Using information and communication technologies and digital health services for self-management support: perceptions of persons with type 2 diabetes treated in Swedish primary health care - A Qualitative Study

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ABSTRACT

Background: Digital health services are increasing rapidly worldwide. Strategies to involve patients in self-monitoring of type 2 diabetes (T2D) on a daily basis is of crucial importance and there is a need to optimize the delivery of care, such as self-management support. Digitalised solutions have the potential to modify and personalise the way in which people use primary health services, both by increasing access to information and providing other forms of support at a distance.

This study is part of a larger project aimed at implementing person-centred interactive self-management support (iSMS) in primary healthcare.

Objective: The aim of this study was to describe perceptions of using information and communication technologies (ICT) and digital health services for self-management support among people with type 2 diabetes treated in Swedish primary healthcare.

Methods: This is a report from a qualitative study, based on interviews analysed using content analysis conducted among people diagnosed with T2D.

Results: Findings suggest that the participants had mixed feelings regarding the use of digital health services for self-management support. They experienced potentials such as increased involvement, empowerment, and safety, as well as concerns such as ambiguity and uncertainty.

Conclusion: Digital health services for self-management are easily accessible and have the potential to reach a wide population. However, targeted training to increase digital skills is required and personalised devices must be adapted and become more person centred to improve patients’ involvement in their own care.
KEYWORDS
eHealth; digital health services; Internet; type 2 diabetes; person-centred care; self-management; primary health care; qualitative research

Introduction
Information and communication technology (ICT) for health promotion, disease prevention, and disease management used in health care (eHealth), is suggested to have a great potential to improve access, quality, safety and efficiency of care, and further prevention, diagnostics, treatment, and self-management among people with chronic illnesses such as type 2 diabetes (T2D) [1-3]. Until about a decade ago, the idea of allowing a digital device to play a decisive role in how T2D is controlled and monitored was unthinkable. Today it is booming in health care with a rapid growth and supply of various applications and interactive systems aimed at improving people’s health behaviour and supporting self-management in chronic illness [4]. The use of digital health services or eHealth is the object of study and the primary terms, interchangeably used in this paper. In these terms, we include using the Internet for searching for medical and health facts via e.g. diabetes websites, using patient portals, blogs, chat rooms and forums. Furthermore, we also use telehealth, telemedicine, tele-monitoring, mobile Health (mHealth), apps, electronic health records, and other uses of digitisation. These technologies are important since they are supposed to provide, improve
and support self-management and the delivery of care at a distance among these patients.

Even if developments and implementations of ICT in health care proceed quickly, opinions about the efficiency of eHealth vary among both patients and healthcare professionals [5-7]. This is a challenge since innovative technologies for use in health care is not possible without the acceptance of patients and healthcare professionals. In order to support people with chronic illness to more readily accept digital health services and to gain the ability and knowledge to use ICT, we need to learn more from these groups of users [8, 9]. In this paper, the focus is on people with T2D and the fact that the prevalence of T2D is increasing, generating a heavy burden on the healthcare system in both developed and developing countries [10, 11]. In Sweden, it is estimated that 4%-6% of the population has T2D [12].

Self-management is a basic and integrated part of the treatment in T2D. Since it is a progressive disease it must be complemented with oral antidiabetic agents and/or insulin injections over time, which could add to the burden of the disease [13-15]. To control the disease progression, people with T2D visit physicians and specialist nurses several times per year to take various tests, adjust medication, and get self-management support aimed at postponing severe complications [16]. People with T2D commonly struggle with complex self-management activities including healthy eating, physical activity, blood sugar testing, self-monitoring and medications [17, 18]. Therefore, to manage diabetes efficiently on a daily
basis over time, person-centred and tailored education and support, as well as collaboration/partnership between patients and healthcare professionals are recommended [13, 19, 20].

The various technologies used in digital health services, such as the Internet, mobile apps, and other kinds of interactive digital tools and devices in health care have a potential to facilitate self-management, which in turn may prevent or postpone disease complications in chronic disease [21-25]. From an economic perspective, eHealth may lead to better cost-efficiency in the health sector [26], and it has a potential to complement or even substitute several personal contacts with healthcare professionals [27]. A challenge though is to integrate goals of person-centred care (PCC) in the implementation of digitised self-management support [5]. One core value in PCC is the development of a mutual and respectful partnership between patients and healthcare professionals. Another is that care plans should be based on patients’ narratives, where a comprehensive view of the patients is important and where autonomy is of great importance [28].

Implementation of ICT in health care is recommended in our society. Both healthcare professionals and patients are recommended eHealth, and care should also be person centred [29, 30]. However, ICT and digitised care and their efficiency to merge goals of eHealth and PCC are not sufficiently evaluated by users. To our knowledge, only a few studies have evaluated the patients’ perspectives on the use of digitised care in primary health care.
The aim of this study was therefore to describe perceptions of using ICT and digital health services for self-management support among people with T2D treated in Swedish primary healthcare.

**Methods**

This study is part of a larger project aimed at designing and implementing person-centred interactive self-management support (iSMS) in primary healthcare in northern Sweden. The overall project has a co-creation design and participants' perceptions are therefore of great value for designing a forthcoming intervention.

**Participants and Setting**

The participants were treated in primary healthcare in a county in northern Sweden. Inclusion criteria in the present study were Swedish-speaking individuals who had been diagnosed with T2D. In total, 11 people (three women, eight men) aged from 50 to 78 years (median = 65) were interviewed. The aim was to reach an even gender distribution, but several women did not want to participate in the study. The duration of T2D among the participants varied from 4 months up to about 10 years. Seven of the participants lived together with a partner, while four were single. Each participant owned a smartphone. The four initial participants were recruited with help from the Local Diabetes Association, and seven using a snowball sampling, that is, enrolled participants suggested names of other people who could be contacted for interviews.
Data Collection

The first author conducted interviews with the participants individually, either in their homes (n = 8) or at the university (n = 3) during 2016. All participants were contacted in personal or by telephone in advance. They received information about the study, and date and place for the interview were decided. At the interview session, each interviewee was informed again and had the opportunity to ask questions or withdraw participation. The interviews performed by the first author lasted between 40 and 80 (median = 60) minutes and were digitally recorded. During the interview, a semi-structured interview guide was used, as well as an ambition to get answers that were narrative nature. The opening question was, “If I say information technology and eHealth, what do you think of?” Examples of other questions were, “Can you please tell me about your experiences of using digital health services in contacts with care?” “Have you ever used any digital technology device in your diabetes self-management? Please, tell me about those experiences.” Probing questions were used to deepen the topics.

Data Analysis

The interview data was transcribed verbatim by the first author and analysed using qualitative content analysis as described by Graneheim and Lundman [31]. Qualitative content analysis is a systematic way to describe variations of content in verbal or written communication [31, 32]. The analysis was performed in several steps. First, all text was read through thoroughly to get a sense of the whole. This reading revealed two
overarching domains – potentials and concerns – into which the text was sorted. The text in each domain was then divided into meaning units consisting of words or sentences related to each other through their content and context. The identified meaning units were then condensed, that is, made shorter without losing the core meaning, and interpreted and labelled with codes. The codes were sorted, based on similarities and dissimilarities, into 12 subcategories within the two domains. The subcategories were then abstracted to five categories (Table 1). Following the steps of the analysis should not be seen as a linear process, rather a process of going back and forth between the steps and between original data and analysed data. All authors discussed the interpretations within every step of the analysis until consensus was achieved [31].

**Ethical Considerations**

The Regional Ethical Review Board at Umeå University approved the study (Dnr 2014-179-31M), and was conducted according to the ethical principles described in the Helsinki Declaration [33]. Before giving informed consent, the participants received oral and written information. It was emphasised that participation was voluntary and that they could withdraw from the study at any time without giving explanation; they were also assured of confidentiality. The transcripts were made anonymous by removing personal information. In addition, quotations were made anonymous with small changes in wordings that did not alter their core meanings.
Results

Five categories within the domains “potentials” and “concerns” were identified in the analysis. The results – divided into two domains, five categories and 12 subcategories – are presented in Table 1 and in more detail in the text. Each subcategory is further enlightened by quotations from the original interviews in the following text.

Table 1. Domains, categories and subcategories describing persons with T2D perceptions of using ICT and digital health services for self-management support

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<th>CONCERNS</th>
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<td>Ambiguity</td>
<td>Insufficient</td>
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<td>Empowerment</td>
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Potentials

Within the domain Potentials, which referred to the positive perceptions of using eHealth resources as self-management support, the categories Involvement, Empowerment, and Safety were highlighted.

Involvement

The importance of being involved in decisions about medication and in discussions about self-management and goals – for example, blood sugar levels – were highlighted. Some had negative perceptions from previous
healthcare contacts when healthcare professionals made decisions “over their heads”. The subcategories related to this category are *Independence* and *Responsibility*.

*Independence*

Independence included striving to handle all demands related to the disease and was expressed as being natural. However, sometimes, social demands made it difficult to remember or prioritise self-management. Using digital health services was described as a key to try harder and as something positive. Some were willing to pay for digital and technological tools that could provide insights and motivation to self-manage their chronic condition.

“I use and have paid for an app on my smartphone, so I can monitor my weight, daily steps and of course my blood sugar. I love it”.

*Responsibility*

The importance of taking responsibility for oneself was highlighted. Those who had used various digital health services previously expressed that it helped them to take more action in their self-management. However, this was something they kept secret and did not always tell their diabetes nurse, since she might apprehend it as being critical of her advice. They also forced the importance of being seen as capable and responsible by the diabetes nurse, something that included that they accepted the
consequences of even unhealthy choices. These participants had often got the advice from their diabetes nurses not to trust information on the Internet and felt that using apps was in a grey zone, almost forbidden. Nevertheless, the participants described how it had helped them.

“It [the app] helped me to take responsibility for a healthier behaviour; I believe I became more confident in myself since I started to use it. Much more than when I got my diabetes diagnosis”.

Empowerment

A number of areas related to eHealth were found important for the management of the participants’ own health. They viewed applications and digital tools as powerful aids for understanding and becoming more aware that enabled them to take control of their disease. Tracking their symptoms and treatments using diabetes apps and participation in online discussions provided them comfort. They learned from online peers by sharing what symptoms helped them take steps to adjust living with type 2 diabetes, what types of treatment they used, and how this worked to strengthen them. As well-informed patients, they could more easily discuss and request different treatments with healthcare providers. The subcategories related to this category are Knowledge, Participation, Engagement, and Freedom.

Knowledge
Increased knowledge was highlighted as an important goal for managing T2D. The participants expressed that they preferred better collaboration between themselves and healthcare professionals. They saw themselves as knowledgeable, capable, and responsible for their own health and self-management. Now, knowledge enabled them to make informed choices, which could lead to better control, something the use of apps could facilitate. Gaining knowledge at one’s own pace was seen as a benefit.

“I can get the knowledge I want about type 2 diabetes [on the Internet], and make up my own goals, step by step at my own pace [using an app]. . . without having to discuss everything with the diabetes nurse”.

**Participation**

Digital health services were perceived as providing opportunities for increased participation, since they could discuss their condition with people other than healthcare professionals. Some gave examples of their adult children’s increased participation when they lived far away. By using a diabetes app the adult children could be updated online and follow the disease process at a distance. They could also easily get in touch with people with diabetes that they could contact through various online portals for patients.

“I especially enjoy being able to reason with others with the same problems on different patient forums. It is a kind of social networking, though I do not leave home often. . .”
**Engagement**

Digital health services and devices made the participants more engaged through an increased awareness about the disease and needs for improved self-management. It was described that they traditionally met a doctor and a nurse semi-annually. Between those visits, the disease-related information was easy to “forget”, and thereby they did not focus on changing habits. Because of an increased use of digital devices, they viewed personal visits at the health care centre as unnecessary.

“I feel more engaged now [using an app for self-monitoring]...I don’t always have to visit the primary health centre if I have problems, some things can be solved through eService on the primary health care centres website...”

**Freedom**

Using digital health services was expressed as increasing the participants’ freedom. They gave examples of the freedom that was related to 24-hour service online. They did not have to wait until the next morning or a Monday, when the diabetes nurse was available if they had problems or had questions during the weekend.

“... anytime during all hours I have the freedom to reflect and get feedback [from patient forums] on my thoughts. I do not have to wait until the next day when the primary health care centre opens. . . as I did before”.

**Safety**
Digital health service was experienced as offering safety. Safeguard components as passwords, encryption systems like an e-ID (BankID or Mobile BankID) and similar technical safeguards for authorisation or access controls strengthened the view of technology as something positive which protected the participants. The subcategories related to the category Safety are *Confidentiality* and *Privacy*.

**Confidentiality**

The participants expressed worries and concerns about the following: that people from their community could witness them visiting the primary health care centre and this could endanger their confidentiality. It could have personal consequences if information about them, known by neighbours could leak to healthcare professionals, e.g. about their families and social circumstances not known by health care. In the next step this information could leak to employers or maybe insurance companies. Sometimes they withheld information from health care professionals due to confidentiality concerns and also could avoid personal visits to the healthcare centre. Online healthcare services were described as more secure, with personal logins, which was seen as trustworthy, and were at times perceived as better than traditional face-to-face visits.

“I trust that all information about me is kept confidential, even if it is online… but I do not know if I can trust that only authorised persons at the healthcare centre have access to my medical records … I mean, my neighbour works there as a secretary … “.
Privacy

It was highlighted that when digitised health is discussed in the media or in popular scientific literature, the ethics, security and privacy risks are often questioned. Despite this, the participants were not worried. Instead, they expressed that lack of privacy was a barrier to visiting healthcare centres in small communities. Participants mentioned breaches of their privacy and had experienced that fellow patients took mobile photos in the waiting room and put them on Facebook. By using online health services, they did not have to “advertise” their problems to other patients in the waiting room, and thereby, they did not feel as vulnerable and exposed.

“When I sit in the waiting room, I could find it problematic to meet neighbours and others. I don’t want to expose myself as an ill person to them. . . I think I would prefer online meetings with my nurse”.

Concerns

Within the domain Concerns, which highlighted the more negative side of the participants’ perceptions of using eHealth services for self-management support, the categories Ambiguity and Uncertainty are highlighted.
The participants expressed ambiguity concerning digital health services and digital devices, such as apps or interactive self-management support. Mostly, it concerned feelings of not being able to manage the technology and that they had too little training and avoided digital devices if they could. The subcategories related to the category Ambiguity are Insufficient support and Incapability.

**Insufficient support**

Being afraid of the new technologies as well as having limited or insufficient technological support increased the risk of not getting the medical advice participants needed. They therefore preferred face-to-face meetings with healthcare professionals. They did not have any family members or friends who could support them and therefore they were afraid of having technical problems.

“What if something goes wrong”?

**Incapability**

Ambiguity also concerned reluctance to use the digital technology due to one’s own incapability. Participants expressed not having sufficient skills to use apps and stated that they hardly managed to use their smartphones due to technical incapability or physical problems as impaired vision or tremor. In addition, memory impairment was seen as complicating the use of websites and apps.

“It’s too difficult to use for me, I can’t even type [on the smartphone].
Uncertainty

Digital systems in general were questioned by participants. They felt uncertain whether they could trust information they came across on the Internet, and they were afraid of problems with eHealth services due to unreliable Internet connections. The subcategories related to the category Uncertainty are Insecurity and Unreliability.

Insecurity

Participants reported insecurity and stated that they saw no value in using technology to manage their health. Furthermore, they did not always trust the quality and authenticity of the information on websites they found and if these websites provided accurate and detailed information about diabetes management. It was considered unsafe to rely entirely on the online information that was available since the content could be medically incorrect and potentially endanger their health.

“I mean, how can I be 100% sure that the information online is correct? It could be fatal”.

Unreliability

Participants highlighted the unreliability of the computer systems. They also said that the lack of Internet connection/broadband in their homes made it impossible to rely on and use the computer or smartphone for eHealth purposes. Participants expressed that even the primary healthcare service could not guarantee reliable computer systems.
Discussion

This study has provided insight about the perceptions that people with T2D may have about using ICT and digital health services for self-management support, and the findings show that the participants are mainly positive, but they have mixed feelings regarding use of eHealth services and digital devices irrespective of whether it was a web or mobile application. On the one hand, they experienced potentials such as increased involvement, empowerment, and safety; on the other hand, they expressed concerns such as ambiguity and uncertainty. One explanation for the variation in perceptions of using digital health services/eHealth services for self-management support could be the participants’ differing capabilities, such as education and computer training.

Several studies report that eHealth is promising with regard to self-management support, and that people with chronic conditions desire tools that effectively reduce the limitations of life caused by disease [34-36]. Alpay et al. [37] concluded that in removing barriers of time and geographical distance in healthcare services – by use of digital and technological services such as video consultations and telehealth – the patients gain flexibility. They get an easier and more convenient access to healthcare, they may even have fewer time-demanding healthcare centre visits, and finally, patients can receive care at a location that does not
require transportation, and in an environment that can be experienced as less threatening.

Regarding the category Involvement, our results highlight that self-monitoring may increase patients’ independence. Similar results are reported by Holtz and Lauckner [38], who showed that people with diabetes could adapt easier to their condition by using their mobile phones in self-monitoring and management of diabetes. Kruis et al. [39] presented that innovative eHealth self-management solutions can support or improve independence among people with chronic conditions. Ahern et al. [40] concluded that the potential of patient technologies can only be accomplished by activating patients to become more engaged and responsible for their own care. In a study by Nijland et al. [35], the authors argued that interactive eHealth applications must be continuously changed and developed to promote individual self-care, through feedback and exchange of information, something that is in line with the value of independence. Interactive eHealth tools designed to provide feedback on patients’ self-monitoring appear to engage patients the most, since personalised and interactive features stimulate active participation by both the patient and the nurse. Nijland et al. [35] reported that the diabetes patients in their study felt better monitored by the feedback they received and were therefore more motivated to take a more active role in the self-management of their illness, something that also led to increased independence.
Regarding the category Empowerment, our results suggest that use of interactive eHealth platforms seems to have a potential to increase patient empowerment through increased knowledge, participation, engagement and freedom. Our findings support previous studies, which report that empowerment can be improved by using digitized approaches in healthcare [5, 37, 41]. Empowerment implies participation and responsibility through increased awareness and knowledge [42]. Self-efficacy is an important aspect of empowerment and relates to change in behaviour [43], which is important for self-management in chronic conditions [37].

Patient empowerment and person-centred care (PCC) are closely related complementary concepts. These do not oppose each other and indeed patient empowerment can be achieved through PCC [44]. Both patient empowerment and PCC are emphasized by health researchers and policymakers and expressed in care policy documents nationally and internationally [7, 20]. Furthermore, it has been suggested that PCC increases patient outcomes and satisfaction in chronic illnesses [45, 46] and type 2 diabetes [47]. Thus, using the Web for medical and health facts is an approach in healthcare that can support empowerment and is facilitated by a shift to PCC that can subsequently improve self-management [25, 30, 48, 49] Digitised access increases patient empowerment and enables them to participate more actively in making better informed choices regarding their health in interaction with health care.
Technological advances for self-monitoring are changing the conditions for chronic disease management. The use of different communication tools and interactive platforms may improve patient participation in decision-making and facilitate for patients to communicate easily with health care professionals [40]. Medical and health information on the Internet, digital health that patients use as in-home monitoring, virtual consultations and mobile apps are also available to users 24 hours a day, 7 days a week [cf. 50] to provide alternatives to them apart from the primary health care centres, and this gives a certain degree of freedom [51]. However, a benefit for healthcare professionals using digitalised technology in self-management support is the option to be in contact with patients more frequently than semi-annually or annually, as is common today [52].

Our participants experienced that use of online technology was seen as something safe, which is confirmed by other studies [53, 54]. Participants were not bothered much about security concerns. Similar results are reported by Spanakis et al. [55], who stated that most patients seem to be willing to disclose information relevant to their condition to their health provider, with no particular awareness of how the patient information is transferred.

The use of digital health services can also reduce the number of visits to the healthcare centres, something that can be experienced as stressful, time-consuming, and expensive. Fewer face-to-face visits might also imply changes in the patients’ perception of self-management support as well as reconfiguring work activities for the diabetes nurse [56]). Encouraging
patients to share their self-monitored data with the diabetes nurse to a higher degree may become a trade-off for fewer visits, thus having health economic implications. This is in line with a study by Eland-de Kok et al. [57] that showed that adapted and person-centred support increased more than semi-annual visits. This may lead to quality improvements and a higher priority for those patients that need face-to-face visits best. A literature review by Hardiker and Grant [58] showed that the use of different online services depended on a number of factors such as the characteristics of users, the kinds of technological issues, characteristics of the digital health services social aspects of users, and the digitised services in use. This requires healthcare professionals to concentrate their efforts where they are needed most, by tailoring services to meet the needs of a broad range of users.

Regarding the category Ambiguities, our results highlight that some of the participants stressed concerns regarding, for example, lacking skills and knowledge about how to use digital health services, which is in line with other studies [59, 60] that have also reported an existing age-related digital division. This division concerns everything from the design of the digital device and screen design to complex commands and procedures, including inadequate training and instructions that can prevent older people from interacting with digital systems. Czaja and Lee [59] reported that predictors of not using digitised technology were, primarily the very old with cognitive decline associated with different aging processes such as vision impairment, and attitudes such as anxiety about computer use.
and the perception that the technology is not useful to them both of which are compatible with our results.

Usually participants in our study were also reluctant about using digital health services and preferred face-to-face meetings with healthcare professionals. Similar results are reported by Currie, Philip, and Roberts [27] who conclude that digitised solutions are not the key for every patient and thus do not have the same impact as a face-to-face meeting with healthcare professionals, since they may create feelings of loss of proximity for some patients. The lack of proximity in digital health services is also highlighted in other studies and is a challenge to overcome. Video consultations could sometimes compensate for the lack of proximity in digitized meetings [61, 62].

Regarding the category Uncertainty, our results highlighted that participants were ambivalent about their views of the reliability and quality of online digital health information. Similar findings report individuals having difficulties using the Internet to find complete and proper information concerning health issues. Not relying on online information in making decisions about treatment and self-management, including whether or not to seek care, may negatively influence the user’s decisions [63, 64].

In our study, we interpreted limited access to Internet connections/broadband as a factor that affects the usefulness of digital health services. This is concurrent with Currie et al. [27], who reported problems for patients living in rural areas as compared with those living in
urban areas concerning the use of technology for health purposes. They highlighted challenges related to slow and unreliable broadband services. Fuji, Abbott, and Galt [65], on the other hand, conclude that instead of primarily focusing on issues concerning Internet infrastructure or a lack of Internet access in rural areas, focus should be placed on overcoming other concerns and barriers among the users. Our results could guide such development.

**Strengths and Limitations**

The findings in this qualitative study cast some light on the experiences of using various digital health services in self-management support among people with T2D treated in Swedish primary healthcare. We view our results as transferable to other groups of patients with similar lifestyle-related chronic conditions in societies similar to Sweden. However, according to Graneheim and Lundman [31], it is up to the reader’s judgement as whether or not the reported findings are transferable to other contexts.

We recruited 11 people with T2D for individual interviews, using a combination of purposive and subsequent sampling [cf. 66], which made it possible to expand the group of participants. However, there is a risk of bias, since our sample may consist of participants with an interest in eHealth. Despite that, our result pointed to a variation of perceptions about the use of eHealth services and could thereby be useful.
The majority of the participants were men and the age range was 50–74 years. It is possible that the outcome of this study would have been different if more women had been included and if the age range had been different, including, for example, very old patients. Nevertheless, the participants in this study are representative of people with T2D and provided rich data.

The interviews were conducted by the first author alone. However, all authors listened to and discussed the interviews, and then were involved in interpretations at every step of the analytical process, something we believe has strengthened the trustworthiness of the study and resulted in a consolidation of the findings.

**Conclusions**

The findings in this study indicate that people with T2D are interested in the use of ICT and digital health services for self-management. However, some also expressed ambiguity about using it. The findings indicate that targeted training is required and that personalised devices must be adapted.

The use of digitising for person-centred self-management support is challenging but can – if implemented appropriately – lead to increasing patient responsibility for their own health and strengthen patients’ empowerment and self-management capabilities. Although the technology of today allows for innovative approaches, there are also ethical aspects to consider when new eHealth services are introduced in healthcare. Some
people may not wish to, nor are able to use digitised technology for various reasons, while others see it as an important complement to or even substitute for traditional health care visits.

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Authors' Contributions
UÖ recruited participants, performed the data collection and transcription. UÖ and ÅH contributed to the main analysis and interpretation of data. UÖ drafted the first version of the manuscript. UÖ, CJO, LJ, UI, and ÅH contributed in editing the manuscript, and all authors contributed and approved the final version of the manuscript.

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Conflicts of Interest

The authors declare that they have no competing interests.

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Abbreviations

ICT: Information and communication technology
iSMS: Interactive self-management support
PCC: Person-centred care
T2D: Type 2 diabetes