decades, from 19.8 million individuals in 2013 to 41.5 million by 2035 [1]. Inactive lifestyle characterized by lack of exercise and poor eating habits are a problem in South Africa leading obesity and subsequently increased diabetes prevalence and complications. Around 7% of South Africans aged 21 to 79 years have diabetes mellitus [1]. The prevalence of DM among South Africans aged 30 years or more has expanded since 2009, and 11 million increase are anticipated in the year 2020 [10]. Statistics SA [2] further points out that diabetes mellitus and different types of heart diseases are part of the ten leading causes of death in all parts of SA. The StatsSA [2], reported that Limpopo Province has DM prevalence rate of 5.2% and is the fourth province with highest DM prevalence, while Western Cape Province leads with of 6.9% DM prevalence.

3. Provision of diabetes healthcare services to outpatients

Diabetes outpatients receive treatment at Primary Health Care (PHC) facilities, which is nurse driven. The South African Department of Health, in an attempt to manage chronic diseases including DM introduced Chronic Disease Outreach Program (CDOP) to follow-up on patients, particularly those with NCDs [11]. In line with CDOP, health professionals such as general practitioners, dietitians, physiotherapists and psychologists regularly visit PHC facilities to see patients requiring their services. Diabetes patients are required to consult these healthcare professionals 2–3 a years. The introduction of the outpatient's services in SA helped in reducing management costs which are imposed by mere presence of diabetes, and more costly in the presence of complications. The outpatient services also helped in improving family involvement in the care of loved ones.

4. Assembling diabetes team for the care of outpatients

The diabetes team for the treatment and care of outpatients at PHC facilities with recognition of the outreach programs by other healthcare professionals who may not be full time at the PHC facilities, and are as follows:

5. Family-centered diabetes care

The FCC is defined as "provision of healthcare in partnership or in recognition that the family has a role to play in the treatment of persons living with chronic

diseases and specifically diabetes" [12]. The FCC is an approach of responding to the needs, values and cultural needs of the patient and FMs [13]. The FCC begins from consultation at the healthcare facility involving healthcare professional, patients and family members, being involved in decision making and shared leadership [14]. Family Members are often asked to share responsibility in support of person living with diabetes, and such activities includes driving patients to appointments, and social and emotional support among others. The FCC in diabetes care has so far produced better outcomes in younger children who are usually cared for by their parents or families, since younger children are unable to perform certain tasks related to self-care [7]. However, the FCC have so far failed to utilize same family support for better care of older people who are mostly affected by diabetes [1].

The aim of the FCC is to maintain and strengthen family bond and roles so as to provide healthy family functioning, and at the same time improving the Quality of Life (QoL) of patients, as well as minimizing new cases involving family members who are already at risk due to family history. Despite the benefits of adequate diabetes knowledge, it is worrisome that international knowledge and awareness of diabetes stays low [15]. In SA, diabetes knowledge among T2DM patients in most affected areas is reportedly inadequate [16]. It is essential for healthcare providers to assess knowledge of patients and family members so as to design appropriate diabetes intervention and educate properly. Therefore, the FCC seeks to close the knowledge gap through family-patient consulting healthcare provider together.

6. Principles of family-centred care

The FCC principles are frequently aligned with a vision of effective health care delivery as described by Johnson and Abraham [17], and are as follows:

- **Information Sharing**: This principle acknowledges that healthcare practitioners, patients and family members all must share information for better care of patients. See **Table 1** on responsibilities of diabetes team. The process of sharing information should be open, objective and without bias [17]. Patients and family members timely are empowered with complete and accurate information for the care and decision-making [18].

- **Respect and Dignity:** Healthcare professionals need to understand that patients are vulnerable and do their best to maintain patients' dignity [19]. After healthcare professionals have discussed medical options with patients and family, they should respect that patients have final decision [17].

- **Participation:** This principle acknowledges that patients and family members have role to play in the care, after being empowered with diabetes care information [18].

- **Collaboration:** This principle acknowledges that healthcare professionals must primarily involve and engaging patients as the main consumer on the involvement or adoption of family-centered care for its successful implementation. Furthermore, once patients have been engaged and approved adoption of FCC, in the provision of ongoing diabetes self-care education and support, patients, families and healthcare professionals jointly make diabetes interventions programs together that considers the needs, strengths, values, and abilities of recipients [17].

Diabetes team	Responsibility
General Practitioners	Clinically assess the patients
	Provide required medical interventions
Nurses	Assess and refer patients and their families to multi-disciplinary team
	Establish diabetes support groups at the PHC facilities
Dietitians	Provide dietary care services
Physiotherapists	Provide exercise care services.
Psychologists	Provide psychological and behavioral care services.
Social workers	Provide services on how best to cope with the disease and also on social relief or grants for the care of diabetes patients.
Patients	Recipient of family-centred diabetes care and share experiences of living with diabetes.
Family members	Recipient of family-centred diabetes care and advocate for patients by expressing additional health challenges which the patients has omitted.
	Provides emotional support to the patient, and care at home.

Table 1.
Diabetes team and their responsibilities.

7. Diabetes self-care, self-care activities and its adherence

Diabetes self-care is explained as "evolutionary process of development of knowledge or awareness by learning to survive with the complex nature of the disease within social context" [20]. Diabetes education is critical and must be practically translated into activities for the achievement of better diabetes outcomes. The self-care activities includes adherence to dietary plan, avoidance of fatty food, regular physical activity and self-glucose monitoring, and foot care, taking of medication (insulin or an oral hypoglycaemic agent), and cessation of smoking [21]. In addition, self-care activities includes good problem-solving skills, healthy coping skills and risk-reduction practices [20]. Integrating self-care activities into patients' daily routine improves diabetes outcomes, minimizes chances of developing complications and diabetes related health problems. Compliance or adherence to diabetes treatment remains a problem, in spite of the advantages of integrating the self-care activities into patients' daily routine.

Diabetes Self-Management Education and Support, and Family as provider of home care to patients.

Diabetes Self-Management Education (DSME) is regarded as "the process of facilitating knowledge, skill, and ability necessary for diabetes self-care" [18], and is provided by healthcare providers. Multi-disciplinary team provides various diabetes care services, therefore, a clear referral system should be developed and implemented. The DSME is provided with the sole purpose of capacitating both patients and family members with skills and knowledge required in self-care practices. Adequate diabetes care knowledge may pursue both patients and their family members to follow healthy lifestyle healthy lifestyle [15], so as to prevent diabetes complications and also reduce new cases, respectively. Sufficient diabetes knowledge also minimizes risk of comorbidity which impact significantly the QoL of patients [22]. However, Ajzen et al. [23] argued that adequate knowledge alone is not sufficient for the adoption of healthy lifestyle, it should be accompanied by positive attitudes. There should be collaboration between the health sector and the

family, since collaboration is one of the principles of FCC. Among the families of patients, there should be dedicated person to represent the family in the interaction and consultation with patients at the healthcare facilities [24]. Spouses and parents can be in charge of both their partners and children; respectively, however, the families may as well nominate a member to represent them. In ensuring the success of the FCC, the healthcare professionals may assure the families that they will be listened, supported and that their doors will forever be opened for any challenges encountered to ease the home caregiving. The family receives home care through consulting together with patients or DSME program. The outpatients receive their diabetes treatment at PHC facility, which is inadequately resourced with other healthcare workers such as dietitians and physiotherapists, who support the PHC facilities. Therefore, there is a need for a well-organized and structured education programme for people living with diabetes for the DSME to be fully functional at PHC level.

Whereas, Diabetes Self-Management Support (DSMS) refers to the "support that is required for implementing and sustaining coping skills and behaviours needed to self-manage on an ongoing basis, and it is provided by family members with recognition that most care happen at the families patients reside" [18]. Family plays especially significant role in diabetes care for better glycaemic outcomes. A study involving 5000 diabetes patients recognizes importance of family, relatives and colleagues in improving well-being and self-management of diabetes [25]. Home care refers to "health or social service provided by formal and informal caregivers to the recipient" [26]. Informal home caregivers are explained as "individuals actively and directly involved in the patient care and support at home without earning any salary for caring and supporting the patients" [27]. The FMs maybe distressed by diabetes status of their loved ones, particularly when they have poor knowledge of the condition or not knowing how best to provide support [25]. Families sometimes have misconceptions, like believing that their loved ones living diabetes know more about the management of the disease, than they actually report. The family as informal caregivers are usually not trained in the care of patients; and as such families are underutilized resource. The success stories related to home care for diabetes patients includes adherence to diabetes treatment and improved quality of life and reduction of prevalence. However, failures of home care which often occurs in the event of inadequate diabetes knowledge includes poor diabetes outcomes and quality of life. Hence the need for family centered diabetes care to improve knowledge of both family and patients.

8. Why adopt family-centred care in diabetes management

Lack of adequate knowledge about illness and inadequate social support contribute to poor control of diabetes [25]. The adoption of FCC is aimed at capacitating both family members through the DSME together with patients at the healthcare facility, which capacitate and empower them with knowledge on how to best become healthcare providers at home, where most of the diabetes care takes place. Adequate social support from knowledgeable family members helps in preventing, delaying and minimizing the severity of diabetes complications, as well as reducing the chances of family members from developing diabetes. Family members are informal healthcare providers at home as they primarily provide Diabetes Self-Management Support. The QoL is regarded as "an estimation of well-being as well as the measurement of health and the effects of health care" [28]. In order to achieve better QoL, it is important to adhere to diabetes treatment and adopt

a healthy lifestyle [3]. Adequate family support also helps in achieving good QoL [29], particularly when the family are knowledgeable with regard to diabetes care.

9. The type of support a family can give to diabetes patients

Living alone is linked with increasing depression, poor diabetes outcomes and increased mortality [30]. The family support and care for patients, with daily living activities which includes meal preparation and consumption, physical activity, collection of medication, bathing, distribution of household chores, bathing and clothing, and honoring of medical appointments. Families also help patients cope `with the diabetes and also may be required to financially support the patients so as to daily meet the activities of daily living. Quality of life and better glycaemic outcomes have been associated with better income [31].

9.1 Supporting family

Family communication needs to be improved during DSME, and also empower them with knowledge and skills essential in positively influence patient health behaviors and subsequently diabetes outcomes. Lack of diabetes care knowledge among family members, result in stress of not knowing how best to care for loved one in need of support, hence adoption of family centred diabetes care empowers family and minimizes the negative psychological impact. Exclusion of families during consultations may lead to families having misconceptions that patients know more about diabetes management than actually patients know, relying on the patients to report to them on how to best care for them [24], leading to inappropriate care. Educating families on diabetes care needs and why the changes are necessary can aid in easing the stress brought along by inadequate knowledge. The family may as well need to be educated on the coping skills. The effective family involvement in diabetes care may help the family accept the lifestyle modifications for the patients and family members' health considering that they are already at risk due to family history [29]. Additional information which should be provided to the family during consultation includes information about the disease, possible treatment alternatives and stress management skills, as well as helping them plan for the future [32].

10. The negative ways family can affect diabetes

Actions of family members in providing support to diabetes patients may be harmful and lead to poor diabetes outcomes [33], particularly when family members who are not trained about care, are not capacitated through DSME on self-care activities. Family culture, way of living and problem-solving skills may additionally contribute in harming the patients and resulting poor diabetes outcomes. The required diabetes self-management activities may be in conflict with the traditional family way of cooking and eating, which may prompt family to not accept the lifestyle modification and new way of doing things [33].

Family members usually support the patients at home through food preparation and may compromise and sabotage patients through cooking and serving unhealthy meals, tempting patients to consume unhealthy food for the sake of peace at home [30]. Additionally, the family members may also discourage patients from regularly taking medications and its adherence, particularly when the patient relies on them for getting and taking medications and meals. Hence the need for family centred diabetes care to minimize the ways family can negatively impact on patients' outcomes for better glycaemic outcomes.

11. Barriers to family-centered Care

- **Understanding Family-Centered Care:** Lack of understanding of the concept of family-centered diabetes care by both healthcare providers and patients may negatively impact on its successful implementation. Hence, there is a need for in-service training of healthcare providers on the family-centered diabetes care for better outcomes [25]. Policy makers and legislatures develops and introduces policies, whilst healthcare providers at any setting are the drivers or implementers of the policies. The drivers of policies need to be trained on the pros and cons of FCC in diabetes care and also given guidelines on family centered diabetes care to minimize confusion and for effective implementation.

- **Support for Practices**: Loss of income and employment may affect provision of support to patients as required by the FCC. Repeated visits and honoring of medical appointments should be observed, and that the spirit of humanity must at all times prevail so as to enable consistent support and care during the loss of income [24]. The South African Government introduced Old-Aged Grant, of which diabetes patients are among the beneficiaries considering that diabetes affects mostly the elderly. The introduction of old-aged grants in SA helped the elderly persons getting and needed support from the family members. Also, the families must be empowered with diabetes care knowledge and how it could also benefit their health, so as to minimize the presence or absence of income being motivating factor for provision of support.

- **Research:** Research helps in informing policy developers, healthcare providers, patients and family members on what should be done in the provision of health formal and informally to the patients. Therefore, lack of adequate research on family centered diabetes care for outpatients may negatively impact on the adoption and implementation of the family centered diabetes care.

12. Advantages of family-centered diabetes care

- **Reduces the diabetes treatment costs:** Diabetes is costly disease to manage, and more costly in the presence of complication. It has been reported that the global diabetes management cost amount to $1.31 trillion, which accounts to 1.8% of 2015 global gross domestic product [34]. The FCC reduces diabetes associated hospital admissions and readmissions costs [35], as well as estimated lifetime health care costs.

- **Improvement of Hemoglobin:** Hemoglobin A_{1c} (HbA_{1c}) improves by 1% in T2DM patients [36].

- **Reduces/prevent complications:** The FCC prevent, delays and minimizes the severity of diabetes complications, improve quality of life and better glycaemic control through lifestyle behaviors such as healthy eating habits, regular physical activity and adherence to intake of diabetes medication.

- **Improves the clinical and psychosocial aspects of diabetes:** The presence of diabetes affect the quality of life of patients and also brings along emotional and psychological burdens resulting in stress and depression, which worsens in the presence of complications such as erectile dysfunction.

13. Conclusion

Adoption and implementation of the family-centred diabetes care can assist in improving better glycaemic outcomes in older diabetes outpatients It will also help in improving knowledge of both patients and family members for improved quality of life and reduction of new cases.

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Author details

Mabitsela Hezekiel Mphasha* and Tebogo Maria Mothiba

1 Department of Public Health, University of Limpopo, South Africa

2 Faculty of Health Sciences Executive Dean's Office, University of Limpopo, South Africa

*Address all correspondence to: pitso85@gmail.com

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