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The influence of diabetes distress on digital interventions for diabetes management in vulnerable people with type 2 diabetes: A qualitative study of patient perspectives

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A B S T R A C T

Background: Digital interventions for improving diabetes management in Type 2 diabetes mellitus (T2DM) are used universally. Digital interventions are defined as any intervention accessed and taking input from people with T2DM in the form of a web-based or mobile phone-based app to improve diabetes self-management. However, the current confidence in digital interventions threatens to augment social inequalities in health, also known as the “digital divide”. To counteract dissemination of the digital divide, we aimed to assess the potential of a tailored digital intervention for improving diabetes management in vulnerable people with T2DM.

Methods: A qualitative design using semi-structured in-depth interviews to explore the perspectives of 12 vulnerable people with T2DM. Interviews were analyzed using inductive content analysis. Vulnerability was defined by the presence of one or more comorbidities, one or more lifestyle risk factors, poor diabetes management, low educational level and low health literacy.

Results: The main themes identified were: “Dealing with diabetes distress” characterized by psychological avoidance mechanisms; “Suffering informational confusion” dealing with inconsistent information; “Experiencing digital alienation” dealing with loss of freedom when technology invades the private sphere; and “Missing the human touch” preferring human interaction over digital contact.

Conclusion: Vulnerable people with T2DM are unprepared for digital interventions for disease management. Experiencing diabetes distress may be an intermediate mechanism leading to nonadherence to digital interventions and the preference for human interaction in vulnerable people with T2DM. Future interventions could include a designated caregiver and an allocated buddy to provide support and assist uptake of digital interventions for diabetes management.

Introduction

Type 2 Diabetes (T2DM) is an increasingly important medical and public health issue due to rapidly growing incidence and prevalence. Worldwide, 422 million people have T2DM [1]. Mortality is twice as high as in the general population and complications lead to a higher demand for sick leave and decreased quality of life [1].

T2DM is a chronic disease caused by a complex combination of genetic factors, socioeconomic determinants and an unhealthy lifestyle [2]. Those afflicted need to maintain a constant focus on diabetes management to prevent or delay diabetic complications. The disease requires lifestyle modifications [3] as diet management, exercise [4], special foot and eye care. Adherence to pharmacological treatment for controlling blood glucose [5], blood pressure [6], and cholesterol level is equally important to reduce morbidity and mortality [7].

There is a steep socioeconomic gradient in the T2DM population where the disease is more common among people with low
The aim of the study was to explore the perspectives and needs of vulnerable people with T2DM to assess the potential for a tailored digital intervention for improving self-management of diabetes.

Methods

The study had a qualitative design using semi-structured in-depth interviews of 12 vulnerable people with T2DM. We chose inductive qualitative content analysis as a flexible and pragmatic method of analysis [24]. This approach is used to interpret text from a predominately naturalistic paradigm [25]. We used an inductive category development, allowing categories to flow from data rather than from theory or previous research [25]. Throughout the research-process, we adhered to the COREQ-checklist [26].

Prior to conducting the 12 in-depth interviews, we hosted three workshops lasting three hours each with the participation of three patients, two investigators and a technical expert in digital interventions. The workshops were conducted to explore the patients’ views and previous experience with digital interventions, if any. We attempted to familiarize the informants with the study to promote patient involvement as the study evolved. For example, we involved informants in designing pictures of possible digital designs and content solutions for the interviews [22]. The nine patients participating in the workshops also participated in the individual interviews.

Sampling

Informants were recruited for interviews from the outpatient Clinic of Endocrinology at a University Hospital in Denmark using the following inclusion criteria: T2DM, >1 comorbidity, HbA1c > 7% and >1 lifestyle risk factors e.g. daily smoking, BMI > 25, sedentary lifestyle, alcohol intake > 7 units for women/week and >14 units for men, low health literacy and low educational level. Comorbidity was defined as the presence of one disease or more in addition to T2D according to ICD-10. HbA1c was determined by the latest recorded lab result before the interview. Lifestyle risk factors were assessed by modified questionnaires from the National Health Survey [27]. We assessed health literacy using the validated health literacy questionnaire HLQ44-DK [28]. Low educational level was defined as a high school diploma or lower. We used a strategic sampling technique with maximum variation in regard to gender, age, duration of diagnosis, level of HbA1c, comorbidity and lifestyle risk factors. We approached 22 eligible individuals fulfilling the inclusion criteria. They were invited to participate by the first author at the outpatient clinic or by letter. Twelve patients agreed to participate. Five people declined participation for the reason of not having the time, three people declined due to not being interested in the subject and two declined for unknown reasons. (see Table 1 Informants characteristics).

Data generation

All informants were interviewed in a quiet location at the hospital using a semi-structured interview guide. The guide covered self-management habits and experiences with use of the internet or smartphone for obtaining information on diabetes management. [The referral to Table 2: Interview guide]. The interview guide was aligned after conducting the first interview. During interviews, we presented pictures of possible digital designs and content solutions, designed at the workshops, to facilitate discussion of digital solutions. Response validation was conducted during interviews by posing clarifying questions. After 12 interviews we decided that saturation was achieved as responses became redundant [29].

The interviews were recorded digitally and transcribed verbatim according to a transcription protocol. The mean duration of the interviews was 65 min. (range 48–93). We used NVivo QRS software program version 11.0 to support our analysis. The interviews were conducted in May-January 2015. All interviews were led by the first author in collaboration with the study nurse.

Data analysis

Qualitative inductive content analysis deals with two levels of analysis: The manifest and the latent content. The manifest content refers to the visible obvious content of the text. The latent content deals with hidden issues that require an interpretation of the underlying meaning of the text [24]. We (ASM, TT and IE) followed the steps described by Graneheim & Lundman: First we (ASM, TT) read all interviews to achieve immersion and gain a sense of whole.
Secondly we (ASM, TT) abstracted and coded the content into condensed meaning units that were confirmed by two authors. Thirdly, we (ASM, TT and IE) identified and revised categories, and finally condensed the latent content of the categories into themes. The themes were confirmed by all authors.

**Trustworthiness**

Credibility and dependability were obtained through our sampling strategy, member checking, investigator triangulation and the use of NVivo for data management. We performed member checking after data analysis by setting up individual one-hour meetings with four selected informants willing to participate. Informants were presented with the four themes and their own contributions were clarified with direct quotes. The informants confirmed and agreed with the themes, albeit one informant (Stuart) expressed that he would have expected the themes to focus more on diet. Transferability was increased by the validation of some of our findings by other studies and discussion among the investigators of different perspectives on the best way to structure our results [30].

**Ethical considerations**

All informants signed an informed consent form after receiving written and verbal information about the study. The study was approved by the Danish Data Protection Agency (Applicant No. 30-1248). The Ethical Committee of the Capital Region was notified of the study and deemed further formal approval unnecessary (case No. 39814).

**Results**

**Demographics**

Our informants were seven males mean age 61 years (range 38–70) and five females mean age 54 years (range 41–61). The average age was 58 years. Eleven were of Danish origin and one was African. The mean duration of diabetes was 12 years (range 4–20), and mean HbA1c was 76 mmol/mol (range 54–103). Five informants were married, one lived with his brother and six lived alone. Informants had one or more of the following risk factors: Daily smoking, alcohol intake >7 units/week for women and >14 units weekly for men, sedentary lifestyle, overweight, and obesity. Twelve informants had low educational level and 11 had low health literacy.

**Qualitative findings**

Four themes, with two sub-themes each, emerged during content analysis: I Dealing with diabetes distress, II Suffering informational confusion, III Lacking technical literacy, IV Missing the human touch (See Table 3 Themes and sub-themes).

**Theme I: Dealing with diabetes distress**

Adherence to diabetes management along with the demands of daily life triggered psychological defense mechanisms that helped
alleviate diabetes distress, while undermining the importance of diabetes management. The informants underestimated the gravity of their disease due to the imperceptible symptom progression and distant long-term complications. Choosing to ignore their disease they employed two defense mechanisms to alleviate their diabetes distress: Rationalization (making excuses) and the ostrich approach (refusing to face reality).

Using rationalization. The informants had creative excuses for avoiding lifestyle changes that they perceived were stressful. One informant rationalized that diabetes and smoking were relatively harmless compared to environmental factors: “Diesel emission is the most dangerous, not passive smoking” (Frank). The same informant asserted that lifestyle changes were unnecessary because he was protected by breastfeeding as a child, and he continued to boost his immunity by drinking large amounts of milk. Other informants switched their focus from changing bad habits to living by their preferences, illustrated by the adage of living fast and dying young: “If you lived quietly for the rest of your life, you might live to be 105, but ‘no thank you’, I don’t want to live like that” (Adrian).

Using the ostrich approach. The informants wanted to comply with the principles of diabetes management and at the same time they neglected the principles that restricted their lifestyle, leaving them in a state of ambivalence and distress. They coped by adopting the ostrich approach that helped them to ignore important symptoms and warning signs of hyperglycemia: “If I had to continue measuring (blood glucose) on a daily basis, I would feel pressured; I would feel guilty and bad about my diabetes” (Nelly). The informants were torn between a regimented lifestyle and the unrestricted life: “I view myself as extremely well-informed and in control! My problem is that between a regimented lifestyle and the unrestricted life: ‘’” (Adrian).

Theme I: Dealing with diabetes distress
- Using rationalization
- Using the ostrich approach

Theme II: Suffering informational confusion
- Distressed by inconsistent health information
- Distressed by the happy-go-lucky attitude

Theme IV: Experiencing digital alienation
- Big Brother is watching me
- My smartphone doesn’t understand me

Theme V: Missing the Human Touch
- Needing a personal caregiver
- Needing a buddy

Distressed by a happy-go-lucky attitude. Informants were unable to relate to campaigns featuring smiling, active people leading healthy lives with diabetes. Rather, they experienced the campaigns as condescending and insincere. The symbolism used to portray health and vitality in the face of chronic disease provoked the informants and added to their diabetes distress: “They (The Danish Diabetes Association) published a folder on sexual dysfunction and I went completely . . . people outdid each other on how poor their sex lives were . . . and they were still happy. Come on . . . wipe that smile off your face, it makes me sick” (Ben).

Theme III: Experiencing digital alienation
The older informants in our study in particular lacked technical literacy and rarely used the internet. Technology represented ways of restricting freedom, leading to digital alienation. The main issues at stake were the fear of control (Big Brother is watching me) and the feeling of frustration (my smartphone doesn’t understand me).

Big Brother is watching me. The informants felt that a smartphone application for monitoring their eating habits would take control of their lives: “Well, If I had to write down what I eat every time I eat, I would feel like something (from the outside) is dictating who I am and I don’t like that” (Jane). According to the informants, digital solutions would impose on their lives and sense of freedom: “Well, I don’t want to be forced to do anything . . . It’s like Big Brother watching, I would want to push the delete button” (George).

My smartphone doesn’t understand me! Most of the informants were technically illiterate as they shunned the use of smartphones, tablets, and other devices. They described their frustrations with computer breakdowns and their trouble navigating on the internet. Most had some kind of smartphone, but only used limited functions. The older informants reverted to handwritten notes and notebook calendars: “My philosophy of life is that the more electronics and that kind of stuff, you have in your house, the more can be broken” (Stuart).

Theme IV: Missing the human touch
Human interaction was valued by the informants as they had limited experience with digitalization. They wanted personal help to solve their health problems. In their disease management it was important to have a dedicated caregiver with a familiar face. The main issues were the need for a designated personal caregiver (healthcare professional) and/or a buddy (a family member, friend or colleague).

Needing a personal caregiver. The informants regarded their nurse or physician as a person of authority, and relied on their treatment
advice. It was uncommon for the informants to question their caregivers even if they lacked confidence in their advice: “I understand that as a general practitioner he has to know a little about everything, he can’t know much about anything in particular (Type 2 diabetes)” (Nelly). The personal caregiver could be difficult to reach by phone and the informants complained of lack of continuity among caregivers. But even with changing caregivers the informants preferred human contact to chatting or surfing on the internet: “I rarely surf the internet for health information, I trust my caregiver completely” (Stuart).

**Needing a Buddy.** Many informants had fragile social networks and needed a “buddy”, who could help manage their diabetes. In this context a buddy is broadly understood as a friend, partner or copatriot, who understands and supports the vulnerable person with diabetes. One informant buddied up with her daughter-in-law to manage her diabetes: “And then my daughter-in-law came along and said; that is not okay” (Nelly). By virtue of their informal status, some buddies failed to give the best advice: “My friend says: ‘stop trying to quit smoking’. Accept that you’re a smoker and stick to it!” (George). The informants all needed some kind of buddy who could help them manage their diabetes. In some cases the formal caregiver was perceived as the buddy. In these cases the informants had very limited social networks and often lived alone. Some informants had previously had a long-term relation with the formal caregiver after participation in longitudinal clinical trials.

**Discussion**

The study aimed to explore the perspectives and needs of vulnerable people with T2DM to assess the potential for a tailored digital intervention to improve self-management of diabetes. Our main findings were described in the four themes of dealing with diabetes distress, suffering informational confusion, experiencing digital alienation, and missing the human touch.

In this study, diabetes distress was the unacknowledged downside of diabetes self-management. Diabetes distress refers to concerns and fears about diabetes management and its complications and may, untreated, lead to poor glycemic control and increased risk of complications [31,32]. The level of diabetes distress can be assessed by the validated 17-item Diabetes Distress Scale [33], consisting of four subscales: emotional burden, physician-related distress, regimen-related distress, and diabetes-related interpersonal distress. Moderate to high distress are considered clinically relevant [32].

Although the informants were not initially screened for diabetes distress, they all demonstrated some aspect of the condition according to the Diabetes Distress scale, except physician-related distress. Lack of perceived control and limited freedom are characteristics associated with diabetes distress [33]. These were common concerns in relation to digital interventions in this group of vulnerable T2DM. In our study, all informants were insulin treated, which has been reported to be uniquely associated with diabetes distress [34]. A longitudinal study found that vulnerable patients suffered severe diabetes distress, and that it remained unchanged or worse during four years of follow-up [35]. This might indicate that caregivers and existing health care interventions do not sufficiently embrace the needs of vulnerable T2DM patients. In addition, digital interventions increase the awareness of living with a chronic disease [36] and might thereby indirectly intensify the experience of distress. As such, the potential interaction between diabetes distress and digital interventions for improved self-management might lead to rejection of digital interventions in this patient group. Consequently, assessment and treatment of diabetes distress might improve the uptake of digital solutions through increased self-efficacy [37] and perception of control [38].

We found that health promotion campaigns had a negative impact on our informants. Other studies have reported that barriers to following advice include age [39], low health literacy [17] and language issues [19]. Additionally, these barriers might become more difficult to overcome due to poor family support, severe comorbidities [40] and stressful life situations that prevail in this group of informants [41–43]. Hence these circumstances may cause vulnerable people with T2DM to prioritize more urgent needs than diabetes self-management leading to rejection of health promotion campaigns. In particular if campaigns are communicated in overly complex terms and inappropriate language for this group of vulnerable people. However, some of the barriers to health promotion campaigns are modifiable. For example, comprehension might be increased by using a simpler design, more accessible language [44] and improving literacy [19]. Further, the content should be easy to decipher [45] and be reliable [39] for the targeted group.

Informants in our study preferred advice from a personal caregiver rather than a digital device. This makes sense as the main concern was to be understood and acknowledged. Likewise, the preference of vulnerable people with T2DM for a compassionate personal caregiver has been found in similar studies. One study of “hardly reached” people with T2D showed that disrespectful caregivers could add to the person’s experience of feeling stupid and distressed [46]. Conversely, a study of regular email interaction with a supportive personal caregiver could infer a sense of safety in people with T2DM [36]. However, regular email interaction is dependent upon the degree of technical proficiency and familiarity with the caregiver [47]. In addition, the benefits of digital interventions might be overestimated if vulnerable people with T2DM are only asked about ease of finding health information online. Navigating a complex digital diabetes portal might be more challenging than simply accessing the site [14,19]. Further, including vulnerable people with T2DM specifically on isolated external determinants of vulnerability such as socioeconomic status [8], may also underestimate the potential challenges of digital interventions. Accordingly, our findings indicate a need for re-thinking the training and role of personal caregivers in caring for vulnerable people with T2DM. Designated caregivers, trained to care for vulnerable people with T2DM and knowledgeable about diabetes distress and digital illiteracy, could combine elements of personalized and digitalized healthcare.

Our findings suggest that informants might benefit from a supportive buddy. The choice of buddy could be important, nonetheless the effectiveness of a buddy depend on the person’s motivation, educational level and ability to find relevant information [11]. Moreover, the nature of the relation between vulnerable people with T2DM and the buddy is also important, as some relations might lead to more distress [48]. A qualitative study reports that vulnerable people with T2DM are reluctant to ask for help in their informal network. This might be due to existing values in the network and fear of imposing undue stress on a limited network, burdened by its own problems [49]. The spouse is often assumed to be the informal caregiver, but exclusive dependence on a spouse might be inadequate in effective diabetes management [50] Family behaviors such as nagging or arguing about nonadherence or questioning the need for prescribed medications are reported to exacerbate distress and nonadherence to pharmacological treatment in vulnerable people with T2DM [48,51]. Hence, support provided by a wider social network might be more effective than a single buddy in vulnerable people with T2DM [10]. Some of these findings are consistent with our study, where the wrong choice of buddy could lead to an inappropriate lifestyle. Accordingly, we suggest a structured approach, where the caregiver may assist in choosing one or more supportive buddies [46]. The choice should include consideration of educational level,
motivation of the buddy [11], and the nature of the relation between the vulnerable person with T2DM and the buddy [48]. Lastly, referral of vulnerable people with T2DM to diabetes support groups, patient organizations and library courses might assist uptake of digital solutions for better diabetes self-management.

Most informants in our study felt intimidated by technology. Insufficient introduction to the use of smartphones and being inexperienced in using the internet may be intermediate mechanisms leading to non-adherence to digital interventions and the preference for offline interaction in vulnerable people with T2DM [39,47]. A review of usability studies of diabetes technologies reported that not only were usability studies rarely published, but more than half of the studies failed to report their user characteristics [15]. This indicates that the needs and perspectives of vulnerable people with T2DM are less likely to be considered when designing future interventions.

Limitations
Firstly, our study was limited by a small sample of informants. This inherent limitation of qualitative research was overcome by strategic selection and reducing redundancy in our findings. Secondly, our results might be biased by a relatively high average age of 58 years, as the trustworthiness of online health information was reported to be negatively correlated with higher age [39]. It may be speculated that younger informants would not have had the same reservations concerning adoption of digital interventions. Thirdly, our informants had a long average duration of diabetes diagnosis of 12 years. This may have influenced our results, as newly diagnosed people with T2DM were more likely to be motivated for using mobile phone interventions for diabetes self-management due to recent diagnosis [52]. Conversely, the high HbA1c of our informants was reported to be a motivating factor for benefitting from a web-based diabetes application [53]. The high number of eligible people with T2DM declining participation may potentially have resulted in selection bias. Similar to previous research recruiting vulnerable people T2DM has been reported to be difficult [46]. However, we argue that our results may have persevered or even been more noteworthy, if decliners had accepted participation.

The first author previously recruited some of the informants for randomized controlled trials. Consequently, this might have resulted in informants being influenced by social desirability, making them reluctant to openly critique digital interventions in order to please the first author. On the contrary, knowing each other from an earlier study could facilitate trust and communication during interviews.

Conclusion
Vulnerable people with T2DM are unprepared for digital interventions for disease management for a number of reasons and diabetes distress is potentially increased by the introduction of digital interventions. Vulnerable people with T2DM prefer personalized care including a designated caregiver and an allocated buddy, who could provide support and assist uptake of digital interventions to diabetes management. Currently, the healthcare system meets these needs inadequately adding to the low adherence and poorer health outcomes in this group of vulnerable people with T2DM.

Conflict of interest
None of the authors have any conflict of interest to disclose.

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References


