

#### ORIGINAL RESEARCH

# A Qualitative Exploration of Facilitators and Barriers for Diabetes Self-Management Behaviors Among Persons with Type 2 Diabetes from a Socially Disadvantaged Area

This article was published in the following Dove Press journal: Patient Preference and Adherence

Nina Ingemann Christensen (b) Sabina Dreier<sup>1</sup> Karin Burns<sup>2,3</sup> Sanne Lykke Lundstrøm (1)<sup>2</sup> Nana Folmann Hempler<sup>1</sup>

<sup>1</sup>Health Promotion Research, Steno Diabetes Center Copenhagen, Gentofte, Denmark; <sup>2</sup>Center for Clinical Research and Prevention, Bispebjerg and Frederiksberg Hospital, Frederiksberg, Denmark; <sup>3</sup>Department of Endocrinology and Cardiology, Copenhagen University Hospital, Hvidovre, Denmark

Background: Enhancing diabetes self-management (DSM) in patients with type 2 diabetes (T2D) can reduce the risk of complications, enhance healthier lifestyles, and improve quality of life. Furthermore, vulnerable groups struggle more with DSM.

Aim: To explore barriers and facilitators related to DSM in vulnerable groups through the perspectives of patients with T2D and healthcare professionals (HCPs).

Methods: Data were collected through three interactive workshops with Danish-speaking patients with T2D (n=6), Urdu-speaking patients with T2D (n=6), and HCPs (n=16) and analyzed using systematic text condensation.

Results: The following barriers to DSM were found among members of vulnerable groups with T2D: 1) lack of access to DSM support, 2) interference and judgment from one's social environment, and 3) feeling powerless or helpless. The following factors facilitated DSM among vulnerable persons with T2D: 1) a person-centered approach, 2) peer support, and 3) practical and concrete knowledge about DSM. Several barriers and facilitators expressed by persons with T2D, particularly those who spoke Danish, were also expressed by HCPs.

Conclusion: Vulnerable patients with T2D preferred individualized and practice-based education tailored to their needs. More attention should be paid to training HCPs to handle feelings of helplessness and lack of motivation among vulnerable groups, particularly among ethnic minority patients, and to tailor care to ethnic minorities.

**Keywords:** diabetes self-management, type 2 diabetes, vulnerable target groups, ethnic minorities, health inequities, socially disadvantaged population

## Introduction

The prevalence of type 2 diabetes (T2D) is rising rapidly in Denmark and internationally. Factors contributing to this increase include aging populations, economic development, increasing urbanization, poor dietary habits, and reduced physical activity. The incidence of T2D is higher among persons with low levels of education, employment, and income<sup>2,3</sup> and 2.5 times higher among non-Western migrants than among ethnic Danes. 4 T2D requires constant daily care; 99% of all diabetes care is self-care.5 Adopting and maintaining effective diabetes self-management (DSM) behaviors in daily life are crucial to preventing diabetes complications and improving diabetes outcomes and quality of life. 6-9 Studies show that diabetes self-care is difficult and few individuals reach treatment goals. 10-12 Poor

Correspondence: Nana Folmann Hempler Tel +45 40 732 591 Email Nana.folmann.hempler@regionh.dk adherence to self-care activities is a major problem. <sup>13–15</sup> Several factors may influence adherence to self-management, including personal and situational challenges, such as attitudes, knowledge, and culture, as well as challenges between patient and provider related to communication and access to and quality of care and education. <sup>12,14</sup>

Diabetes self-management education and support (DSMES) has been shown to enhance self-management for people with T2D, <sup>16–18</sup> and group-based education is particularly effective at improving clinical and psychosocial outcomes in patients with T2D. <sup>19</sup> American Diabetes Association guidelines highlight DSMES as a critical element of care in diabetes, <sup>7</sup> but programs are often based on a generic national disease management program that lacks guidance for meeting the needs of socially disadvantaged persons. <sup>16</sup>

Vulnerability refers to higher risk of developing complications of diabetes and is defined in terms of biological, social, and cultural factors, such as BMI, education, and ethnicity. Vulnerable patients with diabetes experience worse clinical outcomes and are more often hardly reached by healthcare services and education than are non-vulnerable patients. When they do participate, vulnerable patients benefit less from health promotion interventions, compared to patients of higher socioeconomic status. Previous studies have shown that tailoring care to specific groups can be effective in supporting health behavior change. However, little is known about what challenges such interventions should address to ensure participation, retention, and benefit for vulnerable persons.

Knowledge of factors influencing self-management can help inform the content and design of care and support activities. Studies show that barriers to self-care are experienced differently depending on patients' financial situation, culture, and ethnicity, 14,27 but few studies have explored factors influencing self-management among vulnerable people with diabetes. 27

This study focuses on barriers and facilitators related to DSM in vulnerable persons with T2D by exploring the needs and perspectives of patients from a socially disadvantaged area and the perspectives of healthcare professionals (HCPs).

## **Methods**

The study is part of a larger project that aims to develop a framework for diabetes education targeting vulnerable patients with type 2 diabetes.<sup>28</sup> The project is based on a

participatory design approach involving patients and HCPs. Participatory design follows the principle of designing with, as opposed to for, the target group; the intervention is based on the needs of people within the target group, rather than being something they feel is imposed on them.<sup>29</sup> Design thinking methodology is a human-centered approach that takes place in a unique context and tailors the solution to a specific target group.<sup>29</sup> Design thinking follows an iterative process in which ideas and prototypes are developed and subsequently tested and refined, based on feedback from the target group. The process includes three phases: inspiration, ideation and implementation. This study reports findings from the inspiration phase, which focuses on uncovering needs and preferences in the target group. The perspectives of HCPs were also included in the study to provide insight into the entire context of care.<sup>29</sup>

# Setting and Data Collection

The Danish healthcare system is universal and free for all citizens. All health services are financed by general taxes, and 84% of healthcare spending is publicly financed, although most services are free and do not require patient co-payment. Healthcare tasks are split between the Regions and Municipalities.<sup>30</sup> DSMES primarily takes place in municipal settings.<sup>31</sup> However, people with diabetes who have difficulty achieving blood sugar control or experience diabetes complications are referred to regional hospitals, 32 where they are typically offered both indivieducation.31 group-based diabetes dual and/or Consequently, patients in outpatient clinics at Danish hospitals are often considered vulnerable, and data collection was accordingly conducted in a hospital in the southwestern part of the Capital Region. The hospital's catchment area is characterized by a high proportion of Urdu-speaking ethnic minorities, low income and educational levels, and high unemployment rates, compared to the rest of the Capital Region.<sup>33</sup> A previous study in the same geographic area found that high levels of neighborhood deprivation were associated with low participation in health checks.<sup>34</sup>

Data were collected in three workshops with Danishand Urdu-speaking patients and HCPs (Table 1). Family members were also invited to workshops and participated to varying degrees. The Urdu-speaking workshop also included interpreters. The workshops were facilitated by NFH, NIC, KB and SLL. Prior to the workshops, observations of practice and interviews with HCPs were conducted to inform the content and focus of the workshops.

Table I Overview of Workshops and Data Types

Participants and Duration	Discussion Questions	Exercises and Tools Used
Danish speaking patients (n=6) 2 hrs	Participation in DSMES or similar:  What have you participated in?  How did you like it?  Did you bring family members?  What is missing from health services today?	"Who am I?" - Pictures of everyday situations and emotions are selected by participants to describe themselves and their lives     "Goal game" - Statements concerning life with chronic illness are selected by participants to explore needs and experiences in relation to DSM
Urdu speaking patients (n=6) 2 hrs	All discussions were based on visual aids and other exercises	<ul> <li>Visualization of a typical DSMES course to explore experiences with DSMES</li> <li>Visualization of various options in terms of DSMES (individual, group-based, interpreted, mixed/single ethnicity or gender) to explore needs and preferences</li> <li>Case story addressing challenges with food, medication-taking, and exercise</li> <li>"When is diabetes driving me crazy?" – Participants select domains of everyday life where they are most challenged due to diabetes (eg travelling, eating, social gatherings)</li> </ul>
HCPs (n=16) 3 hrs	<ul> <li>How do we identify vulnerable persons and how do we differentiate care?</li> <li>How do we motivate persons with low motivation?</li> <li>What challenges do you experience working with ethnic minority patients?</li> <li>What are the challenges and needs of patients in their everyday life?</li> </ul>	Discussions in small groups     Plenary discussions

In workshops, we used explorative methods to facilitate sharing by patients of their experiences, needs, preferences, and ideas about DSM strategies and challenges in daily life and the need for HCP support. Participatory exercises, such as visual aids and case stories, were also used to engage participants. These exercises and tools were developed in previous research with similar target groups.<sup>35</sup> The three workshops were tailored to the participants, and as such different discussion questions and content were prepared for each workshop (Table 1).

The workshops were audio recorded and transcribed verbatim. The data material analyzed in this study consists of workshop transcriptions as well as field notes produced during the workshops.

# Study Participants

Participants were recruited from the outpatient clinic, where a member of the research team (KB) invited them to participate. We used purposeful sampling stratified by age and gender to achieve our aim of including men and women of varying ages in workshops.<sup>36</sup> The largest ethnic minority population receiving care at the outpatient clinic consisted of native Urdu speakers, and

a workshop was conducted with an Urdu-speaking interpreter.

Six Danish-speaking patients and six Urdu-speaking patients with T2D participated in two separate workshops (Table 2). Compared to Danish-speaking participants, Urdu-speaking participants were younger, more likely to live in multigenerational and larger households, and less likely to have previously participated in DSMES. Three family members also attended the workshops (two in the Danish workshop and one in the Urdu workshop).

Sixteen HCPs also participated in a workshop separately from patients. All HCPs were female and aged 37 to

Table 2 Characteristics of Patients Participating in Workshops

	Danish-Speaking (n=6)	Urdu-Speaking (n=6)
Female gender	3	5
Age, mean (SD)	63.5 (2.9)	50.2 (12.3)
Employed	2	2
Previous participation in	3	1
DSMES		
Household size, mean	1.7 (0.5)	6.2 (1.5)
(SD)		

63 years; they included two senior nurses, nine outpatient clinic nurses, three inpatient nurses, and two physiotherapists. The physiotherapists worked with patients who had diabetes, heart disease, or both; four nurses worked only with patients with diabetes; and ten nurses worked primarily with patients who had heart disease and a high rate of comorbid T2D.

## **Ethical Considerations**

Each workshop began with a thorough introduction to the study and the implications of participation. Verbal and written consent assuring anonymity and confidentiality was obtained from all patients. All participants received a copy of the consent form. The study was conducted in compliance with the Helsinki Declaration, approved by the Danish Data Protection Agency (CSU-FCFS-2015-004), and processed by the National Committee on Health Research Ethics. As incentives for participation, we offered a light meal during each workshop and invited participants to bring their children and other family members/relatives if they preferred.

# **Analysis**

Data were analyzed using systematic text condensation as described by Malterud.<sup>37</sup> The methodology of which is grounded in phenomenological traditions, where the experiences of the participants are presented as they have expressed it themselves, rather than attempting to find underlying meanings in these expressions.<sup>37</sup> The analysis included four phases. We 1) thoroughly read all transcribed workshops to get an overall impression and identify preliminary themes, we then 2) identified and sorted meaning units related to previously identified themes, developing a set of codes. Then we 3) condensed the contents of each coded group and 4) summarized the condensed contents to generate concepts describing the patients' experiences. Patient quotes representing the concepts were selected to illustrate the results. Three authors (NFH, SD, and NIC) read the material thoroughly and discussed the complexity of the content during the analysis process. Subsequently, we combined overlapping themes and deleted those that lacked a sufficient number of relevant text units from the transcripts. Finally, we read through the workshop transcripts to make sure that nothing was overlooked.

# **Trustworthiness**

Several strategies were used to increase the trustworthiness of this qualitative study. Firstly, the credibility of this

study has been improved by using data from three different sources (Danish speaking patients, Urdu speaking patients and HCPs), which has made it possible to shed light on the research question from a variety of perspectives. <sup>38</sup> Further, the researchers involved in the analysis (NFH, SD, and NIC) were of different academic backgrounds (public health, sociology, anthropology), also increasing credibility, ensuring multiple perspectives and a richer interpretation of data. Data collection took place over a short amount of time, only one workshop with each participant group were held, and thus we did not find any issues of dependability. We have addressed transferability of this study by providing a thorough description of the setting and target group, as well as our data collection and methods.<sup>38</sup>

# **Findings**

We identified barriers and facilitators of DSM as expressed by members of vulnerable groups with T2D and HCPs. We categorized the barriers and facilitators by the domains in which they were experienced by both patients and HCPs: 1) access to care and support, 2) social environment, and 3) intrinsic motivation. Within each domain, we identified subcategories related to barriers and facilitators from the separate perspectives of Danish-speaking patients, Urduspeaking patients, and HCPs.

# Access to DSM Support

Access to care and HCP support was identified as an important element related to DSM (Table 3). Barriers were related to access to care services but were experienced differently across the two patient groups and HCPs. Facilitators in this domain were related to how patients were treated or wanted to be treated in available health services.

#### **Barriers**

A common experience among Danish-speaking patients was difficulty navigating between health services. They knew that various services existed but had to seek them out on their own. Seeking out health services was particularly challenging for patients with fewer resources, which was common in this group. This is exemplified in the following quote:

I have asked about an exercise class last time I was there [at the GP] and then I was told, that it is the municipality that must take care of that. Then you are supposed to contact the municipality, which is quite difficult. Maybe

	Health Services	Danish-Speaking Patients	Urdu-Speaking Patients	HCPs
Barriers	Lack of access to health services	Difficulty navigating between various health services	Few or no available health programs to support DSM	Structural barriers to referring patients to other relevant services
Facilitators	Experiencing a person-centered approach in health education	Experiencing a nonjudgmental approach	Learning through a practical approach	Using individualized approaches

**Table 3** DSM Barriers and Facilitators Related to Access to Care and Support

other people find it easier, but I have not been able to get through with anything in the municipality.

In general, Danish-speaking participants described being left alone with their diabetes and feeling that it was up to them to do something about it.

The experience of struggling to navigate through health services expressed by Danish-speaking patients was recognized by HCPs, who talked about patients getting lost in the system, and not being able to refer them to relevant services directly.

Urdu-speaking patients described not having been offered patient education programs to support DSM other than routine consultations with a nurse and doctor. One participant was surprised to hear about an existing DSMES program targeting Urdu-speaking patients in which another patient in the workshop had participated. Neither she nor other participants had been offered a similar program. In her municipality, no DSMES is available to non-Danish speakers.

## **Facilitators**

Patients and HCPs noted that experiencing an inviting approach from HCPs was important for patients to feel motivated to make behavior changes in everyday life. However, Danish-speaking and Urdu-speaking patients had different perspectives on the right approach.

Danish-speaking participants emphasized that HCPs must engage with patients' motivation and avoid moralizing. One participant noted, "That is something, that you should be mindful of (...). Working with this motivational factor in some way, so it isn't just that moralizing fingerwag. That doesn't work, for sure."

Some Danish-speaking participants described being more likely to go home and engage in unhealthy behaviors when HCPs took a moralizing approach.

Similarly, HCPs emphasized the importance of working with patients' motivation and providing different

approaches tailored to their individual differences. One HCP noted the following:

I've got everyone. From the top-motivated patient, to someone who feels completely hopeless. It is difficult, and it also has to do with finding out what type of person is sitting across from you. In what way should things be presented to them? For some people, you need to give them a friendly nudge and, for others, they need a good kick in the pants.

Some HCPs referred to a specific model, describing five motivational types, that helped them analyze the motivation of patients.<sup>39</sup> Others emphasized that HCPs must consider the circumstances of each patient's engagement in education programs.

For Urdu-speaking patients, a facilitator of DSM was learning through a practical approach. A younger woman noted that she would like to be shown how to cook healthy food and how to exercise in the right way. Another young Urdu-speaking woman preferred exercise classes that measured glucose levels to assess how physical activity affected blood sugar control.

In summary, both groups of patients and HCPs experienced structural barriers in access to DSM support. However, Danish-speaking patients primarily emphasized the challenges of navigating the healthcare system, whereas Urdu-speaking patients generally had not been offered any DSM support. Similarly, the two groups of patients described different approaches by HCPs that they found inviting. Danish-speaking participants wanted to experience a nonjudgmental and motivating approach, and Urdu-speaking patients preferred a practice-based educational approach. HCPs recognized the need to approach patients differently.

## Social Environment

DSM behavior was also related to reactions and actions from the social environment (Table 4). Barriers to DSM

Table 4 DSM Barriers and Facilitators in the Social Environment

	Social Environment	Danish Speaking Persons	Urdu Speaking Persons	HCPs
Barriers	Interference from the social environment	Judgment and lack of knowledge from social relations	Judgment, control, and food controversies from social relations	Interference from family members
Facilitators	Peer support	Exchanging knowledge and experiencing community feeling and solidarity with peers	Exchanging knowledge and experiences with peers	Using peer support as a tool in health education

comprised interference and control, which was described by both patient groups and by HCPs. Facilitators in this domain were related to peer support.

#### **Barriers**

Both patient groups described barriers related to judgment and interference from their social environment. Danish-speaking patients described judgment as lack of knowledge on the part of people around them, whereas Urdu-speaking patients described episodes of judgment in the form of being controlled by others or being in social situations in which they could not control what they ate. HCPs also described potentially negative effects of interference from patients' social environments.

Danish-speaking participants described interference from people in their immediate families, workplaces, and public places as an annoyance that was likely to result in rebellious unhealthy behavior, as was the case with moralizing HCPs. A woman reported that her family members sometimes brought up whether she could eat certain food items, which she experienced as undermining her adult status. Another male patient said, "And with the wife at home, focus is sometimes on stupid things, that we should buy sugar free pickles. What is the amount of pickles I chuck down within a year? That is nothing, right?"

Danish-speaking participants often described people around them as overreacting and demonstrating their lack of knowledge about diabetes in an annoying form of interference that disturbed their already challenging daily life.

The experience of being blamed and confronted with guilt related to food was noted by both groups of participants. However, for Urdu-speaking participants, blaming within a multigenerational family was potentially more extensive. For example, an Urdu-speaking grandmother shared that her son used her grandchildren to monitor what her and her daughter-in-law, who also had diabetes, ate.

Similarly, several Urdu-speaking participants experienced food-related conflict because a family member who did not have diabetes did the cooking. In addition, many family members who ate together often did not all want the "healthy" foods. A husband explained: "We all know that we cannot eat the food she makes, because it is for diabetics and such."

HCPs also experienced potentially negative interference from family members. One nurse described family members who undermined the patient's treatment because they experienced diabetes as taking something from them when their mother's diet changed.

#### **Facilitators**

Peer support was identified as a central facilitator of DSM in both patient groups and by HCPs. However, the two patient groups practiced peer support differently. Danish-speaking patients described engagement with peers as particularly important to DSM. For example, many patients indicated that social engagements made it easier to adhere to a healthy lifestyle:

You know there is someone there, right. And that is wonderful. Because, Sunday morning at 8, and someone is there [at the gym], makes you think that perhaps you better get over there. It's enough to get you out of the house, I think. That other people are there [waiting].

In general, peer support as a facilitator of DSM was a central element for Danish-speaking patients. Even during the workshop, they supported one another, offering invitations to join existing exercise classes and other moral support: "But you are sitting here, that means that you are motivated to move on. Because we have all been in that situation. We do it based on the experiences we've had."

As this participant pointed out, patients share common experiences, problems, and feelings related to T2D, which makes the support they give each other different from support they may receive from family and friends.

Peer support took another form for Urdu-speaking participants. When asked, most indicated that they preferred group-based education but generally did not mention any benefit of engaging with peers. However, they shared experiences and knowledge throughout the workshop; for example, one older man gave advice about when to measure blood sugar levels.

HCPs also described peer support as a potential facilitator of DSM. They emphasized that patients can motivate each other through their shared experiences. They also pointed out that peers were able to give each other advice and encourage healthy behavior without seeming moralizing.

In summary, both Danish- and Urdu-speaking patients experienced barriers in DSM in terms of judgment and interference from people in their social networks, which HCPs also recognized. Danish-speaking patients primarily described interference arising from others' lack of knowledge about diabetes. Urdu-speaking participants described interference as either conflict or the need to consider other members of a large family living together. Both patient groups highlighted the importance of meeting peers in educational settings and favored a group-based format. HCPs also described peer support as an important facilitator of DSM.

## Intrinsic Motivation

Intrinsic motivation was identified as a prerequisite to effective DSM, but the feeling of helplessness could undermine motivation. Facilitators were related to practical and concrete knowledge about DSM.

#### **Barriers**

A barrier for motivation in relation to behavior change was the feeling of helplessness (Table 5). Participants described their helplessness in terms of fatigue and a lack of self-discipline. HCPs indicated that group-based education requires motivation, that many patients do not have.

Danish-speaking patients described the lack of selfdiscipline as being unwilling to give up life's enjoyments, such as beer, bacon, and chocolate. One woman described her inability to find strategies for taking care of her diabetes, even though she knew what was good for her:

I know what you should and shouldn't do and all that. But my backbone is telling me otherwise. I can't help it, because I'm too foolish. I have tried everything, and none of it works for me. I just keep going. I just ignore it.

Urdu-speaking participants referred primarily to fatigue as a barrier to DSM, such as exercising. One woman described her helplessness:

That's the thing with diabetes, it is a lifelong illness. It isn't something that goes away. (...) Sometimes you get tired of your illness and you say: "I don't have the strength anymore". I'm tired of injecting myself all the time, so that's why I think: "Well, now I don't want to do it anymore."

Both women quoted here described feeling that they had already tried everything and had been doing so for a long time. Helplessness is reflected in their statements that there is no solution to their problems.

HCPs also described helplessness as undermining DSM. In addition, they expressed personal and professional helplessness reflected in resistance to group-based education, as expressed by a nurse: "When they are as vulnerable, as they are, I just have to say, that you must deal with them individually, while they are in for a check-up anyway."

In general, HCPs expressed that all their patients needed and received special attention. When discussing different contexts for group-based diabetes education, a nurse commented that she could not think of a solution because a group comprising patients of various nationalities and several interpreters would not work. HCPs emphasized that communication with ethnic minorities was generally difficult due to language barriers. Nurses also described ethnic minorities as having limited knowledge about the body and that information provided had to be at a "very low level."

Table 5 DSM barriers and Facilitators Related to Intrinsic Motivation

	Intrinsic Motivation	Danish Speaking Persons	Urdu Speaking Persons	HCPs
Barriers	Feeling helpless	Lacking self-discipline to refrain from unhealthy behavior	Fatigue	Expressing a resistance towards group-based education
Facilitators	Practical concrete knowledge about DSM	Setting individual goals and plans	Receiving practical knowledge of how to self-manage diabetes	Focusing on patients' everyday lives, wishes and goals

## **Facilitators**

For both groups of patients, practical and concrete knowledge was important to engage in and feel motivated for DSM. Danish-speaking patients emphasized the importance of having individualized goals and plans, and HCPs described themselves as already helping patients develop individualized approaches. Urdu-speaking patients emphasized that concrete knowledge such as where to inject insulin was important to daily management of their disease. They described being rarely asked questions about daily management and that meetings with HCP did not allow time for such questions.

Danish-speaking patients expressed a desire for more individualized information from HCPs, exemplified by this comment from a male participant:

I understand people who go to the private [health] sector. Then it is targeted for you specifically. You get to know that you should do this and that. Make a plan for the next month. I'd like that.

When information is too general, patients may feel left to their own devices to decide what advice is relevant for their DSM.

HCPs also pointed out the need for more individualized goal-setting. A nurse suggested that patients would benefit from a more goal-oriented approach. Yet several HCPs described themselves as already using individualized methods. Nurses emphasized the importance of focusing on what is relevant in the patient's personal life. As one said, "We have found that we must deal with whatever is relevant. What challenges do you have in your everyday life? What are you experiencing? And that will differ from patient to patient."

Thus, HCPs experienced individualized goal-setting as facilitating patients' DSM and also described ways in which they were already doing so by asking patients to reflect on wishes and needs and using this information as a stepping stone to goal-setting.

In summary, both Danish-and Urdu-speaking patients experienced helplessness related to health behavior changes required for good DSM. HCPs also described helplessness as a barrier to DSM in the target groups. They felt ill equipped to adequately care for vulnerable patients in a group setting, particularly for ethnic minorities they perceived as having other needs.

# **Discussion**

Danish- and Urdu-speaking patients, as well as HCPs, experienced barriers and facilitators in relation to DSM,

but they had different perspectives on what these entailed. Ethnic Danish patients and HCPs had somewhat similar perspectives regarding issues of navigating existing health services, the importance of peer support, and approaching patients in an individualized way without moralizing. Urdu-speaking patients generally lacked access to diabetes support and preferred a practice-based approach to diabetes education. Both patient groups and HCPs described feelings of helplessness that were reinforced when patients recurrently experienced failure at DSM. Access to health-care, including DSMES, is complex, encompassing the provision, availability, utilization, and benefit of needed services. Barriers to access can exist on system, provider, and patient levels. Our findings include examples of barriers across all three levels.

In terms of system barriers, few Urdu-speaking patients had been offered any DSMES, and HCPs noted the lack of targeted programs to which they could refer patients. In Denmark, women and persons from middle and higher socioeconomic groups most often attend DSMES, and immigrants rarely participate. 42 Studies show that culturally appropriate diabetes education can enhance glycemic control and improve health behaviors, <sup>43</sup> but little is known about effective educational strategies and methods targeting ethnic minority groups with type 2 diabetes. 44-46 Language was also mentioned as a system level barrier because encounters did not always include the services of an interpreter. In Denmark, the use of interpreters requires co-payment for ethnic minority patients with more than 3 years of residence in the country.<sup>47</sup> Cultural adaptation encompasses much more than language, but very few, if any, hospitals have culturally sensitive programs that consider group-specific health beliefs, use peer educators, acknowledge the importance of collectivism (eg. family involvement), and incorporate health education tools and materials that are meaningful to the target group.

At the level of providers, ethnic minority patients may not benefit from encounters with HCPs due to cultural differences. HCPs often had different perspectives on barriers and facilitators for DSM than did Urdu-speaking patients; higher concordance was observed with Danish-speaking patients. Lack of cultural competence can result in healthcare staff having stereotypical views of ethnic minority patients. Some studies have found that HCPs' decisions regarding treatment are affected by stereotypical perceptions of patients' socioeconomic status, race, gender, cognitive capacity, and compliance. Staff Barriers at the patient level can comprise

demographic variables, social structure variables, health beliefs and attitudes, personal enabling resources, community enabling resources, perceived illness, and personal health practices. <sup>41</sup> A compelling need exists to train HCPs in person-centered approaches that actively explore the needs and preferences of all patients, particularly those whose ethnic background differs from that of the HCP.

In addition, the patients in this study described information provided about DSM as being too general. Instead, they preferred individualized and practice-based education. These findings correspond to studies highlighting a lack of person-centeredness in encounters with HCPs and conclude that most diabetes education is based on HCPs' understanding of patients' need for learning, rather than on patients' perspectives. <sup>48,49</sup> Our results also correspond to a recent Danish study showing that vulnerable patients with T2D desire more personalized support from HCPs. <sup>50</sup> Urdu-speaking patients particularly wanted to be more practically engaged in DSM by focusing on exercise or cooking healthy meals. This is consistent with previous findings that vulnerable persons prefer encounters that draw on practical exercises. <sup>22,51</sup>

Several studies show that DSMES programs that rely on person-centeredness and incorporate individual participants' diabetes knowledge, self-management skills, and health literacy levels and provide culturally appropriate health education are better at meeting the needs of persons with T2DM and enhancing self-management. Although HCPs generally agree with the philosophy of person-centered care, translating this framework into actions in practice remains a challenge for many. In group-based education, person-centeredness can be particularly difficult to integrate into the educational setting due to patients' varying needs, values, and preferences.

The present study also found helplessness in both patients and HCPs. Patients expressed helplessness in relation to controlling diet and blood sugar levels. Vallis describes "learned helplessness" as an explanation for why some people give up and accept their fate when they feel they have no control over what happens to them. This term has been used in relation to diabetes treatment and referred to as a psychological trap that can impede any effort to improve DSM. Vallis stresses that "individuals who have developed learned helplessness are less receptive to new learning, put less effort into new learning, do not persevere, and have a pessimistic, self-blaming attitude". Therefore, HCPs must approach patients in a way that acknowledges the difficulty of managing diabetes and avoids setting unrealistic

expectations.<sup>57</sup> Most Danish-speaking participants in our study described DSMES as being facilitated when HCPs approached them without moralizing. However, we also found that patients described experiencing a judgmental approach in their encounters with HCPs, consistent with results of a recent Danish study that showed a tendency for HCPs to moralize and evoke guilt among participants in group-based DSMES programs.<sup>55</sup>

Addressing patients' learned helplessness requires HCPs to address their own helplessness. According to Larsson and Stern (2013), HCPs' learned helplessness can be overcome when an overwhelming clinical situation and its causes are understood and divided into smaller and more manageable components (eg, negative thought patterns, lack of training, and work-related psychological stressors).<sup>58</sup> The authors also stress that learned helplessness on the part of HCPs can be caused by unreasonable expectations about their own performance, such as making patients feel better and helping them control their blood sugar levels. Instead, the authors urge HCPs to shift focus to what can be done, such as offering guidance and support.<sup>58</sup>

# Strengths and Limitations

A strength of our study is the inclusion of both Danishand Urdu-speaking patients from a hospital outpatient clinic located in a socially disadvantaged area and HCPs employed at the hospital. This allowed a comprehensive analysis that illuminated both needs expressed by patients and how HCPs understood and approached those needs. The study population was diverse in terms of ethnicity, age, and gender.

Limitations include the fact that our analysis is based on a relatively small body of empirical data. Consequently, it has not been possible to explore age and gender-based differences in the barriers and facilitators of DSM. A minor limitation is related to differences between the two patient workshops; the exercises and questions used with Urdu-speaking participants were culturally sensitive and previously developed with ethnic minorities.<sup>35</sup> We sought to include vulnerable patients, which can be challenging, and those who participated may not be representative of all vulnerable patients. We defined the patients as vulnerable because they were treated at the outpatient clinic, to which they were referred after a GP and municipality noted a poor response to treatment, complications of diabetes, or both. We attempted to recruit diverse patients by establishing personal contact with each selected patient, making several follow-up phone calls if necessary. We also incentivized participation by providing food and encouraging vulnerable patients to bring family or friends for support. Our findings should be generalized with caution to other groups of vulnerable patients.

## **Conclusion**

Our findings provide insight into barriers and facilitators related to DSM in vulnerable groups with T2D. We found differences between the two groups of patients in needs and preferences for DSM support. It is essential to tailor care and education to different needs among patients. Strategies to ensure this include training HCPs to handle feelings of helplessness and lack of motivation that are particularly likely to occur among vulnerable groups and in complex clinical situations. Moreover, training of HCPs should aim to increase cultural competence of DSM strategies targeting vulnerable groups of patients. It is also important to study reasons underlying helplessness or resistance towards group-based education among HCPs and strategies to prevent and address it. Knowledge of factors influencing DSM in vulnerable groups can aid the development of appropriate diabetes education for vulnerable patients. However, more knowledge is needed about effective educational strategies and methods to effectively support vulnerable groups, particularly ethnic minorities, in DSM.

## **Disclosure**

The authors report no conflicts of interest in this work.

## References

- International Diabetes Federation. IDF Diabetes Atlas. Brussels, Belgium: International Diabetes Federation; 2015.
- Agardh E, Allebeck P, Hallqvist J, Moradi T, Sidorchuk A. Type 2 diabetes incidence and socio-economic position: a systematic review and meta-analysis. *Int J Epidemiol*. 2011;40(3):804–818. doi:10.1093/ ije/dyr029
- Sacerdote C, Ricceri F, Rolandsson O, et al. Lower educational level is a predictor of incident type 2 diabetes in European countries: the EPIC-InterAct study. *Int J Epidemiol*. 2012;41(4):1162–1173. doi:10. 1093/ije/dys091
- Andersen G, Kamper-Jørgensen Z, Carstensen B, Norredam M, Bygbjerg C, Jørgensen M. Diabetes among migrants in Denmark: incidence, mortality, and prevalence based on a longitudinal register study of the entire Danish population. *Diabetes Res Clin Pract*. 2016;122:9–16. doi:10.1016/j.diabres.2016.09.020
- Rubin RR. Psychotherapy and counselling in diabetes mellitus. In: Snoek FJ, Skinner TC, editors. *Psychology in Diabetes Care*. Chichester: John Wiley & Sons Ltd; 2005:235–263.
- Chrvala CA, Sherr D, Lipman RD. Diabetes self-management education for adults with type 2 diabetes mellitus: a systematic review of the effect on glycemic control. *Patient Educ Couns*. 2016;99(6):926–943. doi:10.1016/j.pec.2015.11.003

- Beck J, Greenwood DA, Blanton L, et al. 2017 national standards for diabetes self-management education and support. *Diabetes Care*. 2017;40(10):1409–1419. doi:10.2337/dci17-0025
- Powers MA, Bardsley J, Cypress M, et al. Diabetes Self-management education and support in type 2 diabetes: a joint position statement of the american diabetes association, the American association of diabetes educators, and the academy of nutrition and dietetics. *J Acad Nutr Diet*. 2015;115(8):1323–1334. doi:10.1016/j.jand.2015.05.012
- Cochran J, Conn VS. Meta-analysis of quality of life outcomes following diabetes self-management training. *Diabetes Educ*. 2008;34(5):815–823. doi:10.1177/0145721708323640
- Jones A, Olsen MZ, Perrild HJ, Willaing I. The psychological impact of living with diabetes: descriptive findings from the DAWN2 study in Denmark. *Prim Care Diabetes*. 2016;10(1):83–86. doi:10.1016/j. pcd.2015.03.008
- Ross SA, Tildesley HD, Ashkenas J. Barriers to effective insulin treatment: the persistence of poor glycemic control in type 2 diabetes. *Curr Med Res Opin.* 2011;27(sup3):13–20. doi:10.1185/03007995. 2011.621416
- 12. Wilkinson A, Whitehead L, Ritchie L. Factors influencing the ability to self-manage diabetes for adults living with type 1 or 2 diabetes. *Int J Nurs Stud.* 2014;51(1):111–122. doi:10.1016/j. ijnurstu.2013.01.006
- Pun SP, Coates V, Benzie IF. Barriers to the self-care of type 2 diabetes from both patients' and providers' perspectives: literature review. J Nurs Healthc Chronic Illn. 2009;1(1):4–19. doi:10.1111/ jci.2009.1.issue-1
- Nam S, Chesla C, Stotts NA, Kroon L, Janson SL. Barriers to diabetes management: patient and provider factors. *Diabetes Res Clin Pract*. 2011;93(1):1–9. doi:10.1016/j.diabres.2011.02.002
- Coyle ME, Francis K, Chapman Y. Self-management activities in diabetes care: a systematic review. Aust Health Rev. 2013;37(4):513– 522. doi:10.1071/AH13060
- Steinsbekk A, Rygg LO, Lisulo M, Rise MB, Fretheim A. Group based diabetes self-management education compared to routine treatment for people with type 2 diabetes mellitus. A systematic review with meta-analysis. *BMC Health Serv Res*. 2012;12:213. doi:10.1186/ 1472-6963-12-213
- 17. Davies MJ, Heller S, Skinner TC, et al. Effectiveness of the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed type 2 diabetes: cluster randomised controlled trial. *BMJ*. 2008;336 (7642):491–495. doi:10.1136/bmj.39474.922025.BE
- Deakin T, McShane CE, Cade JE, Williams RD. Group based training for self-management strategies in people with type 2 diabetes mellitus. Cochrane Database Syst Rev. 2005;(2):CD003417.
- Odgers-Jewell K, Ball LE, Kelly JT, Isenring EA, Reidlinger DP, Thomas R. Effectiveness of group-based self-management education for individuals with Type 2 diabetes: a systematic review with metaanalyses and meta-regression. *Diabet Med.* 2017;34(8):1027–1039. doi:10.1111/dme.2017.34.issue-8
- Christensen U, Kristensen EC, Malling GMH. Cities changing diabetes: vulnerability assessment in Copenhagen. 2016. Available from: https://pdfs.semanticscholar.org/f0b6/69a6d9b6e61eab9526df1ffd94 d1e559e6bf.pdf. Accessed September 23, 2019.
- Walker RJ, Gebregziabher M, Martin-Harris B, Egede LE. Independent effects of socioeconomic and psychological social determinants of health on self-care and outcomes in Type 2 diabetes. *Gen Hosp Psychiatry*. 2014;36(6):662–668. doi:10.1016/j.genhosppsych. 2014.06.011
- Sokol R, Fisher E. Peer support for the hardly reached: a systematic teview. Am J Public Health. 2016;106(7):e1–e8. doi:10.2105/ AJPH.2016.303180
- Sokol R, Fisher E, Hill J. Identifying those whom health promotion hardly reaches: a systematic review. Eval Health Prof. 2015;38 (4):518–537. doi:10.1177/0163278715605883

 Coupe N, Cotterill S, Peters S. Tailoring lifestyle interventions to low socio-economic populations: a qualitative study. *BMC Public Health*. 2018;18(1):967. doi:10.1186/s12889-018-5877-8

- Ockene IS, Tellez TL, Rosal MC, et al. Outcomes of a Latino community-based intervention for the prevention of diabetes: the Lawrence Latino Diabetes Prevention Project. Am J Public Health. 2012;102(2):336–342. doi:10.2105/AJPH.2011.300357
- Creamer J, Attridge M, Ramsden M, Cannings-John R, Hawthorne K. Culturally appropriate health education for Type 2 diabetes in ethnic minority groups: an updated Cochrane Review of randomized controlled trials. *Diabet Med.* 2016;33(2):169–183. doi:10.1111/dme. 12865
- 27. Majeed-Ariss R, Jackson C, Knapp P, Cheater FM. A systematic review of research into black and ethnic minority patients' views on self-management of type 2 diabetes. *Health Expect*. 2015;18 (5):625–642. doi:10.1111/hex.2015.18.issue-5
- 28. Andersen JH. Hjertepatienters valg og fravalg af rehabilitering på hospitalet en kvalitativ undersøgelse af dialogen mellem sygeplejersker og patienter ved 1. rehabiliteringssamtale [Heart patients' choice of rehabilition in the hospital A qualitative exploration of the dialogue between nurses and patients]. Region Hovedstaden: Forskningscenter for Forebyggelse og Sundhed; 2016.
- Brown T, Wyatt J. Design thinking for social innovation. Stanford Social Innovation Rev. 2010;8(1):31–35.
- Ministry of Health. Healthcare in Denmark: An Overview. Denmark: Ministry of Health; 2017.
- 31. Den Nationale Diabeteshandlingsplan [The National Diabetes Strategy]. 2017. Available from: https://www.sum.dk/~/media/Filer%20-%20Publikationer\_i\_pdf/2017/Den-Nationale-Diabetes-Handlingsplan/2National%20diabeteshandlingsplan.pdf. Accessed September 23, 2019.
- 32. Forløbsprogram for type 2 diabetes [Care Coordination in Type 2 Diabetes]. 2009. Available from: https://www.regionh.dk/til-fagfolk/Sundhed/Tvaersektorielt-samarbejde/kronisk-sygdom/Forløbsprogrammer/Sider/Forloebsprogram-for-type-2-diabetes.aspx. Accessed September 23, 2019.
- Jensen H, Davidsen M, Ekholm O, Christensen A. Danskernes Sundhed - Den Nationale Sundhedsprofil 2017 [Health Status of the Danes - The National Health Profile 2017]. Copenhagen, Denmark: Sundhedsstyrelsen [National Board of Health]; 2018.
- 34. Bender AM, Kawachi I, Jorgensen T, Pisinger C. Neighborhood social capital is associated with participation in health checks of a general population: a multilevel analysis of a population-based lifestyle intervention- the Inter99 study. *BMC Public Health*. 2015;15: 694. doi:10.1186/s12889-015-2042-5
- 35. Hempler NF, Christensen NI, Laursen DH. Koncept for uddannelse målrettet etniske minoriteter med type 2 diabetes [Concept for health education targeting ethnic minorities with type 2 diabetes]. Copenhagen: Center for Diabetes, Copenhagen Municipality and Steno Diabetes Center Copenhagen; 2018.
- Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health*. 2015;42(5):533–544. doi:10.1007/s10488-013-0528-y
- Malterud K. Systematic text condensation: a strategy for qualitative analysis. Scand J Public Health. 2012;40(8):795–805. doi:10.1177/ 1403494812465030
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24(2):105–112. doi:10.1016/j.nedt.2003.10.001
- CopenRehab. Motivationstyper [Motivational types]. Available from: http://sundhedsmotivation.dk/sumo-typekit/. Accessed October 28, 2019

- Gulliford M, Morgan M, Hughes D, et al. Access to Healthcare. London, UK: Department of Public Health Sciences, King's College; 2001.
- Scheppers E, van Dongen E, Dekker J, Geertzen J, Dekker J. Potential barriers to the use of health services among ethnic minorities: a review. Fam Pract. 2006;23(3):325–348. doi:10.1093/fam-pra/cmi113
- 42. Johansen K, Rasmussen P, Christiansen A. Hvem deltager og hvem deltager ikke i patientuddannelse [Who participates in patient education, and who does not]. København: Det Nationale Institut for Kommuners og Regioners Analyse og Forskning; 2012.
- Attridge M, Creamer J, Ramsden M, Cannings-John R, Hawthorne K. Culturally appropriate health education for people in ethnic minority groups with type 2 diabetes mellitus. *Cochrane Database Syst Rev.* 2014;(9):CD006424.
- Szczepura A. Access to health care for ethnic minority populations. Postgrad Med J. 2005;81(953):141–147. doi:10.1136/pgmj.2004. 026237
- Aronson J, Burgess D, Phelan SM, Juarez L. Unhealthy interactions: the role of stereotype threat in health disparities. *Am J Public Health*. 2013;103(1):50–56. doi:10.2105/AJPH.2012.300828
- Hajjaj FM, Salek MS, Basra MK, Finlay AY. Non-clinical influences on clinical decision-making: a major challenge to evidence-based practice. J R Soc Med. 2010;103(5):178–187. doi:10.1258/jrsm.20 10.100104
- Hempler NF, Ashraf K, Drejer S, Kristiansen M. Hvad betyder det for kommunikationen, når der indgår en tolk [What it means when there is an interpreter involved in the consultation]. iPraksis. 2018;8.
- 48. de Silva D. Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management. London: Health Foundation; 2011.
- Anderson RM, Funnell MM. Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm. Patient Educ Couns. 2005;57(2):153–157. doi:10.1016/j.pec. 2004.05.008
- Bech LK, Borch Jacobsen C, Mathiesen AS, Thomsen T. Preferring to manage by myself: a qualitative study of the perspectives of hardly reached people with type 2 diabetes on social support for diabetes management. J Clin Nurs. 2019;28(9–10):1889–1898. doi:10.1111/ jocn.2019.28.issue-9pt10
- Skinner TC, Cradock S. Empowerment: what about the evidence?. Pract Diabetes Int. 2000;17(3):91–95.
- Olsson L-E, Jakobsson Ung E, Swedberg K, Ekman I. Efficacy of person-centred care as an intervention in controlled trials – a systematic review. *J Clin Nurs*. 2013;22(3–4):456–465. doi:10.1111/ jocn.2013.22.issue-3pt4
- Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. *Med Care Res Rev.* 2013;70(4):351–379. doi:10.1177/1077558712465774
- Vallis M. Are behavioural interventions doomed to fail? Challenges to self-management support in chronic diseases. *Can J Diabetes*. 2015;39(4):330–334. doi:10.1016/j.jcjd.2015.01.002
- 55. Stenov V, Hempler NF, Reventlow S, Wind G. An ethnographic investigation of healthcare providers' approaches to facilitating person-centredness in group-based diabetes education. *Scand J Caring Sci.* 2018;32(2):783–792. doi:10.1111/scs.2018.32.issue-2
- Seligman ME. Learned helplessness. Annu Rev Med. 1972;23 (1):407–412. doi:10.1146/annurev.me.23.020172.002203
- 57. Vallis T. Psychological traps in diabetes management: to be forewarned is to be forearmed. *Can J Diabetes*. 2001;25:31–38.
- Larsson EW, Stern TA. Helplessness in the helpers: etiology and management. Prim Care Companion CNS Disord. 2013;15:6.

Christensen et al Dovepress

## Patient Preference and Adherence

# **Dovepress**

# Publish your work in this journal

Patient Preference and Adherence is an international, peer-reviewed, open access journal that focusing on the growing importance of patient preference and adherence throughout the therapeutic continuum. Patient satisfaction, acceptability, quality of life, compliance, persistence and their role in developing new therapeutic modalities and compounds to optimize clinical outcomes for existing disease

states are major areas of interest for the journal. This journal has been accepted for indexing on PubMed Central. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit http://www.dovepress.com/testimonials.php to read real quotes from published authors.

Submit your manuscript here: https://www.dovepress.com/patient-preference-and-adherence-journal