

# Primary health care–family partnership for better diabetes outcomes of patients: a systematic review

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**Background:** Diabetes mellitus is a lifelong disease requiring daily self-care activities for better outcomes. Although most of these self-care activities for outpatients are taught in primary health care, their actual practice occurs at home where patients stay. Family dynamics or established cultures impact the management of the disease, hence a need for primary health care–family partnership to empower both families and patients with ways to manage the disease. This systematic review aims to describe the primary health care–family partnership.

**Methods:** The literature was sourced using Preferred Reporting Items for Systematic Reviews and Meta-Analysis. The Scopus/Elsevier, ScienceDirect and PubMed databases were used to source literature written in English and published between January 1, 2010 and July 31, 2022. Studies were included if focused on self-care activities, management and family-centred care (FCC); participants were diabetes patients and non-diabetic family members; and primary health care diabetes intervention.

**Results:** A total of 62 publications that met inclusion criteria were used in this review. The included studies include quantitative, qualitative and mixed-method studies, including reports. The process of including these publications involved identification, screening and re-screening in line with set eligibility. The key search strategies resulted in the following sub-headings: diabetes self-care, diabetes self-management education and support (DSMES), family-centred care, and primary health care.

**Conclusion:** Evidence from existing literature shows that primary health care is the source of information, yet actual diabetes management occurs at home. This review recommends the adoption of DSMES and FCC modalities to set the foundation for workable primary health care–family partnerships. The adoption of these joint modalities for partnerships will outline the dos and don'ts in managing diabetes at home. The literature further indicates that family support is critical, therefore primary health care–families partnership may lead to improved adherence to self-care activities and better outcomes.

**Keywords:** diabetes self-management education and support, family-centred care, home, primary health care–family partnership, review

## Introduction and background

Diabetes mellitus (DM) is a lifelong condition, which when inadequately managed leads to serious complications and lower health status and quality of life for patients.<sup>1,2</sup> Patients are required to perform self-care activities on their own to manage their diabetes.<sup>3</sup> Seven self-care activities include healthy eating, physical activity, glucose monitoring, medication adherence, effective problem-solving techniques, healthy coping, and risk reduction. These self-care activities have so far been demonstrated to be crucial to improve diabetes outcomes.<sup>4</sup> Additionally, it was discovered that these self-care activities were positively linked to improved glycaemic management, fewer problems and a higher quality of life.<sup>5–7</sup> Diabetes self-care calls for patients to make dietary and lifestyle changes with the assistance of healthcare professionals to successfully change their behaviour.<sup>8</sup> Diabetes self-management and ongoing support are crucial components that influence metabolic and psychosocial outcomes.<sup>9</sup> However, given that the vast majority of daily diabetes care is provided in patients' homes, family support is therefore essential. It was found that patients rely mainly on personal knowledge and skills in managing disease, but family support remains crucial.<sup>10</sup> Moreover, families may help in the execution of these critical seven self-care activities.

Family in this context refers to a group of persons living together in a household. Family members can assist with

daily tasks, particularly the distribution of household chores.<sup>11</sup> The involvement of the family enhances the quality of care provided to patients.<sup>12</sup> As the prevalence and incidences of diabetes increases there is a need to involve and collaborate with families.<sup>13</sup> The history of diabetes within a family has been found to be increasing the chances of other family members developing the disease.<sup>14</sup> Therefore, their involvement in diabetes care through the adoption of the family embracing the culture of an active lifestyle and healthy eating would lessen the likelihood of acquiring the disease. Adequate and consistent family support has been linked to improved glycaemic outcomes and quality of life.<sup>15</sup> Family support is crucial for enhancing well-being and self-management, including enhancing family cohesion, according to studies.<sup>16,17</sup> It was found that the actions of family members may be harmful to patients' outcomes, particularly when not knowledgeable.<sup>11</sup> Despite advantages linked with family support, families may not know when and how to give patients the right care, which could make their actions harmful to patient outcomes. Therefore, it is crucial to assess the knowledge of family members on how best to care for family members with diabetes. Knowledge is considered a critical component in diabetes care. Hence, this study intends to describe primary health care–family partnership to empower families equally on how to best care for and support patients.

There is currently a lack of information regarding how best family members can provide support to patients. This is despite the recognition of importance of family support and most of the care occurring at home. Most countries have not yet incorporated family support in diabetes care, despite new American Diabetes Association guidelines on diabetes self-management education explicitly recommending it.<sup>18</sup> Families have been shown to be actively involved in the care of children and seriously ill patients compared with adult outpatients.<sup>19</sup> The necessity to collaborate with patients' families in their treatment is recognised at the same time, although the best way to do so and who is responsible for what is not quite obvious. This paper aims to review and describe the primary health care–family partnership in diabetes management.

### Methods and materials

In this work, a systematic review was undertaken. Therefore, performing this review did not need any ethical permissions or authorisation to be obtained to conduct the study. This review describes primary health care–families partnership in the care of patients living with diabetes. This review included two processes of reviews. The first review involved the identification of the studies relating to the topic and further screening. The second review involved a reassessment of the screened publications in line with the set eligibility criteria. Publications were first identified from various electronic databases. These publications included quantitative, qualitative and mixed-method studies. It also included reports from the World Health Organisation, the International Diabetes Association, and the American Diabetes Association.

### Search technique

The search approach involved compiling and summarising current and pertinent literature using Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA). The data were searched several times, and duplicates were eliminated. In the beginning, search terms like 'family support', 'family-centred care', 'home-based diabetes control' and 'self-management' were used. In the field for the abstract and title, these terms were inserted as the medical subject heading. The results of searches that were later restricted to works published between January 1, 2010 and July 31, 2022 and excluded those not written in English.

### Eligibility criteria

According to the following predetermined inclusion and exclusion criteria, studies were evaluated for eligibility:

### Inclusion

- Diabetes-related articles focusing on self-care activities, management, and family-centred care.
- Studies that included patients living with type 1 and type 2 diabetes mellitus, and/or non-diabetic family members.
- Primary health care intervention to improve diabetes outcomes of outpatients.

### Exclusion

- Studies involving as participants admitted diabetes patients in the hospital setting.

### Study selection

Papers published between January 1, 2010 and July 31, 2022, were looked for in the Scopus/Elsevier, ScienceDirect and PubMed databases for this study. Relevance of abstracts was examined based on inclusion criteria, and duplicates were eliminated.

### Results and discussion

Figure 1 shows the flowchart of identification and inclusion of publications in this review. A total of 1 102 publications were initially identified in the first review. Moreover, a total of 234 duplicates were removed resulting in 859 publications. Further screening involved assessment of abstracts, which eliminated 235 and left 624 publications remaining.

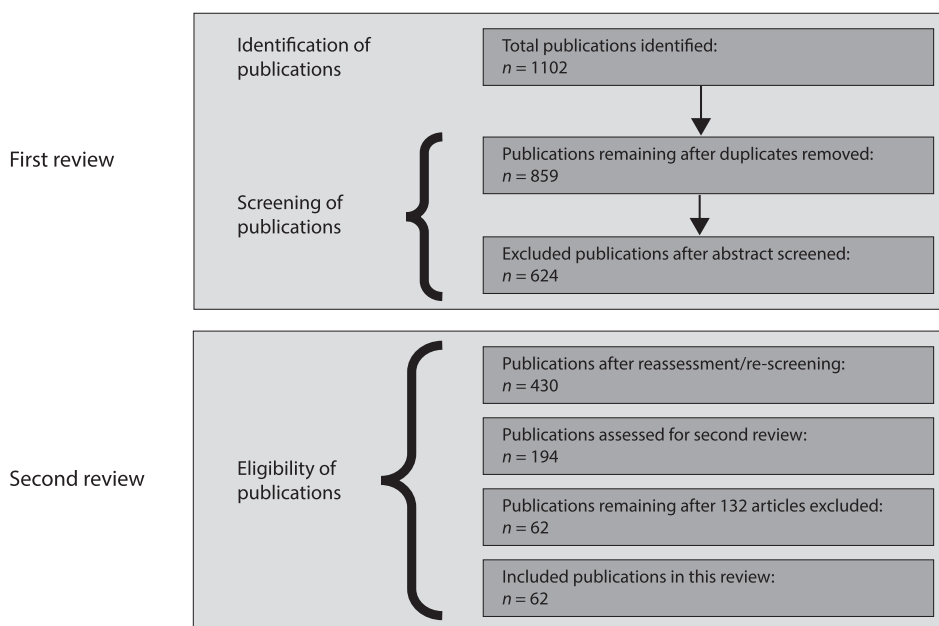
The main eligibility of this review was publications between January 1, 2010 and July 31, 2022. The second review begins with a reassessment of the 624 publications to identify those published within the set eligibility criteria. This process eliminated 430 publications, resulting in the remaining 194 publications. Furthermore, publications were assessed to check whether they meet the inclusion criteria, which led to the elimination or exclusion of 132 publications. Therefore, a total of 62 publications are included in this review.

Table 1 indicates that 37% of publications were associated with family-centred care, and 27% with diabetes self-care activities, followed by 18% linked with diabetes self-management education and support, 10% linked with primary health care, and 8% linked with diabetes and its predisposing factors.

### Diabetes self-care activities

Patients' adherence to self-care activities is a crucial component of the treatment of chronic diseases. It places a strong emphasis on education and self-care abilities and encourages patients to actively participate in creating and managing their treatment plans.<sup>8</sup> So far, it has been established that patients living with diabetes do not adhere to medication use.<sup>20,21</sup> In addition to taking prescribed medications, there are other healthy pursuits that can enhance diabetes patients' quality of life and help to better prevent and manage the disease.<sup>5</sup> Foot care is also recognised as a fundamental self-care activity. The American Diabetes Association further outlined self-care activities that include healthy nutrition, regular physical activity, regular blood sugar monitoring, regular medication use, good problem-solving abilities, healthy coping mechanisms and risk-reduction behaviours.<sup>22</sup> These American diabetes self-care activities could be adapted to the African context. However, feasibility studies are required for adoption in Africa because of different settings. Regular participation in these activities is linked to successful outcomes in diabetes patients.<sup>23</sup>

Various types of research have demonstrated that engaging in and adhering to diabetes-related self-care activities enhances glucose control.<sup>20,24</sup> Adherence to self-care activities could lead to a drop in HbA1c of up to 1%.<sup>23</sup> As a result, microvascular problems such as diabetic retinopathy, cataracts, neuropathy, nephropathy, heart failure and amputations are reduced by about 25%.<sup>25,26</sup> In addition to improved glucose control, adherence to diabetes self-care activities improves physical and psychological health.<sup>6</sup> Psychological problems such as stress, worry and emotional instability were found to be widespread among patients living with diabetes.<sup>7</sup> Poor self-care activities among patients living with diabetes have a significant impact on the development of the disease and its complications.<sup>27</sup>



**Figure 1:** Flowchart of identification and inclusion of publications (adapted from McCalman *et al.*<sup>20</sup>).

**Table 1:** Publications per sub-heading

Sub-topics included in the review	Number of publications	
	Frequency (n = 62)	Percentages
Diabetes self-care activities	17	27%
Diabetes self-management education and support	11	18%
Family-centred care	23	37%
Primary healthcare	6	10%
Diabetes and its predisposing factors	5	8%

In order for health professionals to create effective interventions, it is crucial to analyse the levels of self-care activities as well as the factors affecting adherence.<sup>8</sup> Numerous studies have so far shown that adequate diabetes self-care activities are necessary to effectively manage the disease’s development.<sup>6,7</sup> Patients living with diabetes find it challenging to carry out and integrate diabetes self-care tasks into their daily lives.<sup>7</sup> Therefore, there is a need to motivate and enable patients to boost their self-care activities through a change of attitudes towards treatment. A comprehensive approach is required to improve adherence to self-care activities. Patients must be assessed to establish factors that could influence self-care activities. Demographic, socioeconomic, psychological, health state and the healthcare system have all been found to influence self-care actions thus far.<sup>28,29</sup> It is crucial to give patients the tools they need to take an active role in managing their own health.<sup>30</sup> At this time, the autonomy principle takes effect, and all healthcare professionals are obligated to uphold this ethical principle. Patients need to be informed, empowered and supported in their decision-making. Family support has been found to be critical in diabetes treatment and adherence to self-care activities.<sup>31, 32</sup>

**Diabetes self-management support and education**

The process of actively engaging in self-care activities with the intention of improving one’s behaviour and well-being

is known as self-management.<sup>33</sup> A key component of diabetes care is lifestyle management, which involves lifestyle adjustment, self-management support and education.<sup>34</sup> Diabetes self-management education and support (DSMES) is considered one of the primary components of comprehensive diabetic medical care, along with medication/insulin, diet, and exercise.<sup>18</sup> The advantages of DSMES are extensive and include improved clinical, psychological and behavioural outcomes.<sup>18</sup> This also leads to improved haemoglobin A1c (HbA1C) levels.<sup>27</sup> When compared with patients receiving care using a range of modalities, including lifestyle changes alone, and oral and injectable medication, it has been discovered that DSMES causes an average HbA1C reduction of 0.45–0.57%.<sup>35</sup> DSMES aids in the prevention or avoidance of worsening of problems connected to diabetes as well as mortality from all causes.<sup>18,36</sup> Additionally, it raises the quality of life and encourages lifestyle choices like healthy meal preparation and regular exercise.<sup>18</sup> Participation in DSMES services also improves self-efficacy and empowerment, fosters healthy coping and lessens discomfort due to diabetes.<sup>18,37</sup>

Despite these advantages, the DSMES model is not widely used, because of a lack of support financially and in terms of commitment to the importance of DSMES participation and access.<sup>18</sup> The DSMES model is economical, but resources must be committed to reap its advantages. As a result, the DSMES model needs to be tested in a variety of contexts before being officially approved as a diabetes management strategy. The goal of DSMES is to provide patients with the information, abilities and confidence they need to take ownership of their self-management.<sup>35</sup> This entails working with their medical team, making knowledgeable decisions, resolving issues, creating personal objectives and action plans, and managing their emotions and daily stresses.<sup>38</sup> All healthcare systems and/or providers must determine the appropriate resources that are available in their local regions, as a commitment to this model of care. The DSMES resources in the health system and communities must be known to healthcare professionals for them to make the proper referrals.<sup>18</sup>

There are crucial occasions to offer and alter DSMES: (1) at diagnosis, (2) yearly, (3) when treatment goals are not being met, (4) on the emergence of complications, and (5) when transitions in care and life take place.<sup>18</sup> People living with diabetes require most help during these crucial periods to complete and/or modify their goals and care plans for effective daily self-management.<sup>18</sup> Diabetes is a chronic disease that worsens with time and calls for vigilant attention in order to adapt to changing conditions or circumstances. Therefore, there is a need for continual assessment, ongoing education and learning, self-management planning and ongoing assistance.<sup>39</sup> Family members offer continuous support with regard to the implementation of self-care activities such as medication intake and adherence,<sup>40</sup> and monitoring blood pressure and glucose levels, which are directly linked to effective diabetes management.<sup>41,42</sup> Community healthcare workers (CHWs) can also reinforce the DSMES principles at home. Healthcare workers at the clinic can tell patients how to support diabetics, while CHWs can show them how at home. The CHWs within the South African context encompass the provision of health services by formal and informal caregivers within the home. They are part of the primary health care re-engineering and responsible for bringing healthcare closer to communities, families and individuals, even in the most rural and underserved areas.<sup>43,44</sup> So far, the CHWs' interventions are recognised as a viable and effective strategy for improving diabetes outcomes because they usually deal with difficulties at both the individual and community levels.<sup>45</sup>

### **Family-centered care**

Over the past few decades, the family-centred care (FCC) model has been marketed as a cutting-edge method of delivering healthcare services.<sup>46</sup> This approach accommodates the needs of both the patient and their family members.<sup>47</sup> It recognises that the process of caring for a patient may lead to deterioration of a family member's physical and emotional health, financial situation and social life. This could result in a decline in the standard and sustainability of home care/support the patient requires.<sup>13</sup> The FCC is regarded as a partnership approach to health decision-making between the family and the healthcare provider in the care of the patient.<sup>48</sup> Family involvement has long been recognised as an important aspect of managing one's health.<sup>49</sup> The concept of actively involving the family in care emphasises the idea of collaborative relationships that benefit patients, their families and healthcare professionals.<sup>50</sup> The FCC emphasises the significance of taking into account families and significant others as partners or collaborators in the care of family members with diseases.<sup>51</sup> Established families cultures could affect how patients treat their condition,<sup>52</sup> particularly when family members lack knowledge of appropriate dietary intake. The FCC allows for patients and their family members to consult together in the health care, to improve knowledge for adaptation to a healthy culture of eating and exercise.<sup>53</sup>

The FCC is built on respect for family members' roles as care partners, cooperation between family members and the medical staff, and preservation of family unity.<sup>54</sup> In order to help the person with diabetes, family members are frequently asked to share the duty. These responsibilities involve, among other things, taking patients to appointments and providing social and emotional support. Family members are required to assist patients in important diabetes care decisions, such as managing medication side effects.<sup>55</sup> Patients are supported and cared for by their families throughout everyday activities

such as meal preparation and consumption, exercise, medicine collection, bathing and dressing, home chores and attendance at medical appointments. Families assisting patients managing disease may be required to provide financial support so that they may carry out their everyday activities. Support from family has been linked to better glycaemic outcomes and life quality.<sup>15</sup>

The FCC aims to preserve and improve family ties and roles in order to promote healthy family functioning, while also enhancing patients' quality of life (QoL) and reducing the number of new cases involving relatives who are already at risk due to family history.<sup>12</sup> The reduction of treatment costs,<sup>56</sup> prevention or reduction of complications,<sup>11</sup> improvements of haemoglobin A1c by 1% in T2DM patients,<sup>57</sup> and improvement of the clinical and psychological impact of diabetes by enhancing the quality of life are all advantages of family-centred diabetes care.<sup>11</sup> As younger children are unable to undertake some self-care chores, the FCC in diabetes care has so far resulted in better outcomes for younger children who are typically cared for by their parents or family.<sup>58</sup> Loss of income and insufficient research on family-centred care in diabetes were found to be contributing factors to non-adoption of this model.<sup>59,60</sup> Therefore, this model could be useful in the care of outpatients living with diabetes, considering its benefits. However, further factors affecting the adoption of this model should be investigated or explored.

### **Primary care**

Primary care refers to services offered by medical professionals at the patient's initial point of contact within the healthcare system.<sup>61</sup> Primary care concentrates on individuals and families and is illness prevention oriented. This level of care offers the possibility of continuity of care by enabling early diagnosis, treatment, and referral to secondary and tertiary care. Primary health care (PHC) services are essential in providing comprehensive care and a continuum of care for patients who frequently interact with the health system for treatment.<sup>62</sup> Instead of addressing the social or environmental elements that impact disease progression, primary care should place a greater emphasis on preventative interventions.<sup>58</sup> The main components of PHC include the principles of equitable distribution of health services, efficiency and effectiveness in the provision of health services, and others. Through properly coordinated primary health care systems, these components may help to improve community health including that of family members.<sup>61</sup>

Even though primary health care is recognised as a source of information on managing diabetes, the main challenge is incorporating self-management into clinical practice to meet patients' demands.<sup>62,63</sup> According to Thórarinsdóttir and Kristjánsson,<sup>64</sup> patient involvement could bridge the gap between the patient and HCP's two distinct roles. Patient engagement entails participating in the planning of care, exchanging knowledge, setting one's own goals and engaging in self-management activities.<sup>64</sup> This should be done in conjunction with family involvement to reduce the prevalence and occurrence of diabetes. Therefore, working with families to provide care becomes crucial for primary health care centres. Primary health care providers should adopt strategies such as DSMES and family-centred care to treat diabetes and stop its further spread. However, for these modalities to work, the healthcare providers should receive in-service training on these modalities. In addition to the adoption of these modalities, diabetic support groups constituted by patients and their families should be



created to empower them with knowledge and skills for appropriate home care. CHWs must also be included in diabetes support groups as a critical link between primary health care and families of patients. The CHWs should understand what is expected of families in supporting patients for proper monitoring. The CHWs are familiar with the cultural background of their communities and help patients in developing and maintaining behaviours that promote their health.<sup>65,66</sup>

## Conclusion

The primary objective of any diabetes intervention is the improvement of blood glucose. Evidence from existing literature identifies primary health care as a source of information on how best to manage diabetes. However, the actual management occurs at home where patients reside. As diabetes prevalence and incidence increase, new interventions are required. The literature indicates that the DSMES and FCC modalities emphasise family inclusion in the care. Hence, this review recommends primary health care–families partnership based on DSMES and FCC modalities. This could help in the adherence to self-care activities and achieving better outcomes, considering the benefits of the two modalities.

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