



Københavns Universitet

The influence of diabetes distress on digital interventions for diabetes management in vulnerable people with type 2 diabetes

Mathiesen, Anne Sophie; Thomsen, Thordis; Jensen, Tonny; Schiøtz, Charlotte; Langberg, Henning; Egerod, Ingrid

Published in:

Journal of Clinical and Translational Endocrinology

DOI:

[10.1016/j.jcte.2017.07.002](https://doi.org/10.1016/j.jcte.2017.07.002)

Publication date:

2017

Document Version

Publisher's PDF, also known as Version of record

Citation for published version (APA):

Mathiesen, A. S., Thomsen, T., Jensen, T., Schiøtz, C., Langberg, H., & Egerod, I. (2017). The influence of diabetes distress on digital interventions for diabetes management in vulnerable people with type 2 diabetes: A qualitative study of patient perspectives. *Journal of Clinical and Translational Endocrinology*, 9, 41-47. <https://doi.org/10.1016/j.jcte.2017.07.002>



Original research

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



Anne Sophie Mathiesen ^{a,*}, Thordis Thomsen ^{b,d}, Tonny Jensen ^{a,*}, Charlotte Schiøtz ^{a,*}, Henning Langberg ^c, Ingrid Egerod ^{d,e}

^a Department of Endocrinology, Abdominal Centre, Copenhagen University Hospital Rigshospitalet, Blegdamsvej 9, DK-2100 Copenhagen, Denmark

^b Abdominal Centre, Copenhagen University Hospital Rigshospitalet, Blegdamsvej 9, DK-2100 Copenhagen, Denmark

^c CopenRehab, Section of Social Medicine, Dept. of Public Health, Faculty of Health and Medical Sciences, University of Copenhagen, Henrik Pontoppidansvej 6,1, DK-2200 Copenhagen, Denmark

^d University of Copenhagen, Faculty of Health & Medical Sciences, Denmark

^e Intensive Care Unit 4131, Copenhagen University Hospital Rigshospitalet, Blegdamsvej 9, DK-2100 Copenhagen, Denmark

ARTICLE INFO

Article history:

Received 14 March 2017

Received in revised form 30 June 2017

Accepted 6 July 2017

Keywords:

Type 2 diabetes
Digital interventions
Vulnerable population
Health inequalities
Diabetes distress
Qualitative research

ABSTRACT

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.

© 2017 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

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

* Corresponding authors.

E-mail address: anne.sophie.mathiesen@regionh.dk (A.S. Mathiesen).

socioeconomic status [2]. The prevalence of lifestyle risk factors, such as smoking, unhealthy diet and sedentary lifestyle, is more than threefold higher in the lower socioeconomic groups with the T2DM population following the same pattern [2]. In addition, people with T2DM and low socioeconomic status often have lower health literacy, potentially leading to poorer glycemic control [8,9]. They also have more comorbidity and often limited [10] and less supportive [11] social networks. Consequently, the individual demands of managing lifestyle modification in combination with clustering of risk factors in people with T2DM and low socioeconomic status infer a socioeconomic gradient in morbidity and mortality [12].

From a political viewpoint, digital interventions are potential solutions for improving diabetes management at lower marginal costs. 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 [13]. However, the current confidence in digital interventions threatens to augment the socioeconomic gap in T2DM, increasing the phenomenon known as the “digital divide” [14].

Tailored health interventions for improving diabetes management in vulnerable groups may bridge the digital divide. Nevertheless, most relevant studies are insufficient in reporting baseline characteristics [15] when developing new digital interventions. Moreover, studies fail to investigate the potential impact of digital interventions in vulnerable T2DM subgroups [16]. Further, many studies define vulnerability in relation to isolated characteristics such as socioeconomic characteristics [8], self-reported health literacy [17] or ethnicity [18]. However, these characteristics may not adequately capture the concept of vulnerability [19]. A vulnerable population in general has been described as a disadvantaged sub-segment of the community, requiring utmost care and consideration [20].

In the present study we extended the definition of vulnerability to include the presence of comorbidity and risky lifestyle behaviors. These additional characteristics are relevant as comorbidities may affect adherence negatively and aggravate diabetic complications [21]. Considering risky lifestyle behaviors is crucial for reducing the risk of complications in people with T2DM [3]. Consequently, the vulnerable T2DM population was defined as having one or more comorbidities, one or more lifestyle risk factors, poor diabetes management, low educational level and low health literacy. Before we proceed to develop a digital intervention for improving diabetes management in vulnerable people with T2DM, it is essential to explore the potential for digital interventions from the perspective of the target group [22,23].

Aim

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.

Table 1
Informant characteristics.

Informants (pseudonyms)	Gender	Age	Marital status	Diabetes years	Lifestyle Risk factors and blood glucose management
Angelica	Female	41	Married	4	Overweight, HbA1c “too high”
Nelly	Female	64	Married	4	Overweight, HbA1c “too high”
Larry	Male	38	Married	5	Smoker, obese, HbA1c “dangerously high”
Adrian	Male	64	Living with brother	7	Obese, sedentary, HbA1c “far too high”
Susan	Female	46	Married	11	Obese, sedentary, HbA1c “extremely high”
Ben	Male	58	Married	14	Overweight, alcohol abuse, HbA1c “dangerously high”
Stuart	Male	68	Divorced	14	Smoker, low education, HbA1c “too high”
Jack	Male	70	Unmarried	14	Obese, alcohol abuse, sedentary, HbA1c “within normal limits”
George	Male	67	Unmarried	17	Smoker, overweight, sedentary, alcohol abuse, HbA1c “too high”
Jane	Female	60	Divorced	18	Overweight, HbA1c “within normal limits”
Frank	Male	68	Unmarried	19	Smoker, obese, sedentary, HbA1c “moderately high”
Anne	Female	61	Unmarried	20	Obese, sedentary, HbA1c “extremely high”

Level of HbA1c recommended for type 2 diabetics <48 mmol/mol.

Level of HbA1c in informants: 53–68 mmol/mol: “moderately high”; HbA1c 68–79 mmol/mol: “too high”; HbA1c 80–90 mmol/mol: “extremely high”; HbA1c 91 +: “dangerously high”.

Table 2
Interview guide.*Diabetes management:*

How do you manage the daily demands of your diabetes?

Which elements of diabetes management do you consider most important when gaining new knowledge?

In relation to glucose management and lifestyle recommendations. What do you do in regard to these recommendations?

Concerning diabetes management recommendations, do you often experience having a guilty conscience and why?

What tools do you need to improve your current diabetes management?

Experience with requiring digital health information:

Do you have access to the internet at home and from your mobile phone?

How often do you use the internet and for what?

How do you use the internet for seeking health information?

Digital intervention for diabetes management:

Do you use the internet or your mobile phone for acquiring knowledge on diabetes management and lifestyle recommendations (specific to the problem areas of the informant)?

Considering your experiences with using the internet/diabetes portal/app for managing diabetes; what do you consider to be facilitators/barriers?

Technical design:

What are your wishes for content, design, text, colors?

Pictures of possible design solutions are presented

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

Table 3
Themes and sub-themes.

Theme I Dealing with diabetes distress	Theme II Suffering informational confusion	Theme IV Experiencing digital alienation	Theme V Missing the Human Touch
- Using rationalization - Using the ostrich approach	- Distressed by inconsistent health information - Distressed by the happy-go-lucky attitude	- Big Brother is watching me - My smartphone doesn't understand me	- Needing a personal caregiver - Needing a buddy

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 I don’t want to think about it. It bothers me*” (Ben). To alleviate distress, some informants felt compelled to focus on some aspects of health while ignoring others. Informants were distressed by recommendations for lifestyle changes, but also by their current lifestyle; they were between a rock and a hard place. “*If anything can make the disease (diabetes) worse it’s distress, that’s why I can’t focus on my diet*” (Jack). At the same time, they were painfully aware of the consequences of ignoring their disease indefinitely: “*Well, if something happens to me, knock on wood, I’ll probably regret that I never thought of the complications*” (Susan).

Theme II: Suffering informational confusion

The informants had trouble sorting and digesting the many health promotion campaigns they met. The campaigns were experienced as patronizing, confusing, contradictory and non-informative. As a result the informants were distressed by inconsistent health information and distressed by a happy-go-lucky attitude often seen in health campaigns.

Distressed by inconsistent health information. Health promotion campaigns had the non-intended effect of confusing rather than informing this group of patients. Campaigns were often experienced as unreliable and irrelevant, leading to a sense of meaninglessness and resignation. Larry said: “*Well, then I get confused and almost want to give up*”. The informants were unable to decipher

frequently changing and often contradictory information, adding to their diabetes distress: “*It’s difficult when you suddenly can’t eat this or that. Life is too short to avoid eating everything*” (Anne). This group of patients rarely read health promotional material or surfed the internet for information; the more they read, the sicker they felt: “*I feel that I get the symptoms every time I read about something and then all of a sudden I’m afraid that I’ve got all kinds of imaginary diseases*” (Adrian).

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 compatriot, 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 to 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 reaching 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 overtly 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.

Acknowledgements

Funding for this study was provided by the TRYG Foundation, grant number 103925, the Novo Nordisk Foundation, grant number 6265, the Lundbeck Foundation and the University Hospital of Copenhagen, Rigshospitalet, grant number E-22260-04.

References

- [1] WHO Diabetes. 2016: <http://www.who.int/mediacentre/factsheets/fs312/en/>.
- [2] Stringhini S et al. Association of lifecourse socioeconomic status with chronic inflammation and type 2 diabetes risk: the Whitehall II prospective cohort study. *PLoS Med* 2013;10(7):e1001479.
- [3] Look ARG, Wing RR. Long-term effects of a lifestyle intervention on weight and cardiovascular risk factors in individuals with type 2 diabetes mellitus: four-year results of the Look AHEAD trial. *Arch Intern Med* 2010;170(17):1566–75.
- [4] Thomas, D.E., E.J. Elliott, and G.A. Naughton, Exercise for type 2 diabetes mellitus. *Cochrane Database Syst Rev*, 2006(3): p. CD002968.
- [5] Holman RR et al. 10-year follow-up of intensive glucose control in type 2 diabetes. *N Engl J Med* 2008;359(15):1577–89.
- [6] Holman RR et al. Long-term follow-up after tight control of blood pressure in type 2 diabetes. *N Engl J Med* 2008;359(15):1565–76.
- [7] Gaede P et al. Effect of a multifactorial intervention on mortality in type 2 diabetes. *N Engl J Med* 2008;358(6):580–91.
- [8] Schillinger D et al. Does literacy mediate the relationship between education and health outcomes? A study of a low-income population with diabetes. *Public Health Rep* 2006;121(3):245–54.
- [9] Schillinger D et al. Association of health literacy with diabetes outcomes. *JAMA* 2002;288(4):475–82.
- [10] Koetsenruijter J et al. Social support and self-management capabilities in diabetes patients: An international observational study. *Patient Educ Couns* 2016;99(4):638–43.
- [11] Reifegerste D, Hartleib S. Hypoglycemia-related information seeking among informal caregivers of type 2 diabetes patients: Implications for health education. *J Clin Transl Endocrinol* 2016;4:7–12.
- [12] Lipscombe LL et al. Income-related differences in mortality among people with diabetes mellitus. *CMAJ* 2010;182(1):E1–E17.
- [13] McLean G et al. Digital interventions to promote self-management in adults with hypertension: protocol for systematic review and meta-analysis. *JMIR Res Protoc* 2015;4(4):e133.
- [14] Sarkar U et al. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *J Am Med Inform Assoc* 2011;18(3):318–21.
- [15] LeRouge C, Wickramasinghe N. A review of user-centered design for diabetes-related consumer health informatics technologies. *J Diabetes Sci Technol* 2013;7(4):1039–56.
- [16] Harrison S et al. Are patients with diabetes mellitus satisfied with technologies used to assist with diabetes management and coping?: A structured review. *Diabetes Technol Ther* 2014;16(11):771–83.
- [17] Sarkar U et al. The literacy divide: health literacy and the use of an internet-based patient portal in an integrated health system—results from the diabetes study of northern California (DISTANCE). *J Health Commun* 2010;15(Suppl 2):183–96.
- [18] Sarkar U, Fisher L, Schillinger D. Is self-efficacy associated with diabetes self-management across race/ethnicity and health literacy? *Diabetes Care* 2006;29(4):823–9.
- [19] Lyles CR, Sarkar U. Health literacy, vulnerable patients, and health information technology use: where do we go from here? *J Gen Intern Med* 2015;30(3):271–2.
- [20] Shivayogi P. Vulnerable population and methods for their safeguard. *Perspect Clin Res* 2013;4(1):53–7.
- [21] Valderas JM et al. Defining comorbidity: implications for understanding health and health services. *Ann Fam Med* 2009;7(4):357–63.
- [22] Harris J et al. Involving people with diabetes and the wider community in diabetes research: a realist review protocol. *Syst Rev* 2015;4:146.
- [23] Ekeland AG, Bowes A, Flottorp S. Methodologies for assessing telemedicine: a systematic review of reviews. *Int J Med Inform* 2012;81(1):1–11.
- [24] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24(2):105–12.
- [25] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15(9):1277–88.
- [26] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(6):349–57.
- [27] Robinson, K.L., M; Hansen, BH; Andreassen, AH; Jeppesen, M; Buhelt, LP; Lau, C; Glümer, C. [National Health Survey 2013]. 2013. Research Center of Prevention and Health, The Capital Region of Denmark.
- [28] Al Sayah F, Williams B, Johnson JA. Measuring health literacy in individuals with diabetes: a systematic review and evaluation of available measures. *Health Edu Behav* 2013;40(1):42–55.
- [29] Guest Bunce G, Bunce Arwen, Laura Johnson. How many interviews are enough? An experiment with data saturation and variability. *Fields Methods* 2006;18(1):18–59.

- [30] Lincoln, Y.S.G., E. G., *Naturalistic inquiry*. 1985, Beverly Hills: SAGE.
- [31] Fisher L et al. Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. *Diabetes Care* 2010;33(1):23–8.
- [32] Fisher L et al. When is diabetes distress clinically meaningful?: Establishing cut points for the Diabetes Distress Scale. *Diabetes Care* 2012;35(2):259–64.
- [33] Polonsky WH et al. Assessing psychosocial distress in diabetes: development of the diabetes distress scale. *Diabetes Care* 2005;28(3):626–31.
- [34] Tanenbaum ML et al. Diabetes distress from the patient's perspective: qualitative themes and treatment regimen differences among adults with type 2 diabetes. *J Diabetes Complications* 2016;30(6):1060–8.
- [35] Lipscombe C, Burns RJ, Schmitz N. Exploring trajectories of diabetes distress in adults with type 2 diabetes; a latent class growth modeling approach. *J Affect Disord* 2015;188:160–6.
- [36] Ralston JD et al. Patients' experience with a diabetes support programme based on an interactive electronic medical record: qualitative study. *BMJ* 2004;328(7449):1159.
- [37] Fisher L et al. Impact of baseline patient characteristics on interventions to reduce diabetes distress: the role of personal conscientiousness and diabetes self-efficacy. *Diabet Med* 2014;31(6):739–46.
- [38] Gonzalez JS et al. Distress and type 2 diabetes-treatment adherence: a mediating role for perceived control. *Health Psychol* 2015;34(5):505–13.
- [39] Miller LM, Bell RA. Online health information seeking: the influence of age, information trustworthiness, and search challenges. *J Aging Health* 2012;24(3):525–41.
- [40] Dejean D et al. Patient experiences of depression and anxiety with chronic disease: a systematic review and qualitative meta-synthesis. *Ont Health Technol Assess Ser* 2013;13(16):1–33.
- [41] Vanstone M et al. How diet modification challenges are magnified in vulnerable or marginalized people with diabetes and heart disease: a systematic review and qualitative meta-synthesis. *Ont Health Technol Assess Ser* 2013;13(14):1–40.
- [42] Bandura A. Human agency in social cognitive theory. *Am Psychol* 1989;44(9):1175–84.
- [43] Bandura A et al. Perceived self-efficacy in coping with cognitive stressors and opioid activation. *J Pers Soc Psychol* 1988;55(3):479–88.
- [44] http://assets.pewresearch.org/wp-content/uploads/sites/14/2016/09/PI_2016.09.20_Digital-Readiness-Gaps_FINAL.pdf 2017 [cited 2017 0701].
- [45] Carducci A et al. Mass media health information: quantitative and qualitative analysis of daily press coverage and its relation with public perceptions. *Patient Educ Couns* 2011;82(3):475–8.
- [46] Torenholt R et al. Simplicity, flexibility, and respect: preferences related to patient education in hardly reached people with type 2 diabetes. *Patient Prefer Adherence* 2015;9:1581–6.
- [47] Lyles CR et al. Qualitative evaluation of a mobile phone and web-based collaborative care intervention for patients with type 2 diabetes. *Diabetes Technol Ther* 2011;13(5):563–9.
- [48] Mayberry LS et al. Stress, depression and medication nonadherence in diabetes: test of the exacerbating and buffering effects of family support. *J Behav Med* 2015;38(2):363–71.
- [49] Vest BM et al. Diabetes self-management in a low-income population: impacts of social support and relationships with the health care system. *Chronic Illn* 2013;9(2):145–55.
- [50] August KJ et al. Spouses' involvement in their partners' diabetes management: associations with spouse stress and perceived marital quality. *J Fam Psychol* 2013;27(5):712–21.
- [51] Mayberry LS, Harper KJ, Osborn CY. Family behaviors and type 2 diabetes: what to target and how to address in interventions for adults with low socioeconomic status. *Chronic Illn* 2016;12(3):199–215.
- [52] Arsand E et al. Mobile phone-based self-management tools for type 2 diabetes: the few touch application. *J Diabetes Sci Technol* 2010;4(2):328–36.
- [53] Nijland N et al. Factors influencing the use of a Web-based application for supporting the self-care of patients with type 2 diabetes: a longitudinal study. *J Med Internet Res* 2011;13(3):e71.