

Leveraging the IoT to Enable the Guided Self-Determination Method



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1 Introduction

Chronic conditions also referred to as non-communicable diseases (NCD) are the largest causes of death in the developed world (AIHW 2017; WHO 2014). Moreover, due to their very nature, individuals who develop one or more chronic conditions must continue to live their lives being challenged by both the burden of their condition and treatment. The burden of living with a chronic condition is well established (AIHW 2016, 2018a; WHO 2014). According the WHO Global

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status report on non-communicable diseases report 2014, of the 38 million deaths due to NCDs in 2012, more than 40% were premature, affecting people under 70 years of age. The majority of premature NCD deaths are preventable. Four major NCDs (cardiovascular diseases, cancer, chronic respiratory diseases and diabetes) are responsible for 82% of NCD deaths (WHO 2014). In Australia, 50% of individuals have one chronic condition such as cancer, obesity, diabetes or depression; 20% have at least two chronic diseases (AIHW 2017). An estimated 1.2 million (6%) Australian adults aged 18 years and over have diabetes, with the prevalence tripled between 1989 and 2015 (AIHW 2018b). Given the increasing numbers of individuals presenting with one or multiple chronic diseases today, there is an imperative to develop superior approaches for supporting people in managing chronic conditions so that they enjoy a high quality of life. Correspondingly, there is also an imperative to stem the rising economic burden to healthcare systems and society (WHO 2014).

People living with one or more chronic conditions, their families and their extended social networks experiencing burden of symptoms with severe social and economic consequences that can impact on peoples' quality of life (AIHW 2018a). However, they are also experiencing a burden of treatment related to having to drastically change their behaviours to accommodate recommended lifestyle changes; monitor and manage symptoms at home; and accessing, coping and navigating complex health services. For many people this level of accommodation is overwhelming and time consuming, and it requires a high level of health literacy and often technical skills (Mair and May 2014). The burden of treatment dramatically changes the relationship between people with chronic conditions and health professionals (Mair and May 2014) and demands on health services. The healthcare changes are associated with a higher number of primary care consultations, hospital outpatient visits and hospital admissions (Mclean et al. 2015).

These demands or health service changes required in order to provide safe quality care and treatment inversely vary with the need in the population it serves. This phenomenon is known as the inverse care law which states that the availability of good medical care tends to vary inversely with the need for it in the population served (Hart 1971). Despite the importance of ensuring that resources are allocated in line with the health needs of practice populations, there is evidence that people with chronic conditions are not well served as the system is not geared into the required changes (O'Connor et al. 2016; May 2006; Paterson 2001). Innovative, cost-effective, patient-centred care models are called for to meet these changes.

In this chapter, a research stream that is embarking on identifying a new approach to chronic condition management by focusing on developing the life skills and ability to co-manage their condition, using Guided Self Determination (GSD) is presented. Supported by positive results from Danish studies, the GSD method can alleviate the burden of treatment through creation of provision of insights into one's own challenges and problems and, by empowering citizens/patients, will contribute

to the ongoing paradigm shift towards co-production of health and well-being for people living with one or more chronic conditions (WHO 2016).

Guided self-determination may contribute to this ongoing paradigm shift in how chronic disease management is addressed (Rasmussen et al. 2017a, b). Zoffmann and Kirkevold (2012) explain how GSD can overcome barriers to empowerment which were seldom overcome in usual diabetes care. Zoffmann argues that to realise empowerment, health professionals need detailed knowledge of the barriers, their own roles in these barriers, ways to overcome them, and recognisable evidence of having succeeded (ibid.). Further, through theory-driven, qualitative evaluation, the GSD method helps health professionals to recognise changes consistent with empowerment in dyads of health professionals and people with chronic condition. By completing GSD reflection sheets, clients remarkably improve their ability to identify, prioritise, express, and share unique and unexpected difficulties related to living with diabetes (Zoffmann et al. 2015; Rasmussen et al. 2017a, b). As signs of empowerment, clients and health professionals accomplished shared decision-making, resolved life–disease conflicts, and established meaningful and effective relationships (ibid.).

The GSD method is universal and can be used for both distress in relation to non-chronic conditions and to support treatment/monitoring of conditions. However, the GSD is mainly intended for people living with one or more chronic conditions who are having problems coping and managing their overall situation with respect to physical, emotional or social wellbeing. To illustrate how the method works, we applied the GSD method in a diabetes population although evidence highlights the method can be applied to a palette of chronic conditions, even in multi-morbidity, and can work in most age groups (Zoffmann et al. 2008; Olesen et al. 2016; Jørgensen et al. 2015).

In the following section, the GSD method in the context of diabetes is presented. The role for IS/IT (information systems/information technology) is described, and then key aspects of the diabetes pilot to be facilitated in Australia are highlighted to assess the potential of this approach for managing chronic conditions in Australia.

2 Background: The GSD Method in Diabetes Context

Living with diabetes requires constant discipline and benefits significantly from access to timely and targeted information. On average, a person with diabetes will have contact with health professionals for 10 hours of care per year. For the rest of the year, people with diabetes manage their condition on their own; hence learning to self-manage diabetes is vital for good health outcomes.

Less than optimal self-management can result in serious complications in people with type 1 diabetes. In Australia, 28,036 people with T1DM aged 21–39 years are registered with 5962 in the state of Victoria in Australia. Many of these live in

regional and rural areas, often with little access to appropriate health services. A recent Australian study found this target group reported current health services in rural and regional Victoria do not meet their information and support needs, placing them at a heightened risk for developing serious diabetes complications.

Current educational interventions to achieve glycaemic control are not always successful, particularly in those people who have lost motivation for self-management. People with low motivation are often also put in the “too hard basket” by health professionals which exacerbates the risks for negative and severe physical, emotional and social impacts on people’s lives. Novel strategies are therefore required to assist those with suboptimal glycaemic outcomes to prevent complications and adverse events.

The guided self-determination (GSD) program was developed on basic grounded theory research specifically for people with diabetes by Dr. Vibeke Zoffmann. The GSD program aims to improve the life skills of people with diabetes, i.e., those personal, social, cognitive, and physical skills that enable people to control and direct their lives, and to develop the capacity to live with and produce change in their environment. It is also a method to enhance communication and problems solving skill in health professionals as a part of their professional development (Rasmussen et al. 2017a, b).

Thus the GSD method is designed to guide both people with diabetes having persistent suboptimal glycaemic control and their health professionals through mutual reflection, drawing on a number of semi-structured reflection sheets (*ibid.*). Participants are prompted to systematically explore and express their personal difficulties and experiences with diabetes through words, photos and drawings. Reflections are recorded on worksheets designed to increase participants’ ability to clarify and express their views and prepare them for active participation in the care process (Zoffmann and Lauritzen 2006).

Therefore, GSD is a problem-solving and decision-making method designed to develop life skills and overcome the barriers often occurring in the traditional dialogue between citizens/patients and health professionals, thereby increasing the co-production of health and co-management of the condition (Zoffmann and Kirkevold 2007).

As such, GSD is underpinned by life-skills theory, empowerment theory and motivational theory of self-determination. The program has been tested and proven to reduce HbA1c (up to 0.6%) and to improve life skills in adults with persistently suboptimal glycaemic outcomes of type 1 diabetes (Zoffmann and Lauritzen 2006; Zoffmann et al. 2015; Husted et al. 2011, 2014). The original method comprises eight sessions. An overview of the sessions is outlined in the next section. However, recent studies have shown that GSD can be dosed differently, and even an intervention providing two to four conversations was shown to be effective among cancer survivors (Olesen et al. 2016).

3 Overview of the GSD Course Activities Between Health Professionals and Client/Patient Eight Meetings with Activities

Meeting 1: Collaborating about life with diabetes – Conversation 1: One-to-one conversation, sheet sent to participants prior to meeting, at the meeting discuss three sheets: (1) two ways to use the long-term test (HbA1c), (2) important events and periods in your life and (3) what is currently most challenging or difficult for you living with diabetes?

Activity: Three sheets must be available to health professionals (HP) and patient (P) at the same time so they can work on them together.

Meeting 2: The collaboration process about life with diabetes – Conversation 2: One-to-one conversation, working on two sheets simultaneously around (1) Unfinished sentences – about values, experiences and needs (2) Your plans for making changes in your lifestyle.

Activity: Two sheets must be available to HP and P so they can work on them simultaneously, however, focus will be on the conversation prompted by questions on work sheet 1.

Meeting 3: Your life with diabetes – Conversation 3: One-to-one conversation, working with two sheets simultaneously (1) Pictures, metaphors or automatic thoughts about diabetes and (2) Space for diabetes in your life.

Activity: HP and P work on the sheets (drawing, showing metaphors etc.) and must be able to see and work on the sheets at same time.

Meeting 4: Conversation about agreement to make changes – Conversation 4: One-to-one conversation, working on two sheets simultaneously (1) Agreed description of main challenge or problem in your life with diabetes and (2) “For and against”.

Activity: HP and P work on the sheets (drawing, showing metaphors etc.) and must be able to see and work on the sheets at same time).

Meeting 5: Work to make changes – Conversation 5: One-to-one conversation, working on five sheets simultaneously: (1) ways the described challenge/problem has been solved until now (four pages) and (2) dynamic problem-solving (one page) which is a mutual reflection exercise to how patients can expand their current problem-solving abilities.

Activity: HP and P work on the sheets together and need to be able to read and write on the sheets at same time.

Meeting 6: Status: your goals in relation to blood glucose and HbA1c – Conversation 6: some of the sheets will have been filled out prior to the meeting. The conversation will focus on (1) blood glucose checks and your reasons for doing them, (2) your ideal and actual daily blood glucose levels, (3) advances and

disadvantages of monitoring blood glucose levels, and (4) your plan for achieving blood glucose control in the short and long term.

Activity: HP and P work on the sheets together and need be able to see and work (possible write and draw) on the sheets at same time. The HP will teach (talk and explain sheets).

Meeting 7: New strategies and long-term plan – Conversation 7: One-to-one conversation, working on one sheet simultaneously.

Activity: HP and P need to be able to read and write on same work sheet.

Meeting 8: Hand-over after consultation being integrated into the course and the long-term plan – Conversation 8 between P and HP and the third person (HP).

Activity: Conversation and working on one sheet with three communication points (at least).

Results of a feasibility study (Rasmussen et al. 2017a, b) indicate that the transferability of the GSD method to an online platform. Further, the GSD online program provided demotivated and geographically isolated clients with a novel, inexpensive and readily accessible therapeutic intervention to improve their self-management of diabetes. The GSD online program improved quality of life of clients and the communication between diabetes educators and young adults regarding better diabetes management. Further development and inclusion of new technologies was required and has now been integrated in a newly developed GSD platform in order to fully realise its capacity to engage clients in self-management to improve health outcomes. As with the face-to-face GSD method, diabetes educators using the GSD online program require education and training in GSD methods to optimise their professional role in the program and realise the self-management potential of clients.

The results of the proposed study will be of paramount importance to the future implementation of the online interactive GSD program in Australia. The use of this program in other countries has yielded positive results. The systematic, inclusive and rigorous process of development, modification, refinement and advancement of the online interactive GSD program is pivotal for its future impact on the quality of healthcare services. It is expected that this program will be a substantial positive influence on optimal health outcomes for young adults affected by type 1 diabetes and better enable them to fulfil their potential in work, study and daily life.

4 The Enabling Role for Technology

Today, information and communication technologies (ICTs) are enablers in many aspects of healthcare delivery (Wickramasinghe and Schaffer 2018). However, it has become increasingly recognized as being critical that end users identify, understand, and apply information provided to them through the growing number

and range of electronic resources becoming available these systems must be usable and the content must be understandable (Monkman and Kushniruk 2015). It is also increasingly recognised that the success or failure of health information systems and applications designed for laypeople, patients, and consumers depends on factors related to the match between the demands a system (or application) places on a user and the end user's level of eHealth literacy (Monkman and Kushniruk 2015; Kayser et al. 2015). Norman and Skinner (2006) defined eHealth literacy as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" (p. 3). Identified a new concept for eHealth literacy: a model based on systematic and inductive methods that sought to identify the full range of elements relevant to individuals attempting to understand and use eHealth technologies and digital services. This model, the eHealth Literacy Framework (eHLF), consists of seven dimensions that describe the attributes of the users (information and knowledge about their health), the intersection between users and the technologies (their feeling of being safe and in control and their motivation) and user experience of systems (they work and are accessible and suit users' needs). The eHLF provides a comprehensive map of the individual technology user's health literacy that covers his or her knowledge and skills, the system, and how the individual interacts with the system (Nørgaard et al. 2015) and can be assessed using the eHealth Literacy Questionnaire (Kayser et al. 2018).

These factors associated with eHealth literacy are important to consider in development of next step of GSD platform. The study participants will be aside to fill out a survey comprising validated questionnaires concerning their competence, self-management and communication with HP. Focus group interviews will add qualitative data and in-depth information about the participants' experiences.

The GSD methods aligns with the principle of empowerment. Hence, GSD has a tool that, through reflection exercises, interacts with HP, the system and potentially can enhance patients' eHealth literacy to cope better with their diabetes. Data collection and analysis, as well as communication within the GSD method, is strongly based on documents called reflection sheets. A first step to support GSD by IT (information technology) is to use electronic documents instead of conversation-based hard copy sheets. As a consequence, HPs as well as patients (Ps) would edit and handle those documents on digital devices like smart phones, tablet computers or notebooks. For processing the documents as well as storing, retrieving and analysing the data contained, there is a document management system as a backend application which also comprises security and privacy mechanisms. Document upload and download is done via cellular networks or the internet. There is a large variety of added applications for document management systems which can support GSD-course activities. A prominent one is Co-Authoring which is required in conversations 2, 3, 4, 5, 6, and 7 (HP and P working on the sheets together/simultaneously/at the same time). Guided Self Determination online is thereby an enabling role to support the health professionals need to learn which would be dependent on their specific context but always enabling key lessons and reflections to be stored for later access by them as required. In addition, social media

functions can be helpful to comment or discuss on sheets, either synchronously or independent of time and place. Theory-driven qualitative evaluations have confirmed GSD's ability to realise empowerment in practice in individual conversations for adults with type 1 diabetes (Zoffmann et al. 2015). The online version of the GSD would increase the flexibility of the GSD process, taking into account that HP and patient might be geographically distributed and would like to meet virtually to collaborate. This will make it possible to reach out to otherwise difficult to reach populations.

Given the breadth and depth of the tools and technologies afforded to us by IoT, we anticipate that in the future it would be possible to also include key developments in AR and VR (augmented reality and virtual reality), sensors, mobile, analytic capabilities around prediction and prevention as well as advances in AI (artificial intelligence) and Bots. Clearly, it is important to first establish the approach and delivery. However, the existence of all these technology developments makes the future bright and exciting with possibilities that ultimately will ensure that solutions and strategies can be highly tailored to each individual's needs, level of health and technology literacy so that the end result is a program that enables each individual to manage with critical life skills their chronic condition to ensure they have the highest possible quality of life.

5 Research Methodology and Design

To assess the likely benefits of the GSD method for the Australian environment a two state approach is embarked upon. First, an Australian feasibility study to transfer the GSD method to online was conducted with a small number (11) of individuals with type 1 diabetes and 7 diabetes educators in 2016. Results demonstrated that the transferability of the GSD method to an online platform provided demotivated and geographically isolated participants with a novel, inexpensive and readily accessible therapeutic intervention to improve their diabetes self-management (Rasmussen et al. 2017a, b). In addition, the study found that translating the GSD program to an online platform clearly helped these young adults with type 1 diabetes to improve their capacity to find solution to their pertinent health issues as well as improving communication processes between diabetes educators and patients (Rasmussen et al. 2017a, b). It was however clear that further development and inclusion of new technology were required for the GSD online platform to fully realise its capacity to engage participants to improve diabetes self-management and health outcomes (Rasmussen et al. 2017a, b).

Thus, although results of the feasibility study highlighted potential strengths, a larger-scale proof of concept study was subsequently required. In order to establish full proof of concept of the GSD method in the Australian healthcare environment, a larger scale study was designed. To ensure consistency with the feasibility study outcomes, and building on the feedback from the participants, we chose the same target population of young adults with type 1 diabetes. A pre- and post-

interventional study will use a sequential, two-phase design. The first phase is the delivery of the training program in GSD conversations for diabetes educators to enable facilitation of GSD online with young adults with type 1 diabetes. The second phase is client participation in, and completion of, the GSD online program with a diabetes educator. A strength of this proposed study is the inclusion of patient and diabetes educator feedback informing the design of the new GSD online platform. The proposed two-phase study involves training diabetes educators in the GSD program, and patient completion of the GSD program was conducted over a 6-month period. Surveys will be used to measure young adults' self-management skills before and 3 months after completing the GSD program with their specifically trained diabetes educator. Findings of this study will inform future implementation and scalability of GSD online as an official educational tool in Australia for Diabetes Educators to motivate and assist young adults in self-management of type 1 diabetes, as well as the provision of the GSD online program with other client and patient groups.

Clients or patients will have access to the GSD solution via an online portal. All necessary security and privacy standards are being satisfied and research will commence after ethical approvals are secured.

The results of the proposed study will be of paramount importance to the future implementation of the online interactive GSD program in Australia. The use of this program in other countries has yielded positive results. The systematic, inclusive and rigorous process of development, modification, refinement and advancement of the online interactive GSD program is pivotal for its future impact on the quality of healthcare services. It is expected that this program will be a substantial positive influence on optimal health outcomes for young adults affected by type 1 diabetes and better enable them to fulfil their potential in work, study and daily life.

6 Discussion and Conclusion

The preceding has reported on the early stages of a research stream focussed at designing and developing a new approach to provide superior chronic care management. A central aspect of this GSD method is to empower and engage the client so that he/she can actively participate in their treatment and wellness management. Further, through GSD, clients develop necessary life skills to navigate their life and ensure they can enjoy a high-quality lifestyle irrespective of their chronic conditions. Our initial discussions with key clinicians and consumer groups have been very positive. Based on the strong results from the Danish studies to date, we are confident that the pilot studies when completed will result in similarly strong results.

The burden of the growing prevalence of people with chronic and multi-comorbidities is an enormous burden on our health systems. There is little doubt that current approaches to address the treatment and management of chronic diseases is not adequate and that new approaches desperately need to be developed, designed

and trialled. We contend that GSD is such a method that offers a paradigm shift in the management of chronic care. Moreover, we contend that GSD will enable a high-value, client-/patient-centred superior experience to chronic care management. In this chapter, the enabling role for a web-based platform has been outlined.

Finally, this study has implications for theory and practice, most notably the following: (1) for theory, designing and developing methods to provide superior client-/patient-centred high-value care, extending design science research methodology and user-centred design to IoT technologies in healthcare and, (2) for practice, collaborating across countries to design and develop healthcare technology-enabled solutions and provide clients/patients with a better quality of life, necessary life skills and empowerment to take an active role in their chronic care management. In today's twenty-first century, the tools and technologies that make up the IoT offer us a great opportunity to design and develop solutions to provide all individuals with the appropriate level of care, data and information they require to best manage their health situations and thereby ensure they can enjoy a high quality of life. It is thus incumbent on us to work together and provide the needed solutions so that chronic conditions are no longer a limitation to enjoying a high quality life.

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