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Supporting Diabetes Patient Decisional Needs Through Online Health Communities

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Supporting Diabetes Patient Decisional Needs Through Online Health Communities

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy

in

Bioinformatics and Systems Biology
with a Specialization in Biomedical Informatics

by

Jing Zhang

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2019

This Dissertation of Jing Zhang is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

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2019

DEDICATION

This work is dedicated to my late grandparents, two Sino-Japan war survivors, who nurtured my early childhood curiosity and learning, to my parents, whose formal educational opportunities were taken away due to the Cultural Revolution but instilled in me the importance of education, and to my American families, who inspired and encouraged my educational endeavors.

Finally, I am thankful for my children who showered me with laughter and joy, and my dedicated and loving husband who always believed in me and stood by me through ups and downs. My families near and far, have been an inspiration for my passion of lifelong learning.

RESTRICTIONS

This research project was unintentionally conducted without the approvals for human subject research required by the UC San Diego Institutional Review Board (IRB). Upon learning that the author/investigator conducted the research without obtaining the required approvals, the IRB and UC San Diego Human Research Protections Program (HRPP) determined that no publication of the data and/or analysis and conclusions based on the data is permitted, except for the filing of this dissertation as required with university depositions. In addition, IRB and HRPP determined that the data and analysis of this dissertation may not be used by the advisor.

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LIST OF ACRONYMS

IRB: Institutional Review Board

OHC: Online Health Community

EMR: Electronic Medical Record

A1C: Glycated Hemoglobin

ICD10: 10th revision of the International Statistical Classification of Diseases and Related Health Problems

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Chapter 3 is coauthored with Huh, Jina and Kim, Jihoon. The dissertation author was the primary author of this chapter.

Chapter 4 is coauthored with Huh, Jina; Kim, Jihoon; El-Kareh, Robert; Vermeesch, Amber. The dissertation author was the primary author of this chapter.

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Zhang J, Chen Y, Ashfaq S, Bell K, Calvitti A, Farber NJ, Gabuzda MT, Gray B, Liu L, Rick S, Street RL, Zheng K, Zuest D, Agha Z. Strategizing EHR use to achieve patient-centered care in exam rooms: A qualitative study on primary care providers. J Am Med Inform Assoc. 2015

Doan S, Lin K, Conway M, Ohno-Machado L, Feupe SF, Ross MK, Jiang X, Farzaneh S, Walker R, Alipanah N, **Zhang J**, Xu H, Kim H. PhenDisco: Phenotype Discovery System for the Database of Genotypes and Phenotypes (dbGaP). Journal of the American Medical Informatics Association. 2013

FIELDS OF STUDY

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ABSTRACT OF THE DISSERTATION

Supporting Diabetes Patient Decisional Needs Through Online Health Communities

by

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Doctor of Philosophy in Bioinformatics and Systems Biology

with a Specialization in Biomedical Informatics

University of California San Diego, 2019

Professor Vineet Bafna, Chair
Professor Michael Andrew Hogarth, Co-Chair

By 2015, 30.3 million American people or 9.4% of the US population had diabetes. Diabetes management can be challenging as patients experience evolving information needs around complex lifestyle and medical decisions. As patients' condition progresses, they make day-to-day self-care decisions by identifying or evaluating choices. These choice inquiries along the decision-making process present a valuable research opportunity to uncover and support their decisional needs. As an increasing number of patients visit online health communities (OHCs) to seek answers and exchange information, OHC data provide a platform to study patient decisional needs through choice inquiries. To identify decisional needs and their context, I first conducted a qualitative content analysis of 1000 diabetes OHC posts and found choice inquiries occurred in approximately 20% of member-initiated posts. Medication and treatment, blood sugar control, and food were the most popular topics members made decisions upon. The top list of triggers for posting choice inquiries included having blood sugar problems, filling information gaps, forming specific goals, and resolving information conflict. These results contributed in filling the research gap in understanding chronic illness self-care decision-making.

Second, to understand how choice inquiries are supported, I examined response metrics and found choice inquiries received fewer responses than non-choice inquiries. This finding helped us understand that those wishing to make decisions might have not received adequate information. Thus there is an opportunity to provide appropriate help, such as clinical expertise, to inform such choice inquiries.

Though OHCs provide informational and emotional support coming from peer patients, such support can be limiting for choice inquiries in terms of lacking input from clinical experts. Thus, my last aim was to enhance and diversify information in the patient decision-making context. To this end, I developed an intervention to incorporate clinical expertise into peer patient conversations, and tested the impact of the intervention through psychosocial measures, clinical indicators, and perceived usefulness. Psychosocial outcomes showed significant improvement for all participants in the study, but the intervention did not produce a significant improvement for the test group, compared to the control group. The scarcity of compatible clinical data prevented clinical evaluation of the study. The test group favored the information received compared to the control group, with statistical significance detected in 8 out of 10 information assessment metrics.

The results of the research deepened our understanding of patient self-care decision-making and provided insight into the day-to-day context and challenges experienced by patients. The findings generated directions to improve information quality to better support the decisional needs of chronic illness patients.

Chapter 1: Introduction

1.1: Diabetes and chronic illness management

Diabetes is a chronic condition characterized by elevated levels of blood sugar which over time leads to serious damage of the heart, blood vessels, eyes, kidneys, and nerves[1]. It has a substantial and increasing impact on quality of life. In the US alone, in 2015, 30.3 million people were diagnosed with diabetes[2]. That is a 16.5% increase from 26 million in 2010. Additionally, 86 million, or 1 in 3 Americans, have pre-diabetes[3], which increases the risk of developing type 2 diabetes[4]. Most people with chronic illnesses such as diabetes do not receive appropriate or effective chronic illness management from primary care providers[5]. The burden of day-to-day management of diabetes falls on the patients themselves[6].

Chronic conditions, such as diabetes, progress over time, resulting in evolving information needs from patients. Upon diagnosis, patients with diabetes must absorb information, change habits, and adopt new behaviors[7]. As patients achieve control of their diabetes, new issues arise, necessitating the need to readjust their routines and behavior[8].

To explain the evolving nature of patients' and families' needs, Corbin and Strauss proposed the chronic illness trajectory framework, with “trajectory” referring to the course of a chronic disease in its different stages and phases[9]. The initial phase occurs before any signs and symptoms. The trajectory onset phase occurs with the first onset of signs and symptoms and includes the diagnostic period. The crisis phase occurs when a potentially life-threatening situation arises. The acute phase follows the crisis phase and refers to the period when the patient's symptoms can be controlled by a prescribed regimen. The stable phase starts once symptoms are controlled. The unstable phase occurs when the patient's symptoms are uncontrolled by the previously adopted regimen. The downward phase is characterized by progressive deterioration in mental and physical status. And eventually, the dying phase, which refers to a period of weeks, days, or hours preceding death[10]. An example of the chronic illness trajectory can be seen below:

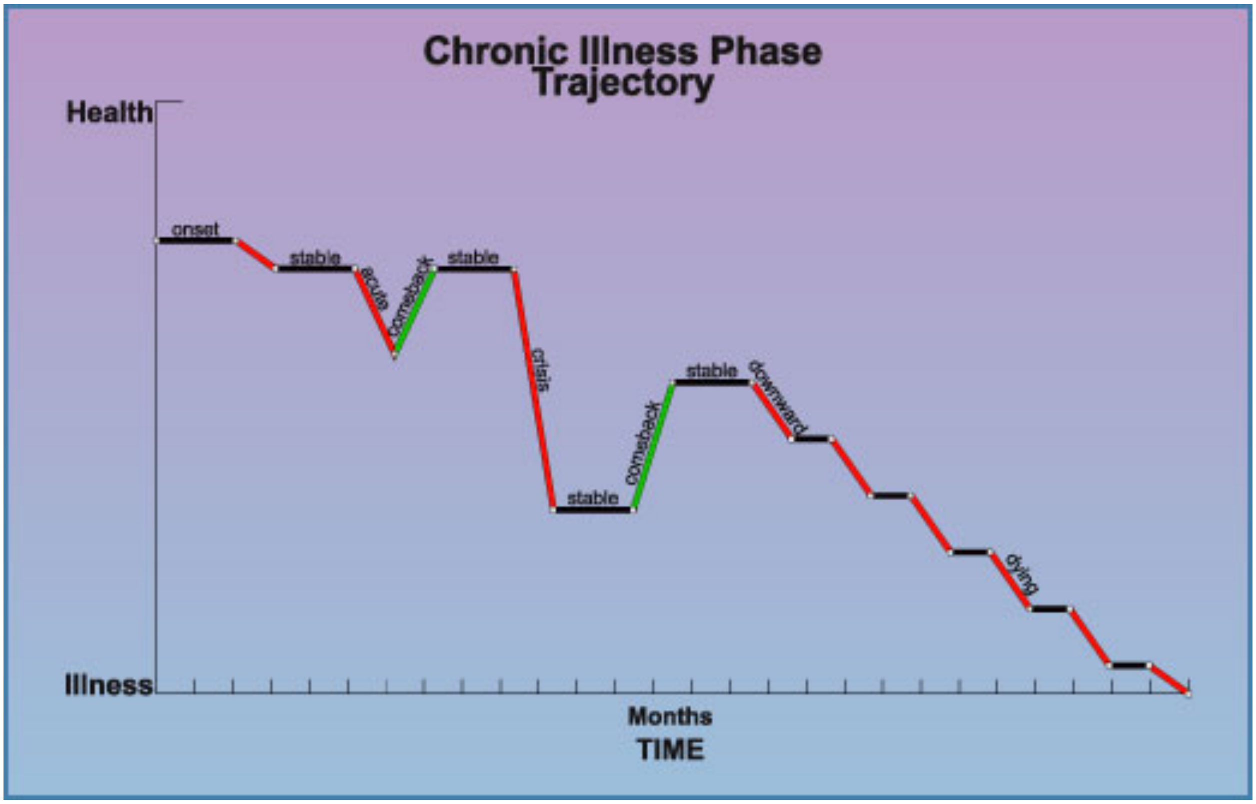


Figure 1.1: Chronic illness phase trajectory. Image credit: http://intranet.tdmu.edu.ua

As such, chronic illness changes over time, with the patient moving from one phase of illness to the next, when there is a transition in the disease state[11]. As patients transition out of stable phases along the chronic illness trajectory[9], they experience increased self-awareness and seek empowerment, through the process of learning, making choices, and identifying changes needed[12]. Patients may have intensified information needs, and face complex decision-making challenges surrounding lifestyle and medical choices. For example, as diabetes patients' conditions develop, help is needed to support them through complicated “step-up” approaches which progress from lifestyle changes to the use of oral medications and finally onto insulin[6]. As patients transition to each phase, they inquire about their choices to decide on the next course of action[6]. Consequently, their inquiries about choices present an opportunity to provide informational support to aid informed decision-making, a process that involves various resources and understanding pros and cons of different choices.

1.2: Patient decision-making

Patients with diabetes make decisions every day that affect their health[6], such as food and exercise choices. Consequently, they express strong desire to gain medical knowledge[13]. As patients experience their chronic illness along the trajectory, their decisional needs evolve as well. As a result, they inquire and evaluate their choices to decide on the next course of action, and need to keep themselves up-to-date about new medications and approaches to care[6]. Patient decision-making take place in various contexts including during clinical encounters[14,15], through patient portals[16], or in online communities[17]. Patient decision-making also spread over a spectrum in regards to patient involvement. Such spectrum have been conceptualized ranging from patients taking on passive roles relying on clinical expertise[18], to shared decision-making where information and preferences are exchanged between patients and clinicians[18,19], and then to informed self-care decision-making, where patients are informed of options and their implications[18]. My research focuses on chronic illness self-care decision-making taking place in online health communities. It is particularly important to provide informational support as patients express desire to gain knowledge and inquire about their choices.

Furthermore, the decision-making process is a complex construct, where the level of rationality involved in the process is still being debated. For example, normative theories of decision-making (e.g., subjective expected utility theory[20]) assumes patients consider decisions rationally and evaluate the risks and benefits of all available interventions[21]. On the other hand, descriptive theories of decision-making (e.g., prospect theory[22]) describes how cognitive biases can cause people to deviate from the rational ideal[23]. The Dual-Process Theory states people make decisions either intuitively or rationally where the latter results in less cognitive bias[23].

While the theories above highlight the various factors that influence people's decision-making behavior, the decision-making process models[24,25] share in common the steps leading to making a decision: establishing objectives, gathering information, then developing and evaluating alternatives. I call the moments of decision-making process, where alternatives are developed and evaluated, *choice inquiries*. Choice inquiries thus provide a critical opportunity to support patient decision-making by informing them about the risks, benefits, and consequences of the choices[21].

Daily decision-making in diabetes can have an immediate impact and result in potentially life-threatening complications[26]. At the same time, effective everyday self-care decision-making has the potential to reduce the burden of illness. However chronic self-care decision-making is not well understood[26]. Previous studies on patient decision-making, focused largely on the shared decision-making between the patient and the clinician[19,27,28], in the medical context where treatment decisions are being made[29–32] . Chronic illness self-care decision-making is distinct in that patient discourse centers around integrating the disease as daily routine[33]. We currently lack complex, grounded, and nuanced knowledge that illuminates individual experience in chronic illness self-care decision-making within a context of common patterns and themes[26].

1.3: Health information Seeking

Self-management accounts for 95% of diabetes care[6]. And self-management is significantly influenced by health and disease-related information that patients acquire[34]. Upon being diagnosed, patients must absorb information, change habits and adopt new behaviors immediately[7]. However, there is a lack of information provided to patients after their formal diagnosis[7,35–37]. Patients are left with questions regarding lifestyle modifications and other required changes[35] and express high desires for information[36]. Of participants diagnosed longer than 12 months ago, more than half reported that the type of information about diabetes that they needed had changed since the initial diagnosis[38]. 60% of patients do not understand what different medicines are available, and many do not understand what their provider is telling them. Only 17% of patients receive information about their treatment every time a prescription is given[6].

Ormandy defined information needs as ‘a recognition that your knowledge is inadequate to satisfy a goal that you have, within the context/situation that you find yourself at a specific point in time’[39]. As circumstances change, patients seek information to inform decision-making depending on their current needs[8]. It is then crucial for us to understand the process and context surrounding information seeking[39]. As such, a variety of theories or frameworks have been developed. These include Wilson’s theory of information behavior[40], Ellis’ identification of key activities within the information seeking process[41], the information search process framework, the information foraging model, and Marchionini’s modes of browsing[42]. Though different terms were used across these studies, such as “active” ,“passive”, “directed”, “semi-directed”, or “undirected”, the concept of active and passive information acquisition was presented, and was characterized by different intentions and focus of the information seeker.

In the realm of health, a health information model was developed by Longo[8] to provide context to understand how diabetes patients receive or seek information. Building on the concept of “active” and “passive” presented in previous information theories, this health information model investigated the interplay of both active information seeking and passive receipt of information. Additionally, this model reflected the nonlinear nature of health information-seeking behavior, where patients seek and incorporate information to help make self-management decisions based on current needs. Through the lens of this health information seeking model, I examine when individuals take action and perform an observable “act of actively seeking information in order to answer a specific query”[40]. Specifically, I focus on the type of active information seeking where patients “access information and use it to make personal health care decisions”[8], driven by their decisional needs. Online Health Communities (OHCs), where peer patients exchange information, provide a critical platform where such active information seeking takes place.

1.4: Online health communities (OHCs)

The costs of care for diabetes is 2.3 times higher than those without. To reduce the costs of care associated with diabetes, diabetes self-management education is a critical element for all people with diabetes and those at risk for developing the disease[43]. Health information is a necessary part of empowering patients[44] to become more educated partners in their care[45]. Traditionally, diabetes education has been implemented in the standards of medical care[46]. However, a large number of patients do not have access to diabetes education[47]. Because diabetes management relies heavily on patients themselves[48], alternative ways to provide needed information to patients could potentially lower the gap in access to diabetes education and lower the costs of care.

According to the Pew internet research center, 51% of American adults with a chronic disease search for health information online[49]. For patients with chronic diseases, OHCs provide a critical source of information[50–52], given the vast amount of anecdotal information available[50,51]. OHCs are internet-based platforms where members interact using modern communication technologies such as blogs, chats, and forums[53]. Through OHCs, patients and their families can learn about an illness, seek and offer support, and connect with those in similar situations[54].

Thus it is no surprise that an increasing number of patients visit OHCs to seek health information[55].

The two main types of social support that OHCs offer--emotional and informational support, have been subjects of research[56]. Biyani et al. identified the two types of support in OHCs through machine learning techniques and found that influential members provide more emotional support as compared to regular members[57]. Similarly, Huh et al. found "caretakers" persona in OHCs, who are long-time posters and provide emotional support to others[58]. Introne et al. also found that the small, densely connected core members of OHCs generate the majority of support for others[59]. Vlahovic et al. examined support matching and satisfaction[60], and discovered receiving emotional or informational support predicted increased satisfaction of the support receivers. Last but not the least, researchers identified the critical role of emotional support in OHCs with regards to community commitment[61] and member satisfaction[57,60].

Although the role of emotional support is being highlighted in OHCs, we know little about how patients seek information from OHCs to aid decision-making. Mamykina et al. showed that much of diabetes self-management involves the need to make quick decisions under uncertain conditions. Examples include deciding on the best time to exercise, making nutritional choices, and deciding on whether or not to take over-the-counter medication [62]. As a result, people come to make sense of these uncertain conditions through discussions with peers in OHCs[63]. This collective sense-making is achieved by constructing shared meaning through deep discussions, back and forth negotiation of perspectives and conflict resolution in opinions[63].

Budak and Agrawal's work[64] further highlighted the significance of informational support where they found informational support takes place more frequently than emotional support in educational Twitter chats. OHC members expressed more satisfaction when they sought and received the informational support they needed, but less satisfaction when they sought informational support but received emotional support[60]. To facilitate support elicitation and receiving, the conceptual model of social support elicitation and provision was developed by

Wang et al[65]. The researchers concluded that question asking was effective in eliciting informational support. More research is underway to make use of OHC content, such as text classification methods[66,67], and visual decision-making techniques[68]. OHCs are filled with collective knowledge that has great potential to support the evolving decisional needs of patients.

As a characteristic of OHCs, patients gain support through the narratives of peer patients. Patient narratives act as a double-edge sword for aiding informed decision-making[69–71]. Narratives can be powerful in their persuasiveness and are known to strongly influence one's health belief[69]. At the same time narratives can be harmful, as they create biases and discourage individuals from systematically evaluating information[70]. In addition, the quality of online health information varies widely, with much of the information lacking accuracy and completeness[72]. Failure to address the quality of information obtained by patients can lead to serious consequences[73,74]. Given the advantages and pitfalls in patient narratives, an opportunity exists to integrate clinical expertise and to enhance the OHC information environment.

In this thesis, I present research done to understand contextualized individual experience in chronic illness self-care decision-making and share findings on how to enhance and diversify information in the OHC environment. The research focused on diabetes because it is a common and complex chronic condition[52]. The larger, future goal is to be able to see how the findings in this thesis apply to other chronic conditions.

Next in chapter 2, I investigate patient decisional needs through qualitative content analysis. The results will lead to the identification of choice inquiries shared in an OHC along with their contexts. In Chapter 3, I assess how well decisional needs in OHCs are met by comparing response metrics of choice inquiries to those of non-choice inquiries. In Chapter 4, to address the gaps and needs identified in prior chapters, I develop an intervention to integrate clinical expertise to the responses of choice inquiries. The effectiveness of the intervention will be tested through a randomized controlled trial (RCT) with 165 participants, using psychosocial measures and clinical indicators. Finally, I summarize qualitative findings drawn from comments and participant interviews, and demonstrate the differences in information assessment between the control and test group.

Chapter 1 contains materials published in the companion of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing, and in the proceedings of 15th European Conference on Computer Supported Cooperative Work Doctoral Colloquium, 2017. Zhang, Jing. The dissertation author was the sole author of this material.

Chapter 2: Patient decisional needs in a diabetes OHC

For chronic illness self-care decision-making, there is a lack of complex, grounded, and nuanced knowledge that illuminates individual experience[26]. The decision-making process includes establishing objectives, gathering information, developing and evaluating alternatives, making the decision, implementing a plan of action, and reflecting on the decision[24,25]. I call the moments of decision-making process where alternatives are developed and evaluated c*hoice inquiries*. These choice inquiries are manifested in OHCs as members post questions to identify unknown choices or evaluate known choices for decision-making. Since OHCs are filled with collective knowledge (e.g., members often review new diabetes-related products in OHCs[17]) they have the potential to support patients in their chronic illness management[33,75,76]. To fill the gap in understanding individual experience in chronic illness self-care decision-making, I conducted qualitative content analysis to uncover decisional needs through choice inquiries on a diabetes OHC. Of the 1000 posts reviewed, choice inquiries occurred in one fifth of member-initiated posts. The majority of the choice inquiries were for patients themselves, and most of the rest were for significant others. Slightly over half of choice inquiries aimed to identify choices, and one third evaluated choices. Popular topics were medication and treatment, blood sugar control, and food choices. Key triggers that brought members to post choice inquiries included experiencing blood sugar problems, filling information gaps, forming specific goals, and resolving information conflict. The results show OHCs can benefit from a combination of clinical and peer patient expertise.

2.1: Research questions

To investigate patient decisional needs through choice inquiries, I aim to answer the following research questions:

RQ2.1: How prevalent is patient decision-making through choice inquires in the diabetes OHC?

RQ2.2: How much do OHC members identify choices vs. evaluate choices?

RQ2.3: Who do OHC members make decisions for?

RQ2.4: What do OHC members make decision on?

RQ2.5: Why do OHC members inquire about choices?

Although people with diabetes make decisions everyday of their lives that will affect their health[6], we do not know the magnitude of patient self-care decision-making happening through online health information seeking. RQ2.1 will help answer this question by exhibiting the scale in which decision-making takes place in the OHC environment and provide direction to support patient decisional needs. RQ2.2 shows the proportion of choice inquiries, in terms of how OHC members identify choices versus evaluate choices. Results from RQ2.2 will shed light on the knowledge gap in patient self-care decisions and guide efforts to inform patients of their choices. RQ2.3 aims to understand the magnitude of from whom the choice inquires come, and at the same time discover caregivers' experience, who can become isolated and distressed with inadequate information[77]. Though prior research looked into decision support and information needs for diabetes patients, findings were limited to treatment decisions[78–80]. The result of RQ2.4 will expand our knowledge of self-care decision-making, which is by nature intertwined with day-to-day life[50]. Furthermore, findings from RQ2.4 will serve as a knowledge base for developing more comprehensive patient information support. Lastly, RQ2.5 examines the motivation and context as why individuals pose choice inquiries. Such context provides useful insights[81] to healthcare providers to understand more fully the values and concerns as well as unique circumstances and constraints of those they serve[26,82].

2.2: Methods

I performed qualitative content analysis on one of the most commonly used and publicly available online diabetes communities, WedMD.com[52]. The identity of the community members was anonymized due to privacy concerns.

For each post, I extracted: title, author name, body content, posting date, and whether the post is a thread initiating post or a response. The extraction resulted in 71,177 posts between 2007 and 2014, which were saved onto a local database program. After excluding responses and moderator posts, 8690 thread initiating posts by members remained. I randomly sampled 1000 posts (~11.5%) from 560 unique members for content analysis. The content analysis was guided by a codebook developed from literature review and prior research[78,83]. The codebook provides instruction on filtering posts relevant to the study, and furthermore, posts that identify and evaluate choices as suggested in the decision-making literature[24,25].

Relevance: The post is relevant if (1) it solicits input from others AND (2) is about: diabetes care, including everyday lifestyle behaviors (e.g., diet, exercise), its related complications, or other conditions experienced by the member. An example of a post that is irrelevant would be: *"Is it same as an Email or what I don't understand?"* Even though the post solicits input, it does not contain diabetes care or other complications. Thus, this post is coded as "irrelevant".

Choice Inquiry: Among the relevant posts, if the member inquires about choices that a decision could be made upon, then it is coded as "choice inquiry". Choice inquiries contain identifying unknown choices, evaluating known choices, or both. An example of a choice inquiry would be: "*Hi I was wondering about these fruit sugar I read about that says it only takes a small* *amount of insulin to digest. Is this for real? Also anyone know where you might find this sugar? I am guessing a health food store..."* The post seeks to evaluate a fruit sugar as a choice, and also seeks to identify choices of places to locate the sugar. It is thus coded as a "choice inquiry".

Though the codebook was developed prior to analysis, it was iteratively refined by two coders. First, coder 1 and coder 2 reviewed together 50 randomly chosen posts from the 1000 posts, adjusted the codebook to capture the dimensions of the dataset, and incorporated changes to the codebook. Following that, the two coders reviewed another 50 posts each independently to assess inter-rater agreement. With good agreement established for identification of choice inquiries (k >=0.8), coder 1 and coder 2 then coded the remaining 900 posts, 450 each. Lastly, both coders reviewed each other's coding results to ensure accuracy. For the posts that were coded choice inquiries, the coders also identified various contextual factors surrounding decision-making, such as how (inquiry type), what (topics), who (subjects), and why (triggers).

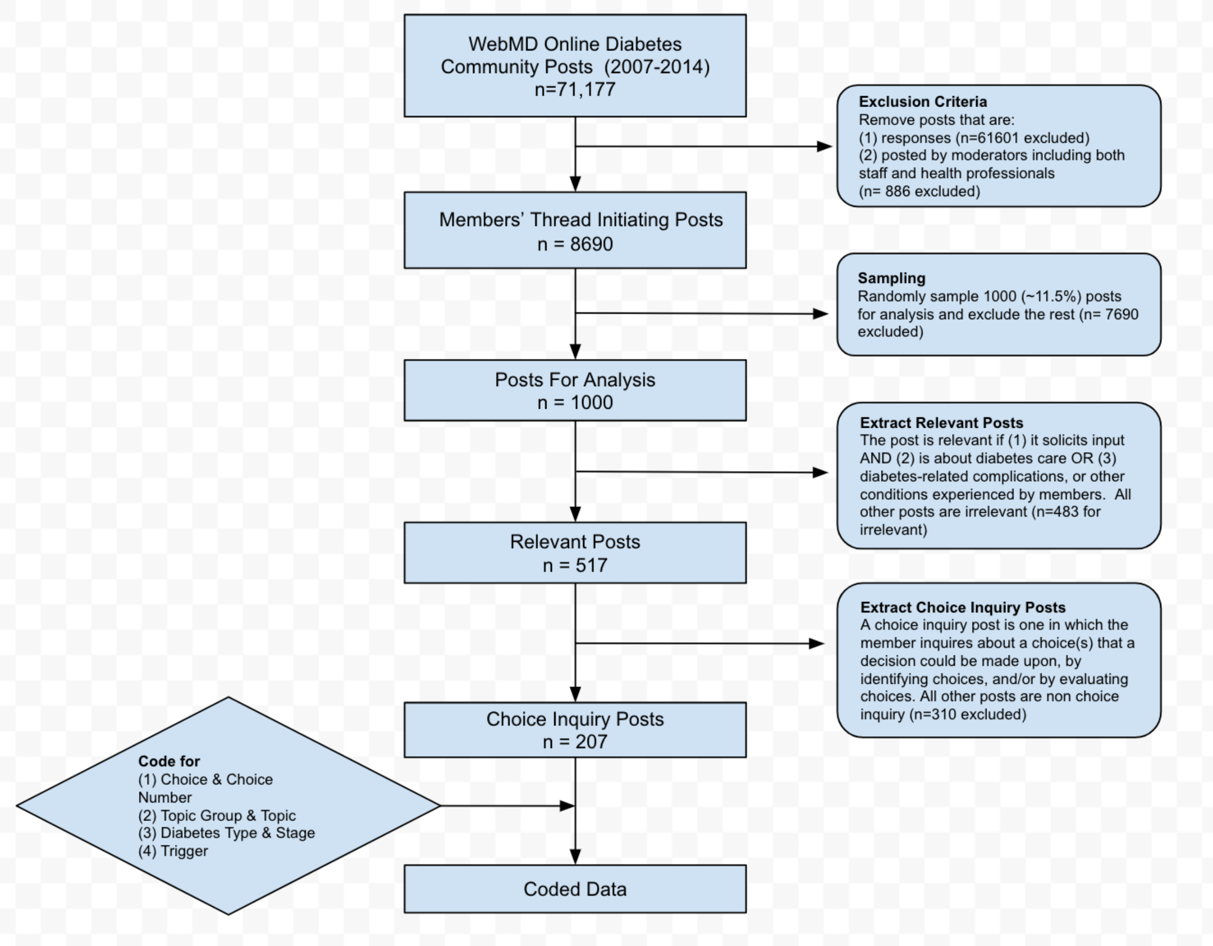


Figure 2.1: Qualitative content analysis process for OHC inquiries.

2.3: Results

2.3.1: RQ2.1 The prevalence of choice inquiries

Slightly over half of the 1000 posts were relevant to this study (51.7%). “Relevant” posts were ones that solicit input and were about diabetes care or its complication. Decision-making in the form of choice inquiries took place in 20.7% of OHC posts (207 out of 1000, Figure 2.2).

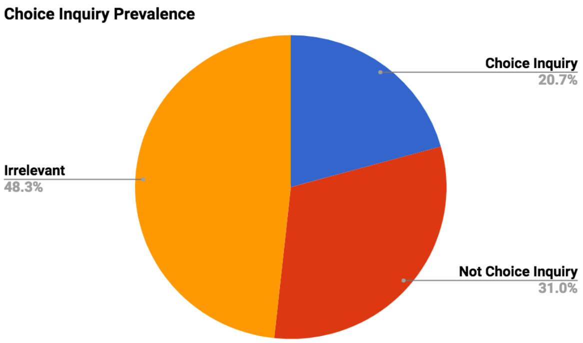


Figure 2.2: Choice inquiry prevalence in the diabetes OHC.

2.3.2: RQ2.2 How much do OHC members identify choices vs. evaluate choices?

Since the knowledge of choices is necessary for making informed decisions[84], I was interested in how members obtain knowledge of choices as they make inquiries. To do this, the inquiries were further categorized based on whether the member sought to identify unknown choices, evaluate known choices, or both. For example, one member asked: "*Hello, I am T2. I recently tasted a sugar free beer. I know it is better for me not to drink alcohol. But sometime I do. Am I better with a sugar free beer?*" Since this member knew of the sugar free beer choice and he was getting input on whether it is better than other alcoholic drink choices, this post was coded as "evaluate choice". Slightly over half (54.6%, 113 out of 207) of choice inquiries identified choices only, one third (33.8%, 70 out of 207) evaluated choices only, and the remaining 11.6% (24 out of 207) both identified and evaluated choices.

2.3.3: RQ2.3 Who do OHC members make decisions for?

The majority of the choice inquiries were about making decisions for oneself (84.5%, 175 out of 207). However, a small number of the posts (15.5%, 32 out of 207) sought to make decisions for others (Figure 2.3). I examined the "others" category and found "significant other" topping the list. “Significant other” included husband, wife, boyfriend or girlfriend. An example of this would be: “*Hi, we are still in the process of deciding whether the pump is good for my husband. He is an incredibly restless sleeper. Would this have any adverse effects on the pump?”* Following “significant other”, members posted on behalf of their children, parents, other family members, or friends.

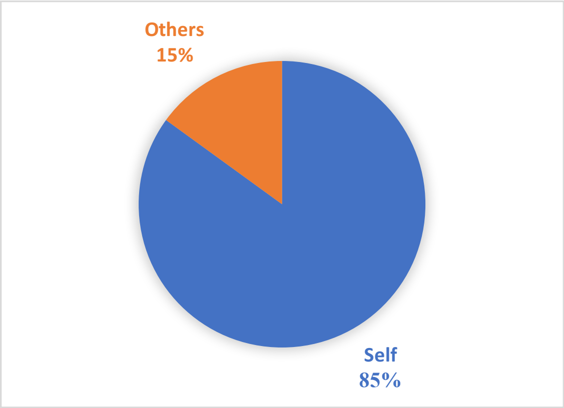


Figure 2.3: Who OHC members make decisions for.

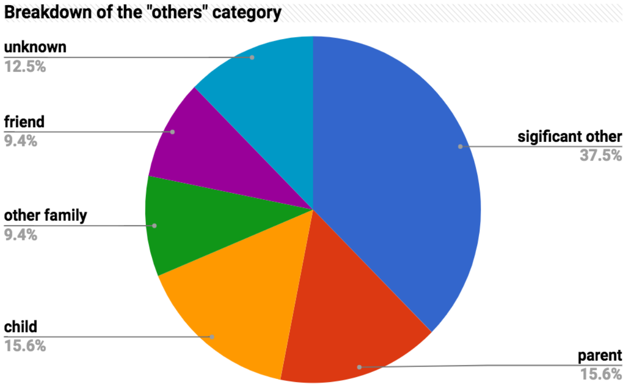


Figure 2.4: Who OHC members make decisions for when it is not about themselves.

2.3.4: RQ2.4 What do OHC members make decision on?

The content analysis informed topics OHC members needed to gather information for and make decisions on. These included a range of topics specific to diabetes care, from oral medication, to insulin pumps and dietary supplements. The complete list and the breakdown from the analysis is shown in Figure 2.5.

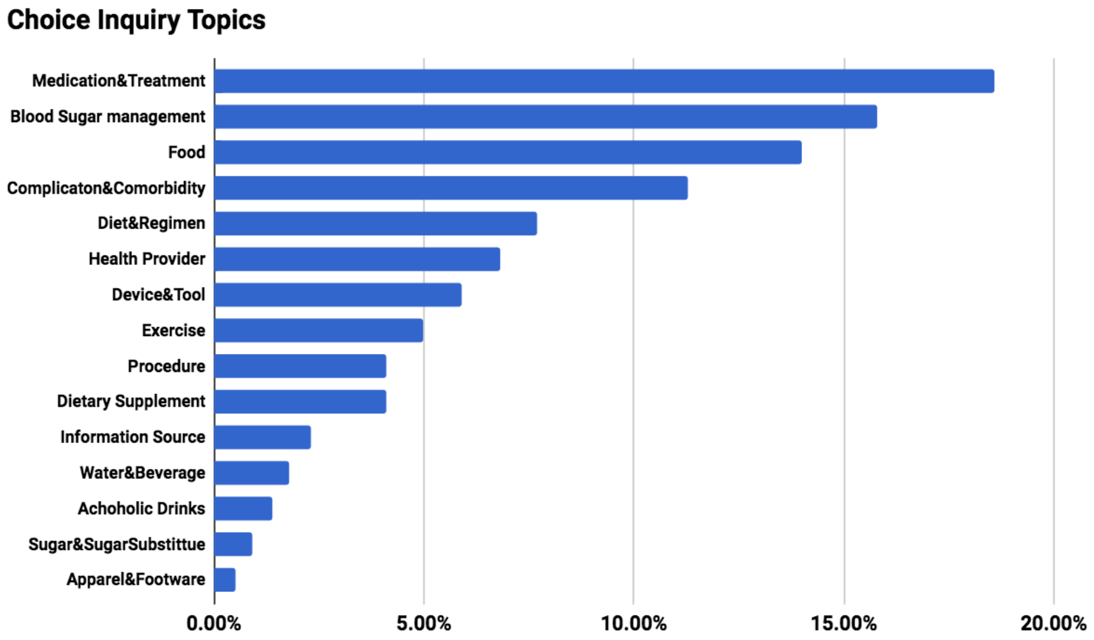


Figure 2.5: The topics of choice inquiries.

Medication and treatment was the most popular topic, accounting for one in five choice inquiries. Medication and treatment refers to substance(s) used to treat diabetes, its related complications or other conditions experienced by members, such as oral medication, and insulin. Members were concerned about medication efficacy, side effects, costs, and when is the best time to take medication (example 1). Members sometimes expressed inquiry in detailed narration, including personal medical history and responses to medication (example 2).

> *Example 1: What medication(s) can/should be prescribed for a Type 2 Diabetic, elevated LDL-C, with Renal disease? What's safe?*
>
> *Example 2: Good evening. I am a diabetic who also suffers with a herniated disk. I have been revisited by a lot of pain in recent weeks as the nerve has become inflamed. My physician has injected predisolone as well as prescribed further tablets of the same drug and Cataflam, all of which has sent my blood glucose sky high (383+). What drugs are there for such a situation (diabetic/inflamed nerve/pain) that would be suitable/safe for a diabetic?*

Blood sugar management followed medication and treatment as the second most popular topic in choice inquiries. Members expressed needs in learning ways to keep blood sugar under control: "*Does someone have some good ways to lower my blood sugar*?" Similar to medication and treatment, these inquiries sometimes included detailed, personalized information. In this example, there is a running log of events and blood sugar numbers:

> *My blood sugar is out of control! ...On the 20th, at 12:15 AM my reading was 84. At 1 PM I took my evening meds and ate a Pop Tart, went to bed about 3 AM. At 9:30 AM my BS was 66. I wasn't real hungry so I drank a can of Glucerna. I had another can about 12:45 PM and a third can about 3:30 PM. At 5 PM my BS was 68...At 9 PM my BS was 90... At 12:45 AM on the 21st it was 88...At 6:30 AM by BS was 70. ...any suggestions on how to get back under control besides keeping track of the BS and eating?*

Following blood sugar management, food was the third most popular topic. Newly diagnosed patients were eager to learn diabetic friendly food choices, as illustrated in this example: "*As a newbie I am wondering about breakfast...Love my coffee and cream...What is the better creamer? fat free or sugar free? liquid creamer or powder creamer*?" Veteran patients expressed long-term struggles coping with food cravings: "*I was diagnosed with type 2 diabetes in 1999, and I have always loved cakes... I have tried to resist cakes...but it's impossible for me to say no... I would like to know what you would suggest as a way to overcome that craving before it kills me*?"

2.3.5: RQ2.5 Why do OHC members inquire about choices?

Patients with diabetes reconstruct life with illness through the process of learning, making choices, and identifying needed changes[12]. This process was reflected through their choice inquiries in this OHC, triggered by various problems, events, or changes along their illness trajectories. These triggers were important to identify because they indicate when in the illness trajectory patients need information to support decision-making. The triggers also contextualized the motivations behind decision-making. Key triggers identified in this study included blood sugar problems, filling information gaps, forming goals, and resolving information conflict.

Filling information gaps

When patients do not receive adequate or useful information through conventional channels, they fill their information gaps through OHCs[58]. One member aimed to confirm the applicability of prior knowledge on new choices: "*A few years ago I attended a diabetes class where the instructor said strawberries and watermelon were ok for diabetics to eat because of their water content. Now I need to confirm this. The strawberries would be plain - no sugar of course. What about other melons? Honeydew and Cantaloupe*?" Another member desired information on whether it is ok to get tattoos now that she is diagnosed with type 2 diabetes. These examples highlighted the need to fill the gaps between generic static information patients receive as part of usual care, and the dynamic and highly individualized information they need to manage evolving chronic conditions.

Forming specific goals

Members sought choices as they formed specific goals. Weight management was a popular goal among members. For instance, a member was "*trying to lose weight by dieting*" but she had trouble walking. As a result, she inquired about exercise choice as a starting point so she "*can work up to a point that will result in... losing enough weight to begin a walking regimen*". While much of diabetes-related weight management focused on losing weight, weight gain also surfaced as a goal to achieve. One member asked "*how to gain weight even though you are diabetic and underweight*" and inquired what supplements were available for people with diabetes to gain weight. Another member acknowledged that she might be "*an anomaly*" but she needed help to keep the weight on. Besides weight management, members aimed for prevention, where the ones at risk would decide on preventative measures to stop themselves from progressing to diabetes.

Coping with blood sugar problems

Blood sugar control is a key aspect of diabetes self-care which was reflected in our findings as one of the top trigger for choice inquiries, accounting for one fifth. Members expressed frustrations regarding lack of control over blood sugar: "*I'm having a very hard time keeping my bg (blood glucose) in check...*" or they were puzzled by unexpected rise in blood sugar: "*My blood sugar just spiked to 260 and I don't know what to do...*". They also faced the challenge of coping with low blood sugar and blood sugar swings: "*I've been having problems with low BS...*" *"First my sugar was high now I'm having lows 66 70 and 80s when it gets low how do you know how much juice or sweets you should eat to get it up a little..."*

Resolving information conflict

Members of OHCs received health information from various sources such as their doctors, diabetes educators, peer patients, or internet searches. The diverse sources of information resulted in information conflict when inconsistency occurred or when members were not able to make sense of it. As an example, a member received two opposing views on physical activities and sought to resolve the conflict on the OHC: "*Any ideas for exercise? I have type 2 diabetes and suffer from foot ulcer foot Dr says stay off your feet! Endocrinologist says you are not exercising enough. Any ideas?"* Another member received conflicting instructions on which healthcare provider to see for a retina exam and came to the OHC to decide between an ophthalmologist and an optometrist. In another example, a member stated frustration on making sense of "prediabetes" and its respective impact: "*Is there anywhere on this earth, literally, that has the official word on whether or not there is such a thing as 'prediabetes' or 'borderline'?"* The member continued: "*I'm just confused and aggravated" because* "*everywhere I look and try* *to find information, all the information I find contradicts itself. One source says normal is 4.5-6.0. Another source says it's 4.7-5.6. It's enough to drive someone crazy. I'm just trying to figure all this out."*

2.4: Summary

Patients with chronic illness face the challenges of making sense of bewildering symptoms, reconstructing order, and maintaining control over life[85]. The daily requirement of decision-making is an important aspect of the challenges in chronic illness self-care, with patients having to select from options in a wide range of issues, however this process is less well understood[26]. As a result, a more relevant way of conceptualizing everyday self-care decision-making, grounded in the personal and social context of people's lives is called for[82]. In response to this, the findings filled a gap in understanding decision-making and provided the context that gives rise to decision-making in OHCs, namely the how (inquiry type), what (topics), who (subjects), and why (triggers). The knowledge generated through this study sheds light on patients' experience and challenges in day-to-day management of the disease, and in particular, when they inquire about choices to make decisions upon. The results show OHCs can benefit from a combination of clinical and peer patient expertise. Specifically, the descriptive results on topics generated from the study illuminate the areas where OHC members could benefit from clinical expertise.

Chapter 2 is coauthored with Huh, Jina. The dissertation author was the primary author of this chapter. Chapter 2 contains materials published in the companion of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing, and in the proceedings of 15th European Conference on Computer Supported Cooperative Work Doctoral Colloquium, 2017. Zhang, Jing. The dissertation author was the sole author of this material.

Chapter 3: Meeting decisional needs on the diabetes OHC: comparing response metrics between choice and non-choice inquiries

In Chapter 2, I defined choice inquiries along the patient decision-making process, identified instances of choice inquiries in the diabetes OHC, and discovered contexts surrounding such inquiries. But how do choice inquiries compare with the rest of the inquiries (non-choice inquiries) in terms of response metrics[86], which indicate community interaction success[87]? In this chapter, I report the response metrics of the 1000 randomly sampled diabetes OHC inquiries, and compare the differences found between choice and non-choice inquiries. Findings showed choice inquiries received fewer responses.

3.1: Research questions

The aim for this chapter is to compare choice inquiries with non-choice inquiries with regards to response metrics investigating: the non-response rate, response quantity, unique responders, and response speed. I address the aim through the following research questions:

RQ3.1: How much portion of choice inquiries did not receive any responses compared to non-choice inquiries?

RQ3.2: Among the inquiries that received responses, how many responses did choice inquiries receive, compared to non-choices inquiries?

RQ3.3: How many unique responders responded to choice inquiries, compared to non-choice inquiries?

RQ3.4: How long did it take for the choice inquiries to receive the first response, compared to non-choice inquiries?

In online communities, the benefits people receive come from the presence and activity of others[87]. Therefore OHC inquiries receiving no responses do not effectively provide informational support to members. RQ3.1 will present the proportion of choice inquiries receiving no support, as compared to non-choice inquiries. Following that, RQ3.2 and RQ3.3 examine the number of responses and unique responders between choice and non-choice inquiries. Lastly RQ3.4 will show the differences between how fast the first response is received, between choice and non-choice inquiries. Response quantity aspect of the response metrics showed that choice inquiries are not properly supported[87], compared to the non-choice counter-part . Without communities' willingness to responds to member inquiries, needs of the individuals are not met. At the same time, the findings also present an opportunity where clinical expertise can provide additional support to add value to choice inquiries.

3.2: Methods

The analysis in Chapter 2 had resulted in a coded dataset of 1000 posts, with choice and non-choice inquiries identified. I extracted the responses to these 1000 posts from the original OHC dataset. To understand the response metrics, I compared between choice and non-choice inquiries regarding the non-response rate, response quantity, number of unique responders, and response speed.

3.3: Results

3.3.1: RQ3.1 Non-response rate

15 out of 207 choice inquiries received no responses (7.2%), while 46 out of 793 non-choice inquiries received no response (5.5%). The difference was not statistically significant (proportion test: X-squared = 0.574, df = 1, p-value = 0.449).

Table 3.1: Response metrics of the 1000 sampled posts in the diabetes OHC. (*p < 0.05).

Response metrics	Descriptive Statistics	Choice Inquiry	Non-choice Inquiry
Non-response rate	Percentage	7.2%	5.5%
Response quantity*	Range	[1,53]	[1,65]
	Median	4	4
	Mean	5.36	6.50
Number of unique responders	Range	[1, 13]	[1,26]
	Median	3	4
	Mean	3.73	4.27
Response speed (minutes)	Range	[1,29427]	[1,29626]
	Mean	747.36	486.79
	Median	93	77

3.3.2: RQ3.2 Response quantity

For the inquiries that received responses, I compared the number of responses received between choice inquiries and non-choice inquiries. Choice inquiries received up to 53 responses, whereas non-choice inquiries received up to 65 responses. Choice inquiries on average received 5.36 responses, while non-choice inquiries received 6.50 responses. Wilcoxon test showed a significant difference between choice and non-choice inquiries (W = 64778, $p < 0.05$).

3.3.3: RQ3.3 Number of unique responders

On average, 3.73 unique responders responded to choice inquiries, while 4.27 unique responders responded to non-choice inquiries. However, there was no significant difference in the number of unique responders between the two groups (Wilcoxon test: W = 65512, p-value = 0.055).

3.3.4: RQ3.4 Response speed

To measure response speed, I studied the time it took for an inquiry to receive a first response, given that at least one response was received. On average it took 747.36 minutes for choice inquiries to receive a first response, while it took 486.79 minutes for non-choice inquiries. The difference was not statistically significant (Wilcoxon test: W = 59288, p-value = 0.575).

3.4: Summary

Chapter 2 uncovered diabetes decisional needs expressed through choice inquiries in the diabetes OHC. Following that, in this chapter I examined the response metrics to the 1000 coded posts. People come to online communities seeking informational and social support, and they only receive the benefits when the community responds[87]. In the case of choice inquiries, members gather information about choices to make decisions upon. However choice inquiries received fewer responses. Inadequate support can lead to failed community interaction, resulting in unmet needs for the individuals[87]. This finding helped us understand that those wishing to make decisions might not be getting adequate information. Thus there is an opportunity to provide appropriate help, such as clinical expertise, to inform such choice inquiries.

Chapter 3 is coauthored with Huh, Jina and Kim, Jihoon. The dissertation author was the primary author of this chapter. Chapter 3 contains materials published in the companion of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing, and in the proceedings of 15th European Conference on Computer Supported Cooperative Work Doctoral Colloquium, 2017. Zhang, Jing. The dissertation author was the sole author of this material.

Chapter 4: Developing and testing an intervention to support patient decisional needs in the diabetes OHC

Findings from Chapter 2 and Chapter 3 illustrated the need to decrease informational conflict and provide more support as patients gather information to make decisions in the OHC environment. Prior literature also suggested professional clinical input in the context of peer support[88–90] can benefit patients by providing clarification and clinical perspective [76,91]. In this chapter, I propose an intervention to integrate clinician expertise with patient narratives in the diabetes OHC. The effectiveness of the intervention will be tested through a randomized controlled trial (RCT) with 165 participants. I will compare how participants perceive OHC content with and without the intervention. Results from the RCT showed improved psychosocial outcomes for patients in self-efficacy and self-care. The intervention effect was not statistically significant between the control and test groups in self-efficacy, self-care, distress, or BMIs. Qualified clinical data from the Electronic Medical Record (EMR) were too scarce for analysis. Instead, I presented visualization of these diabetes care data and discussed limitations and recommendations for future research that attempt to reuse EMR data. Lastly, participants assessed information presented to them. The information enhanced with clinical expertise were favored, showing significantly higher rating in 8 out of 10 assessment metrics.

4.1: Research questions

In this chapter, I aim to develop and test an intervention to support patient decision needs. Through a RCT and qualitative analysis, I address the following research questions:

RQ4.1: Will the OHC intervention with additional clinical expertise improve patient psychosocial outcomes?

RQ4.2: Will the OHC intervention with additional clinical expertise have an impact on the diabetes related clinical indicators?

RQ4.3: Will the OHC intervention with additional clinical expertise be perceived useful? The goal of RQ4.1 and R4.2 is to evaluate the effect of the RCT intervention, by using validated psychosocial instruments[92–96] and traditional clinical indicators for diabetes care[97–99]. RQ4.3 will allow us to compare participant perception of OHC information with and without intervention, using metrics for information usefulness and decision-making. In addition, RQ4.3 includes qualitative analysis to aid us in interpreting findings, and situate them in context.

4.2: Method

4.2.1: Study design

The goal of the RCT study is to create a high quality, diversified online health information environment through the inclusion of clinical expertise in peer patients' information exchange environment. This study was reviewed by the University of California San Diego Institutional Review Board (IRB). Some of the data collected for this research did not observe IRB guidelines, and therefore, the source data is embargoed by UC San Diego. I targeted population currently in the UC San Diego's health system database. Potential participants received a participation invitation link to a screening questionnaire, which will filter them to only those who meet the inclusion criteria of: adults diagnosed with pre-diabetes, at risk for diabetes, or diagnosed with type 2 diabetes, can read and write in English, and has weekly access to the Internet. I will recruit at least 150 participants, half of whom will be randomly assigned to the control group and the other half to the test group.

The RCT involves a 4 week intervention utilizing OHC discussion threads with choice inquiries, with and without clinician expertise, administered in the form of 12 information assessment surveys. Every week, the control group participants will be reminded to review 3 OHC discussion threads. The test group will be also asked to review the same OHC discussion threads, which contains additional clinical expertise to the same peer-patient conversations that the control group receive. For each thread, participants from both groups rate the perceived usefulness of the health information[100] and provide free text comment.

The goal of the RCT is to enhance the OHC content with clinical expertise and help individuals with diabetes improve their self-efficacy, self-care, and decrease diabetes related distress, as they engage and reflect on the OHC discussions pertaining to decision-making. The psychosocial aspects of diabetes care will be evaluated through main surveys, namely pre-survey, post-survey, and follow up survey. These main surveys will be administered at baseline, which is immediately before the study, at 4 weeks, which is immediate after the study, and then at 6 weeks, which is 2 weeks after the study. Additionally, clinical indicators for those participants who consented will be extracted from the EMR for evaluation. Lastly, I will compare the participant feedback on the information assessment between the control and test group, both quantitatively and qualitatively. At the conclusion of the study, some participants were selected for semi-structured interviews. Study timeline is shown below.

♦•___ • ___ • ___ • ___ • ___ • ___ • ___ • ___ • ___ • ___ • ___•♦………………………………..♦

Week1 Week2 Week3 Week4 Week6

Pre-survey Post-survey Follow up

♦ denotes main surveys: pre-survey, post-survey, follow up survey
• denotes reflection questions in the form of 12 information assessment surveys sent 3 times each week for 4 weeks.

Figure 4.1: RCT study timeline.

4.2.2: Study materials

Information assessment surveys

The study is composed of 12 information assessment surveys that contain a conversation thread on choice inquiries from online diabetes communities, along with a series of questions that assess perceived usefulness of the information. The control group receive conversation threads as they are in the OHCs while the test group receive conversation threads enhanced with clinical expertise provided by a clinical collaborator. The clinical collaborator is identified as “UCSD_NursePractitioner” in the conversation thread.

To generate the12 information assessment surveys, I reviewed choice inquiries from Chapter 2 with the clinical collaborator. The ones that were too long, with too many responses, and were too low in trustworthiness and poster competence were excluded. Finally, I decided on 12 conversation threads that covered a range of topics and were representativeness of various stages of diabetes self-management.

Once the 12 conversation threads were finalized, the clinical content was developed with the collaborator by incorporating comments necessary to help answer the question in the inquiry. Lastly, a set of prior validated survey questions on content usefulness, information adequacy, and decision-making were adapted and added to the end of conversation threads to aid participant self-reflection and solicit feedback. As an example, participants were asked what they find useful or not used for in the information provided. They were also asked to rate on a Likert scale if the conversation thread provides relevant, comprehensive information, and if the information makes it easier for decision-making.

Main surveys

Main surveys for the RCT include a pre-survey, a post-survey, and a follow up survey. They contain identical psychosocial instruments on self-efficacy, self-care, and diabetes distress. The pre-survey also includes participant demographic information while the post-survey solicits additional feedback on overall study experience. These main surveys will be administered immediately before the study, immediately after the study, and then 2 weeks after the study. The validated instruments along with their respective measures are listed below (Table 4.1).

Clinical indicators

Traditional clinical measures to assess the success of diabetes interventions include A1C, blood glucose, and blood pressure[97]. These clinical indicators for consented participants will be extracted from the EMR. Participant weight and height were collected in the main surveys and thus Body Mass Index (BMI) will be calculated and assessed along with the clinical indicators.

Table 4.1: RCT study outcome measures.

Measurements		Survey/Source
Psychosocial measures	Self-efficacy	Diabetes Empowerment Scale Short Form[92,93] (DES-SF) (α = 0.85) [101]
	Self-care activities	Diabetes Self-Management Questionnaire (DSMQ) (α = 0.84) [94]
	Diabetes Distress	Diabetes distress Screening Scale (DDS2)[102] (α=0.93) [95,96]
Clinical indicators	A1C, Blood glucose, Blood pressure, BMI	Traditional diabetes intervention success clinical measures [97–99]
Information assessment	Perceived usefulness Information adequacy Trust	Instrument to measure user perceived service quality of information presenting web portals [103,104] Information Seeking Survey Group Instrument[105]

Interview protocol

At the conclusion of the study, some participants will be selected for semi-structured exit interviews. The interviews protocol focuses on the feedback of the study process, participant information needs, decision-making process, and the wishes for diabetes self-care information.

4.2.3: Study recruitment

In-person recruiting

Participant recruitment for the study started with in-person recruiting at UC San Diego Health System’s diabetes self-management clinics. I established rapport with the diabetes educator managing the clinics and was invited to introduce the project to other diabetes educators at their monthly meeting. After that, I gained permission to attend diabetes education classes at various clinics throughout San Diego. The diabetes education classes are offered to UC San Diego Health System’s patients when they are first diagnosed with diabetes. I attended the education classes weekly for a period of three months to understand patient experience regarding information needs. Having had the opportunity to establish credibility and introduce the project in-person, I enrolled 11 out of the 24 patients at the diabetes education classes. The enrollment rate was high but since the class volume is small (usually 3-6 attendants per class), it was not an efficient way for high volume recruiting. Therefore, I started a mass emailing campaign.

Mass emailing campaign

Once a MailChimp mass emailing campaign was created, my next goal was to establish a broad yet targeted pool of candidates to recruit from. I focused on the UC San Diego Health System’s network of patients since they have established trust with UC San Diego, and I can gain access to their patient information, with IRB approval and patient consent.

The clinical eligibility criteria for participants included being diagnosed with type 2 diabetes or pre-diabetes, or at risk for diabetes. These criteria were converted to ICD10 codes, which classify clinical conditions in the EMR. Based on the ICD10 codes, a query was done EMR clinical database to filter patients meeting the eligibility criteria. The query resulted in a total of 27888 email recipients. After removing duplicate and non-working email addresses, 9835 unique email recipients remained. Since the 24 participants recruited in-clinic appeared in the email list, they were removed during the email campaign. I sent a recruitment letter to the email recipients in batches of 2000 overtime to ensure manageability.

Table 4.2: Participant clinical eligibility criteria and matching ICD10 codes.

Eligibility criteria	**ICD 10 codes**
At risk/pre-diabetes	ICD 10 R73.09
diabetes type 2	ICD 10 E 11.65 (with hyperglycemia – high glucose)
diabetes type 2 w/o complications	ICD 10 E 11.9
Diabetes Mellitus Type 2	ICD 10 E11

Mass emailing campaign for the first batch of 1998 email recipients (2 email addresses no longer in use) resulted in 81 responses in eligibility forms (4.3% of response rate). Subsequent patches also maintained a response rate between 4-5%.

4.2.4: Study execution

The mass emailing campaign generated 456 study signups, out of which 69 were not eligible (under the age of 18, Type 1 diabetes, unknown condition, or no enough information to assess eligibility), and 201 were non-responsive. 186 participants from the email campaign enrolled in the study and 32 of them withdrew. With the 11 participants recruited in-person, there were a total of 165 participants for the study and they were randomized into control (n=87) and test group (n=78).

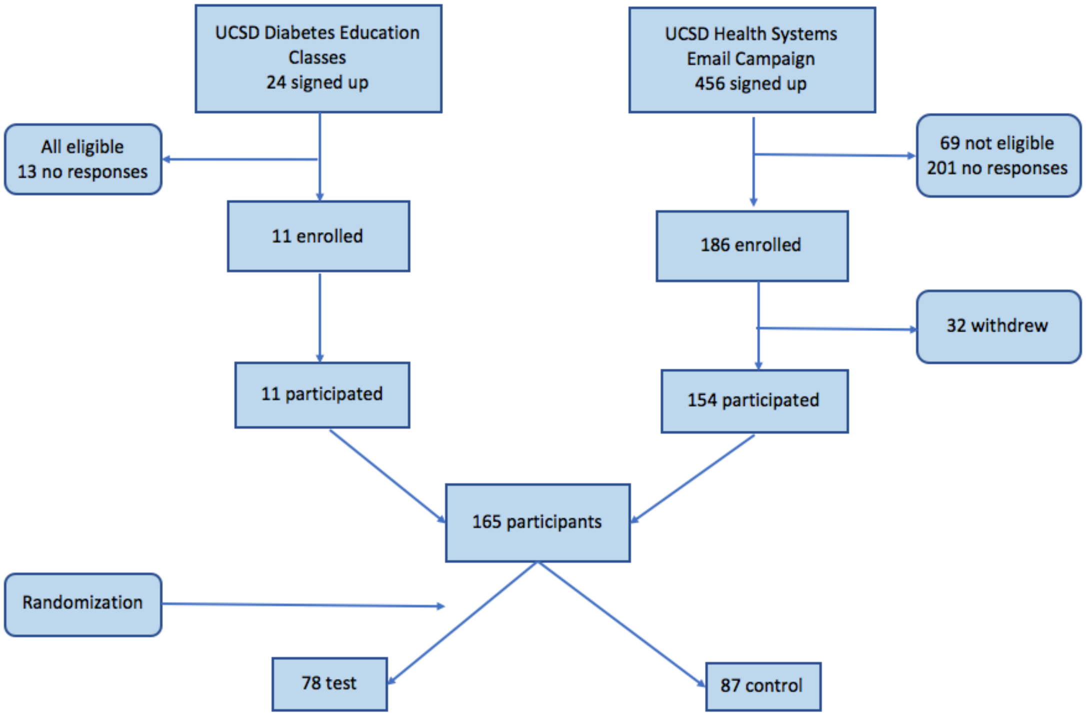
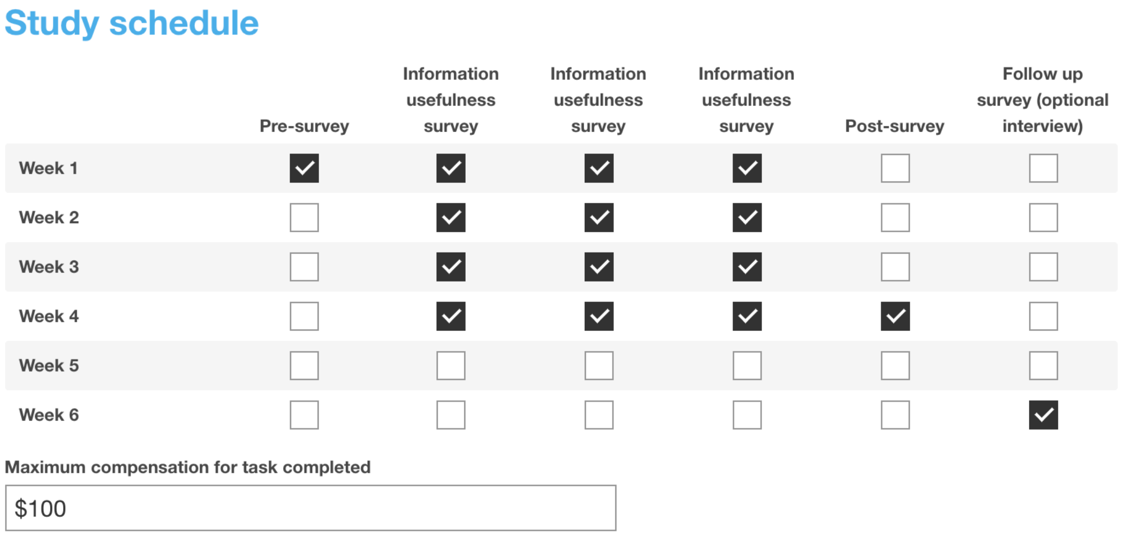


Figure 4.2: RCT study flow chart. 11 participants recruited at the diabetes clinic participated in the study. 155 recruited from email campaign enrolled in the study. A total of 165 participants were randomized into control and test groups in the RCT study.

As soon as participants signed up for the study, they completed an eligibility questionnaire. For those who were eligible, an email was sent to them to confirm eligibility, provide study schedule and compensation details.



Study schedule

	Pre-survey	Information usefulness survey	Information usefulness survey	Information usefulness survey	Post-survey	Follow up survey (optional interview)
Week 1	☑	☑	☑	☑	☐	☐
Week 2	☐	☑	☑	☑	☐	☐
Week 3	☐	☑	☑	☑	☐	☐
Week 4	☐	☑	☑	☑	☑	☐
Week 5	☐	☐	☐	☐	☐	☐
Week 6	☐	☐	☐	☐	☐	☑

Maximum compensation for task completed

$100

Figure 4.3: RCT study schedule for participants. The study includes 12 information assessment surveys, 3 per week for 12 weeks. Participants also complete a pre-survey, a post-survey, and a follow up survey immediately before, immediately after, and 2 weeks after the study.

The study participants were instructed to complete the main surveys and 12 information assessment surveys. After the pre-survey, 3 information assessment surveys were sent to participants on Monday, Wednesday and Friday each week, for 4 weeks. A reminder was sent on Saturday. All 3 information assessment surveys for that week were due at midnight on Sunday. The following Monday, a weekly summary of task completions with compensation to date was provided to participants. Participants receive $10 for completing each main survey, $5 for completing each information assessment survey. The rest $10 were incentives to encourage task completion.

4.3: Results

4.3.1: Participant demographics

In the demographic portion of the pre-surveys, participants were asked about gender, age, relationship status, education, employment, race/ethnicity, income and stage of diabetes journey. Slightly over half of the participants (53%) are between the age of 55 to 74, 60% of them female, 40% male. The top represented race is white/Caucasian (61%), followed by Hispanic (15%) and Asian/Pacifica Islander (11%). More than half of the participants are married (54%) with one third working fulltime and one third retired. The majority of the participants have some college or above (89%), with earnings distributed across income brackets. In terms of where they are on the diabetes journey, 9% participants identified themselves as newly diagnosed wishing to learn basics of diabetes management, 41% were intermediate wishing to learn strategies of managing diabetes, and 35% were veteran wishing to learn how to handle complications and burnouts. The average height for participants was 66.8 inches (SD = 4.4) and the average weight was 297.8 pounds (SD = 53.8). The Body Mass Index (BMI) based on reported height and weight is 32.52 (SD=7.2). The difference in demographic categories between the control and test group was calculated[106]. Fisher test was used when data were categorical, and t-test was used when data were continuous. The control and test group did not show significant differences in age, gender, race, relationship, employment, income, education, diabetes journey stage, height, weight, or bmi values.

Table 4.3: RCT study participant demographic characteristics.

Demographics	All Participants (N = 165)	Control (N =87)	Test (N=78)
Age			
18-24	5 (3%)	3	2
25-34	10 (6%)	6	4
35-44	22 (13%)	13	9
45-54	30 (18%)	16	14
55-64	46 (28%)	21	25
65-74	41 (25%)	22	19
75 or older	11 (7%)	6	5
Gender			
Female	100 (60%)	47	53
Male	65 (40%)	40	25
Race			
American Indian or Alaskan Native	3 (2%)	1	2
Asian / Pacific Islander	18 (11%)	14	4
Black or African American	11 (7%)	4	7
Hispanic	25 (15%)	15	10
White / Caucasian	100 (61%)	51	49
Multiple ethnicity / Other	8 (5%)	2	6
Relationship status			
Married	89 (54%)	46	43
In a domestic partnership or civil union	4 (2%)	1	3
Divorced	22 (13%)	9	13
Separated	3 (2%)	2	1
Widowed	8 (5%)	4	4
Single, never married	27 (16%)	17	10
Single, but cohabiting with a significant other	12 (7%)	8	4
Employment status			
Disabled, not able to work	27 (16%)	14	13
Employed, working full-time	56 (34%)	30	26
Employed, working part-time	11 (7%)	5	6
Not employed, looking for work	7 (4%)	3	4
Not employed, not looking for work	9 (5%)	5	4
Retired	55 (33%)	30	25
Income			
$10,000 to $24,999	24 (15%)	11	13
$25,000 to $49,999	25 (15%)	15	10
$50,000 to $74,999	29 (18%)	19	10
$75,000 to $99,999	13 (8%)	6	7
$100,000 to $124,999	18 (11%)	9	9
Prefer not to answer	21 (13%)	12	9
Other	35 (21%)	15	20
Level of education			
8th grade or less	3 (2%)	2	1
Some high school, but did not graduate	2 (1%)	1	1
High school degree or equivalent (e.g., GED)	8 (5%)	4	4
Some college or 2-year degree	54 (33%)	28	26
4-year college graduate	38 (23%)	18	20
More than 4-year graduate	54 (33%)	30	24
Other	6 (4%)	4	2
Diabetes journey stage			
Newly diagnosed. I want to learn the basics of diabetes management.	15 (9%)	6	9
Intermediate. I know the basics, and now I want to learn strategies to help me take control of my diabetes.	68 (41%)	33	35
Veteran. I have learned it all, and now I need help handling complications, burnout, and the emotional aspects of diabetes.	57 (35%) 24 (15%)	35 13	22 11
Other	1 (1%)	-	1
Missing data			

Table 4.3: RCT study participant demographic characteristics, cont.

Demographics	**All Participants (N = 165)**	**Control (N =87)**	**Test (N=78)**
Height (in inches)	67.00	67.00	66.00
Median	66.80	67.09	66.49
Mean	57.00 – 82.00	57.00 – 82.00	58.00 – 79.00
Range			
Weight (in pounds)			
Median	200.00	200.00	203.50
Mean	207.8	208.9	206.60
Range	99.00 – 375.00	99.00 – 365.00	114.00 – 375.00
BMI			
Median	31.01	31.00	31.14
Mean	32.52	32.39	32.66
Range	17.56 – 51.55	17.56 – 50.90	19.97 – 51.55

4.3.2: RQ 4.1 Psychosocial measures

The main surveys included 3 validated survey instruments to measure psychosocial outcomes: Diabetes Empowerment Scale-Short Form (DES-SF), Diabetes Self-Management Questionnaire (DSMQ), and Diabetes distress Screening Scale (DDS2).

Diabetes Self-efficacy

Diabetes psychosocial self-efficacy was measured through Diabetes Empowerment Scale. The self-efficacy score is the mean of the 8 items in the instrument. Participants in both the test group (with clinical expertise integrated) and the control group (without clinical expertise) demonstrated significantly higher self-efficacy after the study compared to before the study ($p < 0.01$). The effect was sustained through follow up. However, the change in self-efficacy level was not significant between the control and the test group (Welch two ample t-test: $t = -0.332$, $df = 123.37$, p-value = 0.740).

Table 4.4: Diabetes self-efficacy outcomes.

	Before study self-efficacy	**After study self-efficacy**	**Follow up Self-efficacy**	**Before and after (paired t-test)**
Control	3.633 (n = 87, SD= 0.690)	3.909 (n =74, SD=0.610)	3.966 (n= 73, SD = 0.610)	t = -3.572, df = 72, p < 0.001**
Test	3.612 (n= 73, SD = 0.610)	3.936 (n= 68, SD= 0.711)	3.986 (n=70, SD= 0.711)	t = -3.031, df = 66, p = 0.003**

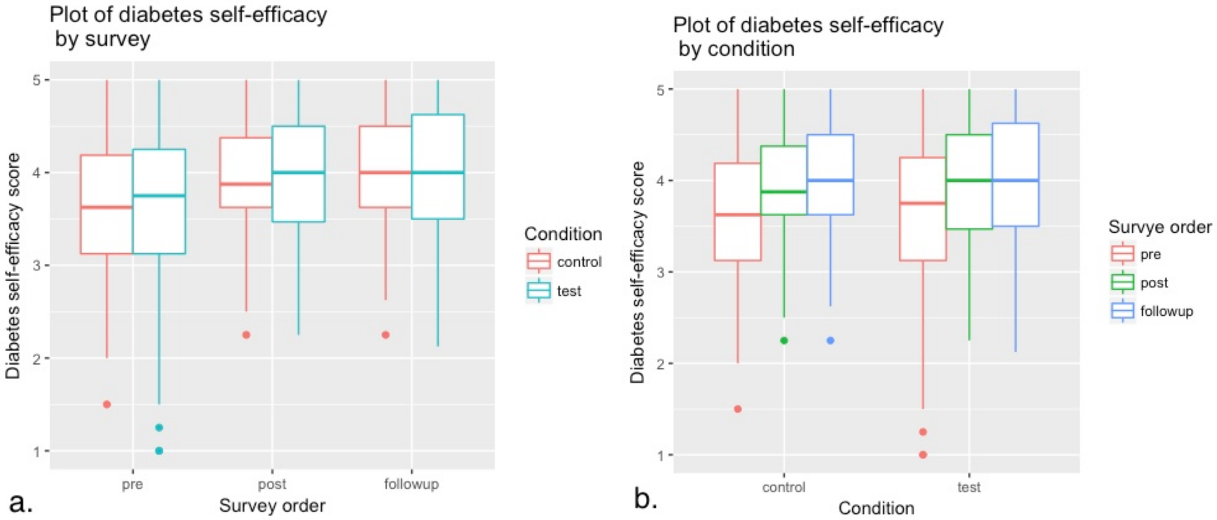


Figure 4.4: Diabetes self-efficacy outcomes.
Both test group and control group demonstrated significantly higher self-efficacy after the study compared to before the study. The effect was sustained through follow up. The change in self-efficacy level was not significant between groups.

Diabetes self-care activities

Diabetes self-care activities were measured through Diabetes Self-Management Questionnaire (DSMQ). Participants in both the test and the control group demonstrated significantly higher self-care scores after the study compared to before the study ($p < 0.01$). However, the change in self-care outcomes was not significant between the control and the test group (Welch two sample t-test: t = -0.640, df = 129.02, p-value = 0.523).

Table 4.5: Diabetes self-care activities outcomes.

	Before study self-care	**After study self-care**	**Follow up self-care**	**Before and after (paired t-test)**
Control	6.360 (n=87, SD= 1.662)	6.540 (n=74, SD= 1.575)	6.712 (n=73, SD= 1.636)	t = -2.213 df = 71, p = 0.030*
Test	6.379 (n=78, SD= 1.857)	6.827 (n=68, SD= 1.678)	6.917 (n=70, SD= 1.678)	t = -2.606, df = 66, p-value = 0.011*

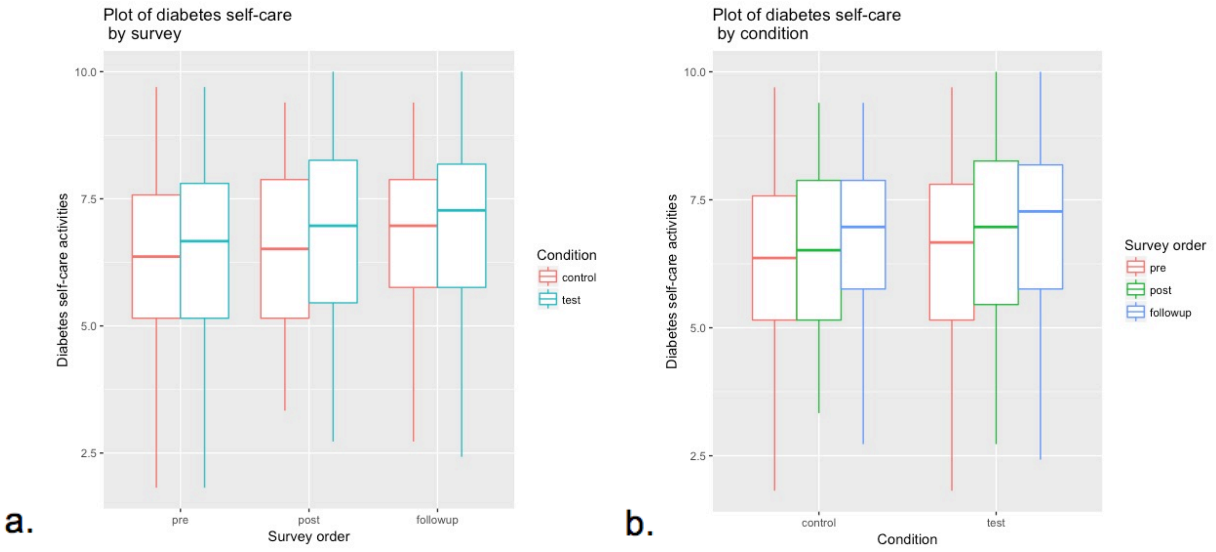


Figure 4.5: Diabetes self-care outcomes.
Both the test group and control group demonstrated significantly higher self-care measures after the study compared to before the study. The change in self-care was not significant between groups.

Diabetes distress scale

Diabetes distress level was measured through Diabetes Distress Screening Scale. Participants in neither test group or control group demonstrated significant changes in distress level between before and after the study. The change in distress scale was not significant between the control and the test group (Welch two sample t-test: t = 1.391, df = 134.22, p-value = 0.165).

Table 4.6: Diabetes distress outcomes.

	Before study distress scale	**After study distress scale**	**Follow up distress scale**	**Before and after (paired t-test)**
Control	2.667 (n=87, SD= 1.374)	2.642 (n=74, SD= 1.396)	2.644 (n=73, SD=1.406)	t = -0.252, df = 71, p = 0.801
Test	2.474 (n= 78, SD= 1.483)	2.276 (n=68, SD= 1.371)	2.254 (n=70, SD= 1.371)	t = 1.666, df = 65, p= 0.101

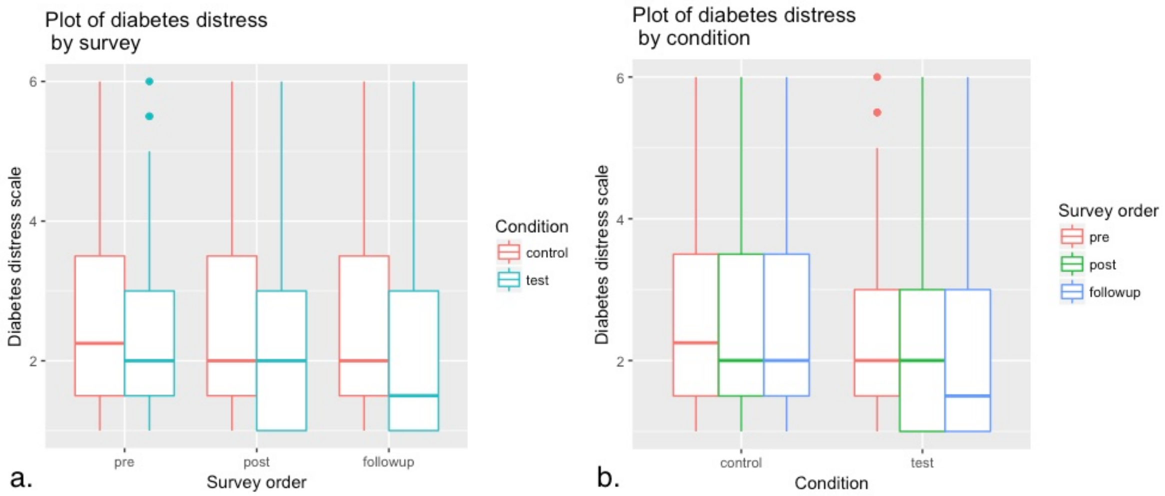


Figure 4.6: Diabetes distress outcomes.
Participants in neither test group or control group demonstrated significant changes in distress level between before and after the study. The change in distress scale was not significant between groups.

4.3.3: RQ 4.2 Clinical indicators

140 participants consented to having diabetes relevant clinical indicators extracted from their EMR, where their clinical care data were deposited. Lab data including blood glucose and A1C, vitals data containing blood pressure were obtained over a span of 5 years and half,

between 04/2012 and 09/2017. Some participant data were missing due to conflicts with prior informed consent and missing information in database. Following the RCT protocol of collecting data within a 7-day window before and after the intervention, only 8 data points from 4 participants qualified. The scarcity of qualified clinical data posed limitation to assess clinical effect of the RCT, but provided an opportunity to examine the trend and availability of clinical indicators relevant for diabetes care. Descriptive statistics are shown below.

Table 4.7: Descriptive statistics for clinical indicator data points.

Entire collection period: **5.5 years (4/2012 – 9/2017)**	**Blood Glucose**	**A1C**	**Blood Pressure**
Total number of data points	2448	838	4131
Number of participants with data points **(% out of all who consented)**	97 (69.3%)	96 (68.6%)	111 (72.3%)
Data points per participant	Mean: 25.24 Median: 13 Range: [1, 253] SD: 40.90	Mean: 8.73 Median: 8 Range: [1, 26] SD: 6.28	Mean: 37.22 Median: 27 Range: [1, 153] SD: 33.43
Study Running Period: **5 months (4/2017 – 9/2017)**	**Blood Glucose**	**A1C**	**Blood Pressure**
Total number of data points	190	80	407
Number of participants with data points	64	58	83
Data points per participant	Mean: 2 Median: 2.97 Range: [1, 27] SD: 3.81	Mean: 1.38 Median: 1 Range: [1, 3] SD: 0.64	Mean: 4.90 Median: 4 Range: [1, 19] SD: 4.14

Additionally in the EMR, 9 variations of blood glucose measures were observed. The variable exhibited both syntax and semantic variations. To ensure consistency, only data with lab name of “GLUCOSE” for blood glucose, and with lab name of “GLYCO HB(A1C) were included to demonstrate data trend.

Table 4.8: Syntax variations of clinical indicators from the EMR.

Blood glucose	**A1C**
GLUCOSE	GLYCO HB (A1C)
GLUCOSE (POCT)	HEMOGLOBIN A1C (POCT)
GLUCOSE-LABCORP	HEMOGLOBIN A1C / HEMOGLOBIN TOTAL -LABCORP
GLUCOSE-QUEST	HEMOGLOBIN A1C-LABCORP
GLUCOSE, ART	HEMOGLOBIN A1C-QUEST
GLUCOSE, ART RC	
GLUCOSE, OTHER	
GLUCOSE, VEN	
GLUCOSE, VEN RC	

Blood glucose

To provide a quick way to analyze data collection frequency and availability, I used visualization through boxplots and counts (see figures below). Majority of the participants have under 25 blood glucose data points on a yearly basis, over the entire duration of data collection allowed by the IRB. Two extreme outliers have data points in the 200 range. Closer inspection on the outliers showed intense and consecutive blood glucose data collection over several days, indicating possible hospitalization.

Next I examined monthly data between April - September 2017, which covered study periods for all participants consented to data collection. Most participants have 1-2 data point per month. I decided on using sphere size to represent the counts of participants with specific data point counts. The visualization provided a quick overview of data availability, informing compatibility with the research design. In this case, a significant amount of participants have 1 data point on a monthly basis.

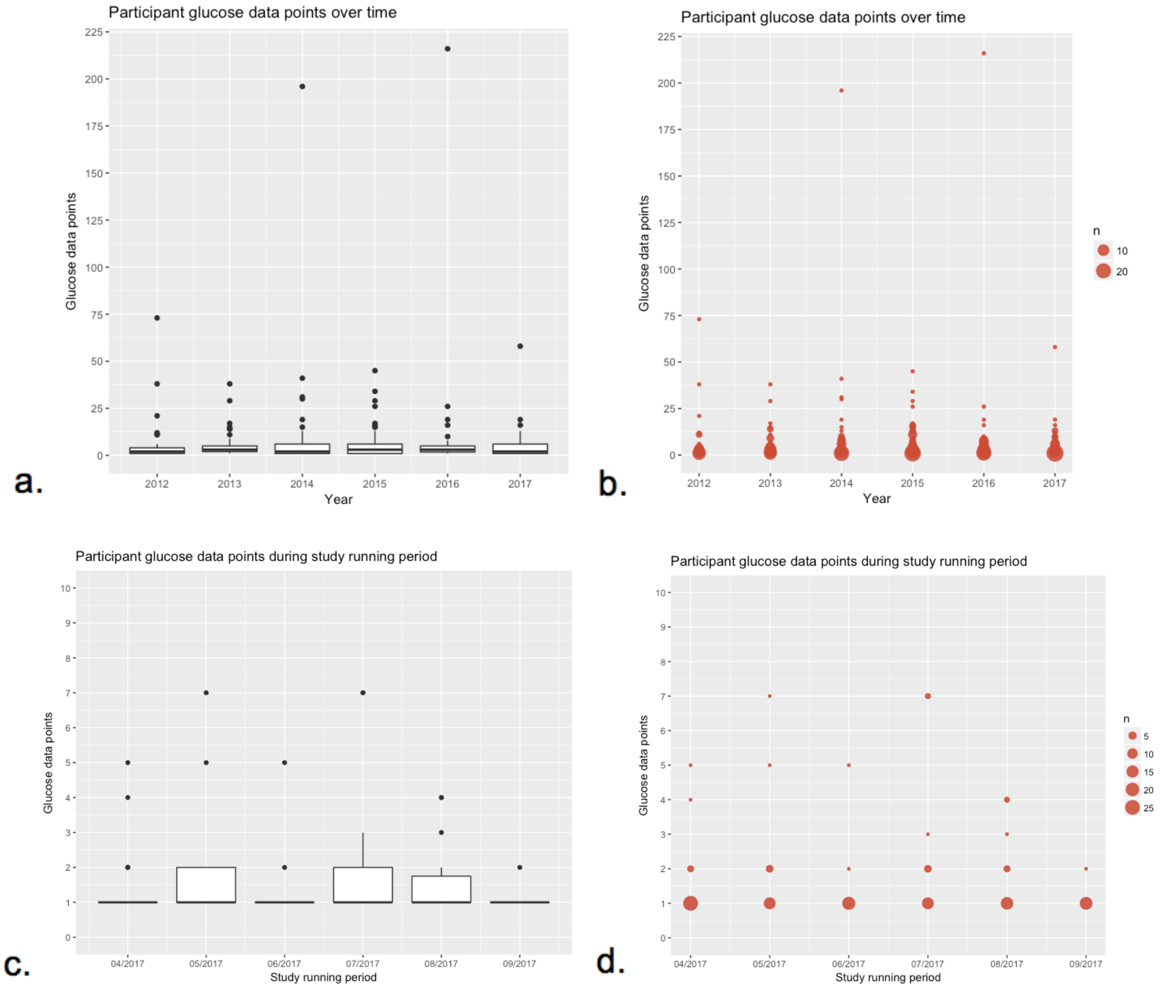


Figure 4.7: Visualization of blood sugar data points for study participants. Yearly glucose data points were under 25 for most participants. Monthly glucose data points range between 1 to 2 during the study period.

A1C

A1C is a common blood test to gauge how well diabetes patients manage their diabetes and is measured primarily to identify the three-month average plasma glucose concentration. It is usually taken twice a year[107]. It is expected that A1C data would be much more scare than the blood sugar data. As shown in the visualization, majority of the participants have 5 data points or less on a yearly basis. A few participants had slightly more data points, with an upper limit of 8. However the range of data for blood glucose was not observed for A1C. On a monthly basis, most only have 1 data point.

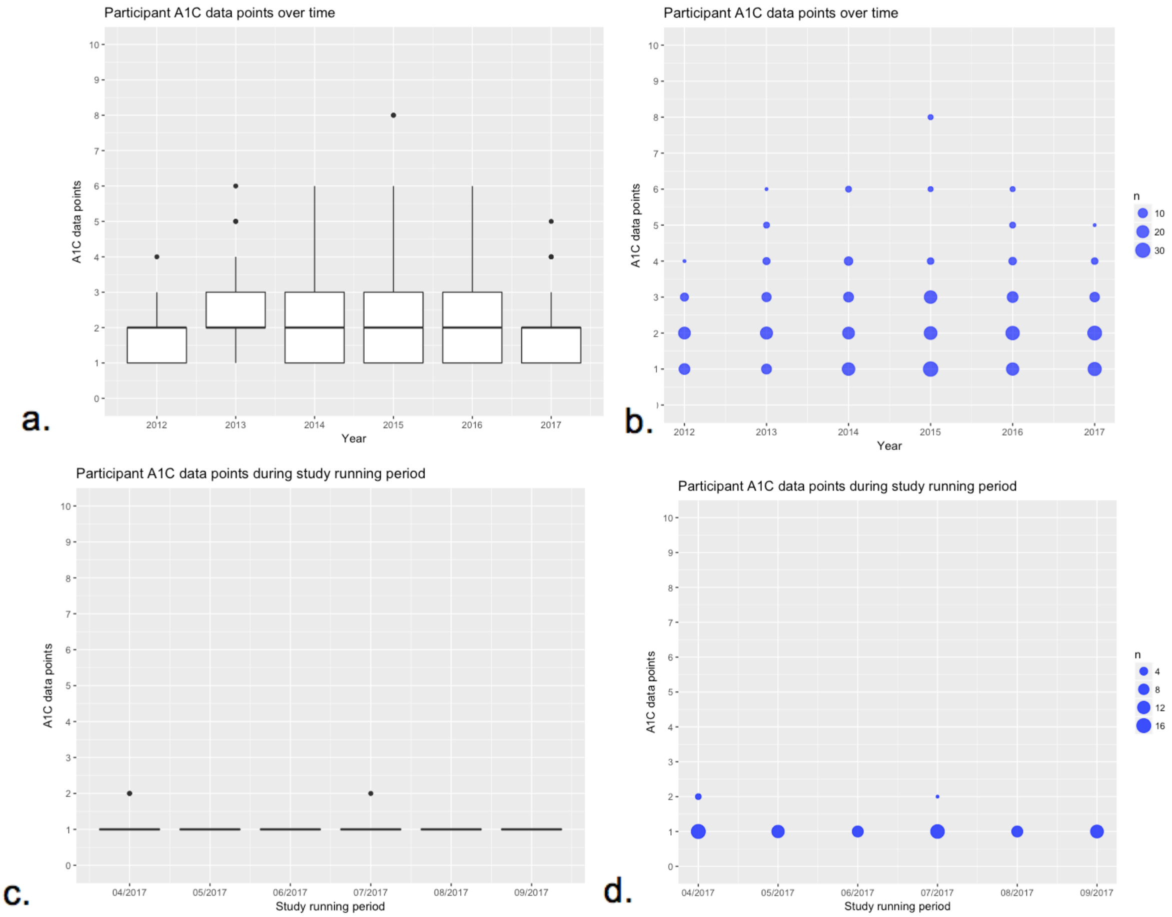


Figure 4.8: Visualization of A1C data points for study participants. Yearly A1C data points range between 1 to 3 for most participants. The majority of the participants have 1 monthly A1C data point during the study period.

Blood pressure

Blood pressure is part of the vital sign data[108] (or vitals for short) commonly measured at patient visits. Hypertension control is an important goal for type 2 diabetes patients, because high blood pressure increases chance for dangerous events such as heart attacks and strokes[109]. Blood pressure data points are more evenly distributed compared to blood glucose, with most of the participants having 2-12 data points, and the amount of people for the data point bracket were also even, as shown in the visualization below. During the active study running period, most participants have 1-2 data points.

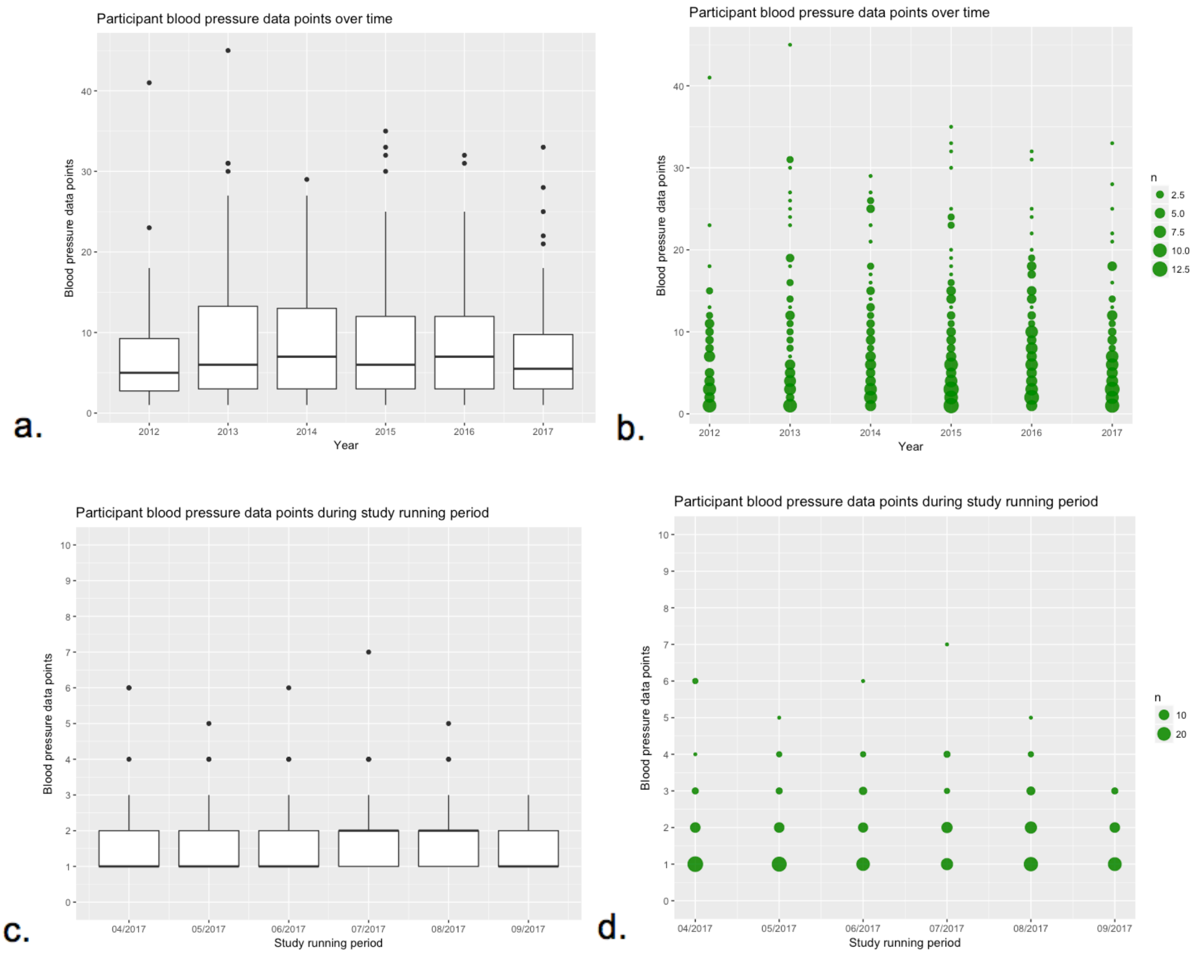


Figure 4.9: Visualization of blood pressure data points for study participants. Yearly blood pressure data points range between 2-15 for most participants. Monthly blood pressure data points for most participants range between 1 to 2 during the study period.

BMI

Body Mass Index (BMI) was obtained through participant self-reported data in main surveys. BMI was calculated using participant body weight and height. Neither test group or control group showed significant change in BMI values between before and after the study. The difference in change in BMI between control and test was not significant (Welch two sample t-test: t = 0.263, df = 127.4, p-value = 0.793).

Table 4.9: Participant BMI outcomes.

	Before study BMI	**After study BMI**	**Follow up BMI**	**Before and after (paired t -test)**
Control	32.389 (n=87, SD= 7.500)	33.098 (n=74, SD= 7.662)	32.695 (n=73, SD= 7.465)	t = 0.289, df = 71, p = 0.773
Test	32.660 (n=78, SD= 6.833)	32.290 (n=68, SD= 6.962)	32.100 (n=70, SD= 6.962)	t = 0.841, df = 65, p = 0.403

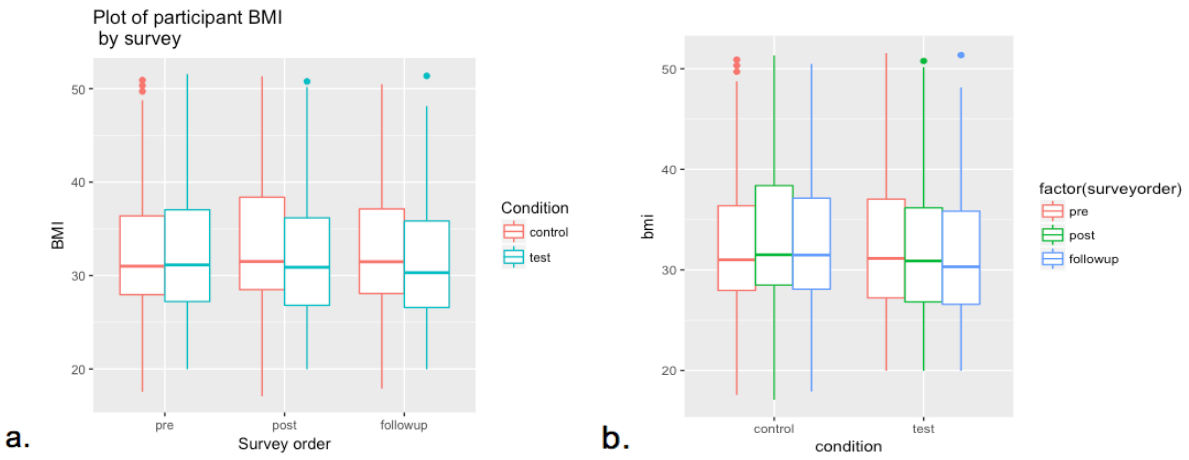


Figure 4.10: Participant BMI outcomes. Neither the test group nor the control group showed significant change in BMI values between before and after the study. The difference in change in BMI between control and test was not significant.

4.3.4: RQ 4.3 Information assessment

The RCT included 12 information assessment surveys. Each information assessment survey contained a conversation thread chosen from the diabetes OHC, along with a series of questions that assess the information. The control group received conversation threads as they are while the test group received them enhanced with clinical expertise provided by the clinical collaborator.

Quantitative results

The information assessment survey contained 10 questions that assessed information presented in the conversation threads through perceived usefulness, information adequacy and how well the information aided decision-making. Participants were asked to rate on a Likert scale of 1-7, with higher scores indicating more usefulness, satisfaction etc.

Participants perceived the information presented with clinical expertise as significantly more up-to-date, unique, truthful, and they trusted the competence of the responders more (Welch two sample t-test, $p<0.05$). The information with clinical expertise also received significantly higher rating from participants on all three aspects of decision-making: the information improves effectiveness of decision-making, makes it easier to make a decision, and is useful for decision-making (Welch two sample t-test, $p<0.05$). Lastly, participants rated information with clinical expertise significantly higher in overall satisfaction (Welch two-sample t-test, $p<0.01$). The statistics for the control group and the test group are shown below.

Table 4.10: Information assessment quantitative results. *p<0.05, **p<0.01

Topic	Control mean (SD)	Test mean (SD)	P value
Number of participants	87	78	-
Number of data points	929	867	-
The conversation thread provides relevant information. (1:strongly disagree; 7: strongly agree)	4.94 (1.81)	5.06 (1.73)	0.156
The conversation thread provides up-to-date information. (1:strongly disagree; 7: strongly agree)	4.73 (1.68)	4.93 (1.62)	0.011*
The conversation thread provides unique content. (1:strongly disagree; 7: strongly agree)	4.50 (1.70)	4.75 (1.60)	0.001**
The conversation thread provides comprehensive information. (1:strongly disagree; 7: strongly agree)	4.27 (1.84)	4.38 (1.75)	0.209
I believe the conversation thread provides truthful information. (1:strongly disagree; 7: strongly agree)	4.99 (1.65)	5.26 (1.59)	<0.001**
I trust the competence of the posters in the conversation thread. (1:strongly disagree; 7: strongly agree)	4.57 (1.76)	4.90 (1.65)	<0.001**
The information improves the effectiveness of my decision-making. (1:strongly disagree; 7: strongly agree)	4.24 (1.84)	4.47 (1.82)	0.007**
The information makes it easier to make my decision. (1:strongly disagree; 7: strongly agree)	4.21 (1.85)	4.41 (1.80)	0.020*
The information is useful in my decision-making. (1:strongly disagree; 7: strongly agree)	4.31 (1.92)	4.57 (1.85)	0.003**
Overall satisfaction (1:completely dissatisfied; 7: completely satisfied)	4.55 (1.70)	4.79 (1.71)	0.003**

Qualitative results

In information assessment surveys, participants were also asked 1) what information is useful or not useful to them in the conversation thread 2) what kind of information would be helpful for their decision-making, 3) to explain their satisfaction rating. I performed thematic analysis of participant comments and developed themes surrounding contextualized preferences for OHC information. The control group desired expert content or input from health professionals, while the test group expressed that the clinical expertise should provide more explanation, be more personable, and bring value by confirming information. For all participants, the information was useful when it compared pros and cons, presented alternatives, presented personal experience, and had a combination of layman's easy-to-understand responses and confirmation by medical professionals. When the information was irrelevant, contradictory, lacked facts, failed to establish trust, and contained no new knowledge, the participants found it not useful.

To further understand participants' decision-making challenges and gather design requirements to support decisional needs, semi-structured exit interviews were conducted with 12 participants. The interview questions focused on information needs, challenges and wishes for informational support. The interviews ranged from 20 minutes to 1 hour in length. The interviewer reinstated information during conversations to confirm accuracy. All interviews were audio-recorded and then transcribed verbatim into text. I used the grounded theory approach[110] to identify salient and recurring themes from the interview data. The challenges experienced by participants included concerns for inaccurate and incomplete information, their individual constraints such as cost and phobia. Participants wished for professionally validated information with facts and narratives presented separately, as well as a new information delivered to them in a personable fashion.

4.4: Summary

Participants in the RCT showed improved psychosocial outcomes after the study in two measures, self-efficacy and self-care. The intervention effect was not statistically significant between the control and test groups.

Information assessment showed the information enhanced with clinical expertise was ranked higher in all aspects of information assessment by patients, with 8 out of 10 metrics being statistically significant. Participants voiced concern for information lacking facts, accuracy, and comprehensiveness in the OHC environment. OHC information might contradict with other information sources participants receive, thus making the information not useful for decision-making. On the other hand, participants found relevant, specific, and new content useful. While personal experience was valued, ‘refereed’ content is desired. The ‘refereed’ content refers to information validated by health professionals, a process discussed consistently in the qualitative data. The caveat to health professional input was that it has to meet patients’ expectation to “add value” by providing explanation and confirmation. As for information delivery, the content should be personable and easy to understand.

The assessment also aimed to evaluate decision support from conversation threads with choice inquiries. Information enhanced with clinical expertise provided significantly more effective support for decision-making. Participants further commented on ways to aid decision-making, through presenting alternatives and comparing pros and cons of choices. Lastly, decision-making was an “ongoing struggle” for diabetes patients. Participants expressed wishes to incorporate individual constraints beyond clinical considerations in decision support, such as medication costs, insurance, and personal fear.

Chapter 4 is coauthored with Huh, Jina; Kim, Jihoon; El-Kareh, Robert; Vermeesch, Amber. The dissertation author was the primary author of this chapter. Chapter 4 contains

materials published in the companion of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing, and in the proceedings of 15th European Conference on Computer Supported Cooperative Work Doctoral Colloquium, 2017. Zhang, Jing. The dissertation author was the sole author of this material.

Chapter 5: Discussion

A significant amount of diabetes patients seek health information online[55,111] and an increasing amount of people go to OHCs for information[55]. But the quality of online health information varies widely[112]. To enhance and diversity information, I incorporated clinical expertise in OHC conversation threads pertaining to decision-making. Information assessment generated positive results in favor of OHC content enhanced with clinical expertise, showing quantitative evidence to support patient preference to include clinician input in the online peer patient environment[88–90]. With over 50 million American adults using the Internet to make critical health decisions[113], this finding is particularly relevant in demonstrating the benefit of clinical expertise in the patient decision-making context[105]. However caution has to be exercised since the source of clinical expertise was identified as “UCSD Nurse Practitioner” in the study. Prior research demonstrated the social norm of favoring authorities leading to over-valuing authority sources over peer-sourced content[114]. Qualitative analysis of patient comments provided directions on how to further improve the delivery of clinical expertise: with specific and updated information, in a personable, and easy to understand tone, and most importantly, providing validation and explanation.

Effective self-care decision-making has the potential to reduce the burden of chronic illness[26]. Patient decision-making research, however, so far has mainly been oriented towards discrete treatment decisions (e.g., whether to undergo a particular surgery). Decision-making for chronic illness self-care in contexts other than patient provider interaction, such as online health information seeking and peer patient interactions in social media, has been understudied[26,81,115,116]. Chronic illness self-care decision-making is difficult to study because it is complex and intertwines with everyday life[26,116]. With access to rich personal self-care experience [50,51], OHCs can help us understand historically underexplored contexts around patients’ daily decision-making processes.

The findings of this research presented the magnitude and diversity of decisional needs. This is the first attempt to quantify choice inquiries taking place in an OHC environment. Weymann et al. found blood sugar control, oral medication, and acute complication to be the most relevant treatment decisions needing support[78]. Weymann's patient population was a convenience sample of patients affiliated with the university hospital, and those in diabetes self-help groups, while this research drew from 7 years of OHC data reflecting real-life issues. People expressed similar needs in the context of OHC, with medication, insulin, blood sugar control and complication accounting for half of the choice inquiries. Weymann et al's study was done using a questionnaire with seven pre-defined decision areas, while this research allowed granularity when coding for choice inquiry topics. Much of chronic illness self-care has focused on treatment decision-making, medication compliance, and symptom control[82]. Issues concerning the complexity of self-care decision-making is "less well understood" [26]. The results from this research led to the identification of a broad range of issues containing the nuisances of everyday life. These issues are central to self-care and necessitate decision-making. For example, OHC members inquired about sugar substitutes because sugar substitutes help limit their sugar intake[117] and there are many choices to choose from. Members also inquired about sugar free beer, cake recipes, diabetic friendly footwear, low-sugar fruit options, the best time of the day to check blood sugar, strategies to cope with food cravings, and ways to cope with medication side effects. As such, this research answered the call and paved the way for "a new conceptualization of self-care decision-making in chronic illness"[82] incorporating the complexity and uniqueness of patient decisions.

Patient education traditionally aims at increasing compliance to physician-defined therapeutic aims and treatment strategies[118]. In contrast, patients have complex[119] and individualized needs. Findings from this research revealed the various contexts and motivations that patients incorporate when considering choices[82]. The diabetes OHC showcased many personal circumstances. Some examples include fear for needles which delayed a member from switching to insulin, and concerns for having tattoos as a diabetic. The context of decisions provides useful insights[81] to healthcare providers to understand more fully the unique circumstances and constraints of those they serve[26,82]. Patient education material can also benefit from incorporating individualized decision support to balance patients' personal constraints[82].

In online communities, conversations have a critical role in contributing to the success of the community and individual members[120]. People benefit from the presence and activity of other members[121]. Findings of response metrics to OHC inquiries showed [86] choice inquiries had lower response quantity. The findings implied that members' choice inquiries received less than desired support, compared to the rest of the community inquiries. As a result, important problems concerning decision-making might not be discussed. When there is a lack of response, the members trying to gain information and support receive no benefit[120]. Inadequate response can lead to failed community interaction, resulting in unmet needs for the individuals[87]. Online community research examined various mechanisms to solicit responses, such as social psychology theories of social loafing and goal setting[117], promoting group similarity and uniqueness[122], and rhetorical strategies of incorporating self-introduction and staying on-topic[84]. This research helps us understand that those wishing to make decisions do not receive adequate information. The reason could be that peer responders exhibit caution in offering direct input that influence others' decisions. Instead, they might redirect the poster for professional expertise[33]. Prior research found "see your doctor" responses discourage community participation[33], leading to fewer responses. On the other hand, members might feel more encouraged in contributing in a non-decision-making context, as found in non-choice inquiries. Future work is called for to examine what led to the lower response metrics for choice inquiries. Since only quantitative response metrics have been examined, future research could benefit from assessing the quality and impact of responses through content review of inquiries and responses. This finding also indicated an opportunity to provide more support to inform choice inquiries. Because the quality of decisions depends on the quality, quantity and variety of information presented during the decision-making process[105], I developed an intervention to integrate clinical expertise in the responses.

Both the control and the test groups of the intervention showed improvement in psychosocial measures of self-efficacy and self-care between before and after the study. The study showed promising results in that exposing participants to relevant OHC discussions pertaining to decision-making, and further engaging them with reflection questions, had a positive impact on their psychosocial measures. However, research has shown that psychosocial measures such as self-efficacy can be influenced by several factors such as performance accomplishments, verbal persuasion and psychological state[123,124]. It was not known what other factors patients could have been exposed to during the course of the study. Future study could incorporate a baseline group with no OHC content administered to account for the psychosocial measure change as a result of time. The study was unable to show a benefit in self-efficacy, self-care, distress, or BMIs from the four-week intervention between groups. The study effects would likely be amplified by 1) engaging the participants with direct interaction with the responders and the clinician in the OHC conversation threads, or 2) engaging the participants to post and receive answers for their own choice inquiries regarding diabetes care.

With the adoption of EMRs, an increasing quantity of data have been deposited in the system, providing unprecedented opportunity for data reuse[125]. In this research, with the help of EMR data, I was able to recruit from a targeted and broad pool of 9835 potential participants. The extraction process was timely and cost-effective[126]. While EMR data reuse can reduce clinical research costs and inefficiency[126], researchers also cautioned that EMR data from clinical settings may be “inaccurate, incomplete, transformed in ways that undermine their meaning, unrecoverable for research, of unknown provenance, of insufficient granularity, and incompatible with research protocols”[125]. EMR incompatibility can be described as lacking consistency with research standards, in terms of timing, quality, and comprehensiveness[125,127]. This concept of “EMR data incompatibility” also applies to the context, where I attempted to analyze clinical indicators of the participants using retrospective EMR data. Clinical data collection and research data collection have different priorities. Patient clinical care data were collected by healthcare practices for clinical and billing purposes[127]. The characteristics of such data collection is that it is limited to what the healthcare providers believe is necessary, at intervals depending on clinical and non-clinical factors. On the other hand, research protocols tend to be highly structured, and strict with inclusion and exclusion criteria[125]. The characteristics of research data collection is that it is thorough and rigorous, at pre-defined intervals[125]. And in my research, this incompatibility resulted in scarcity of clinical data available for the RCT. This finding showed the importance of determining EMR data compatibility for the intended research[126]. In Chapter 4, I presented visualization as a method to inform EMR data compatibility. For example, the blood sugar visualization showed the majority of participants had fewer than 25 data points on a yearly basis. However there was a big range with outliers contributing to around 200 data points in some years. This knowledge can be used to assess likelihood whether adequate blood sugar data exist for a specific research purpose, such as for comparing diabetes interventions. The trend for each individual’s data count can also be visually analyzed to aid accessing compatibility with studies such as RCTs, where multiple data from the same patient need to be collected at different times. At the same time, caution should also be taken that patients contributing to more data points might be due to more sever conditions thus can potentially bias research.

The scarcity of clinical data available for the RCT led to my exploration of EMR data compatibility through visualization. The implication is that more analytical methods, such as visualization techniques should be developed to overcome the limitation of EMR data reuse[127] On a final note, if research calls for quality recording of clinical data[126 127], then the researchers should plan clinical data collection in tandem with the intervention, aligning existing collection with the study schedule.

Though patient decision-making takes place in various contexts with various degrees of patient involvement, this research in particular, contributes to understanding self-care decision-making that happens in OHCs and informs how healthcare providers, educators, system developers, and researchers should approach supporting patients' everyday decision-making process. In light of the findings, I propose developing an interactive decision aid for self-care choices enhanced with clinical expertise. Sepucha et al. illustrated the quality of the decision-making process can be improved by helping patients feel informed about the options, as well as the risks, benefits, and consequences of the choices[21,118]. Guided by this measurement construct, we can develop an interactive decision aid constructed from existing responses and updated with ongoing responses. The choices and relevant patient experience will be extracted, and enhanced with clinical expertise. Since the mechanism of comparison is central in human decision-making[128], this process can be externalized by presenting choices with pros and cons and in an easy-to-compare format.

The research has some limitations. First, since all RCT participants were recruited from the UC San Diego Health System, there might have been a bias due to only one healthcare setting and one geographic location being studied. Second, the study intervention and outcome measures were delivered online, so only patients with regular internet access could participate. Thus, the study runs the risk of limited generalizability and of excluding a part of the diabetes population who could otherwise benefit from the intervention. Lastly, due to the scope of the study, data from one diabetes OHC was collected. Decisional needs of patients could also be expressed through other channels, such as during clinical encounters, in diabetes education classes, or through email and text between patients and healthcare providers. Future study can broaden the scope to include various data sources beyond the peer patient OHC environment.

References

1. WHO. World Health Organization, Diabetes Programme [Internet]. Available from: http://www.who.int/diabetes/en/

2. Centers for Diesease Control and Prevention. 2017 National Diabetes Statistics Report. Estimates of Diabetes and Its Burden in the United States. 2017.

3. Center for Disease Control and Prevention. Prediabetes, could it be you? [Internet]. Available from: http://www.cdc.gov/diabetes/pubs/statsreport14/prediabetes-infographic.pdf

4. American Diabetes Association. Diagnosing Diabetes and Learning About Prediabetes: American Diabetes Association® [Internet]. 2016 [cited 2017 Sep 1]. Available from: http://www.diabetes.org/diabetes-basics/diagnosis/

5. Rothman AA, Wagner EH. Chronic illness management: what is the role of primary care?. Ann Intern Med [Internet]. 2003 Feb 4 [cited 2016 Sep 20];138(3):256–61. Available from: http://www.ncbi.nlm.nih.gov/pubmed/12558376

6. Association of the british pharmaceutical industry. The Diabetes Information Jigsaw Seek knowledge for informed choice and better health. 2006.

7. Beeney LJ, Bakry AA, Dunn SM. Patient psychological and information needs when the diagnosis is diabetes. Patient Educ Couns [Internet]. 1996 Oct [cited 2016 Jun 25];29(1):109–16. Available from: http://linkinghub.elsevier.com/retrieve/pii/0738399196009391

8. Longo DR, Schubert SL, Wright BA, LeMaster J, Williams CD, Clore JN. Health information seeking, receipt, and use in diabetes self-management. Ann Fam Med [Internet]. 2010 Jul 1 [cited 2017 Oct 26];8(4):334–40. Available from: http://www.ncbi.nlm.nih.gov/pubmed/20644188

9. Corbin JM, Strauss A. A nursing model for chronic illness management based upon the Trajectory Framework. Sch Inq Nurs Pract. 1991;5(3):155–74.

10. McCorkle R, Pasacreta J. Enhancing Caregiver Outcomes in Pallative Care. Cancer Control [Internet]. 2001;8(1):36–45. Available from: http://www.ncbi.nlm.nih.gov/pubmed/11252271

11. Griffiths F, Borkan J, Byrne D, Crabtree BF, Dowrick C, Gunn J, Kokanovic R, Lamb S, Lindenmeyer A, Parchman M, Reis S, Sturt J. Developing evidence for how to tailor medical interventions for the individual patient. Qual Health Res [Internet]. 2010;20(12):1629–41. Available from: http://www.ncbi.nlm.nih.gov/pubmed/20663934

12. Emery C. Women living with chronic illness experienced transition that involved stages of distress and a quest for ordinariness. Evid Based Nurs [Internet]. 2003;6(2):63–63. Available from: http://ebn.bmj.com/cgi/doi/10.1136/ebn.6.2.63

13. Duggan C, Bates I. Medicine information needs of patients: the relationships between information needs, diagnosis and disease. Qual Saf Heal Care [Internet]. 2008;17(2):85–9. Available from: http://www.ncbi.nlm.nih.gov/pubmed/18385399

14. Abadie R, Weymiller AJ, Tilburt J, Shah ND, Charles C, Gafni A, Montori VM. Clinician's use of the Statin Choice decision aid in patients with diabetes: A videographic study nested in a randomized trial. J Eval Clin Pract. 2009;15(3):492–7.

15. Nannenga MR, Montori VM, Weymiller AJ, Smith SA, Christianson TJH, Bryant SC, Gafna A, Charles C, Mullan RJ, Jones LA, Bolona ER, Guyatt GH. A treatment decision aid may increase patient trust in the diabetes specialist. the Statin Choice randomized trial. Heal Expect. 2009;12(1):38–44.

16. Reynolds TL, Ali N, Mcgregor E, O'Brien T, Longhurst C, Rosenberg AL, Scott ER, Zheng K. Understanding Patient Questions about their Medical Records in an Online Health Forum : Opportunity for Patient Portal Design. In: 2017 American Medical Informatics Association (AMIA), In Press. 2017.

17. Hilliard ME, Sparling KM, Hitchcock J, Oser TK, Hood KK. The Emerging Diabetes Online Community. Curr Diabetes Rev. 2015;11:261–72.

18. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: A narrative review. Patient Educ Couns [Internet]. 2006;60(2):102–14. Available from: http://linkinghub.elsevier.com/retrieve/pii/S0738399105000546

19. Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: The case of diabetes. Heal Expect. 2006;9:25–36.

20. Karni E. Savages' Subjective Expected Utility Model. In: Durlauf SN, Blume LE, editors. The New Palgrave Dictionary of Economics. Second Edi. Palgrave Macmillan, 2008.; 2008. p. 1–12.

21. Sepucha KR, Borkhoff CM, Lally J, Levin CA, Matlock DD, Ng CJ, Ropka ME, Stacey D, Joseph-Williams N, Wills CE, Thomson R. Establishing the effectiveness of patient decision aids: key constructs and measurement instruments. BMC Med Inform Decis Mak [Internet]. 2013;13 Suppl 2:S12. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=4044563&tool=pmcentrez&rendertype=abstract

22. Kahneman D, Tversky A. Prospect Theory: An Analysis of Decision under Risk. Econom J Econom Soc. 1979;47(3):263–91.

23. Kahneman D. A perspective on judgment and choice: mapping bounded rationality. Am Psychol. 2003;58(9):697–720.

24. Mann L, Harmoni R, Power C, Beswick G, Ormond C. Effectiveness of the GOFER course in decision making for high school students. J Behav Decis Mak [Internet]. 1988;1(3):159–68. Available from: http://search.ebscohost.com/login.aspx?direct=true&db=bth&AN=16566640&site=ehost-live

25. Guo KL. DECIDE: a decision-making model for more effective decision making by health care managers. Health Care Manag (Frederick) [Internet]. 2008 Apr [cited 2016 Sep 15];27(2):118–27. Available from: http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00126450-200804000-00005

26. Thorne S, Paterson B, Russell C. The Structure of Everyday Self-Care Decision Making in Chronic Illness. Qual Health Res. 2003;13(10):1337–52.

27. Gionfriddo MR, Leppin AL, Brito JP, LeBlanc A, Boehmer KR, Morris MA, Erwin PJ, Prokop LJ, Zeballos-Palacios CL, Malaga G, Miranda JJ, McLeod HM, Rodriguez-Gutierrez R. A systematic review of shared decision making interventions in chronic conditions: a review protocol. Syst Rev [Internet]. 2014;3(1):38. Available from: http://www.systematicreviewsjournal.com/content/3/1/38

28. Scott GC, Lenert LA. What Is The Next Step in Patient Decision Support? AMIA Annu Symp Proc. 2000;784–8.

29. Sawka CA, Goel V, Mahut CA, Taylor GA, Thiel EC, O'Connor AM, Ackerman I, Burt JH, Gort EH. Development of a patient decision aid for choice of surgical treatment for breast cancer. Heal Expect [Internet]. 1998;1(1):23–36. Available from: http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=1999053918&site=ehost-live

30. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, McPherson R, Bunn H, Graham I, Drake E. A decision aid for women considering hormone therapy after menopause : decision support framework and evaluation. 1998;33:267–79.

31. Feldman-Stewart D, Brundage MD, Van Manen L, Svenson O. Patient-focussed decision-making in early-stage prostate cancer: Insights from a cognitively based decision aid. Heal Expect. 2004;7(2):126–41.

32. O'Connor AM, Wennberg JE, Legare F, Llewellyn-Thomas HA, Moulton BW, Sepucha KR, Sodano AG, King JS. Toward the "tipping point": Decision aids and informed patient choice. Vol. 26, Health Affairs. 2007. p. 716–25.

33. Huh J. Clinical Questions in Online Health Communities:The Case of "See your doctor" Threads. Proc 18th ACM Conf Comput Support Coop Work Soc Comput - CSCW '15 [Internet]. 2015;1488–99. Available from: http://dl.acm.org/citation.cfm?id=2675133.2675259

34. Chernyak N, Stephan A, Bächle C, Genz J, Jülich F, Icks A. Assessment of information needs in diabetes: Development and evaluation of a questionnaire. Prim Care Diabetes [Internet]. 2016 Aug [cited 2016 Jul 20];10(4):287–92. Available from: http://linkinghub.elsevier.com/retrieve/pii/S1751991815001680

35. Peel E, Parry O, Douglas M, Lawton J. Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions and views about information provision. Patient Educ Couns [Internet]. 2004 Jun [cited 2016 Aug 2];53(3):269–75. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15186863

36. Duggan C, Bates I. Medicine information needs of patients: the relationships between information needs, diagnosis and disease. Qual Saf Health Care [Internet]. 2008;17(2):85–9. Available from: http://www.ncbi.nlm.nih.gov/pubmed/18385399

37. Lamberts EJF, Bouvy ML, van Hulten RP. The role of the community pharmacist in fulfilling information needs of patients starting oral antidiabetics. Res Soc Adm Pharm. 2010;6(4):354–64.

38. Grant J, Chittleborough C, Taylor A, Cheek J, Phillips P. What do people with Diabetes want to know? Education and information needs of people with diabetes [Internet]. 2008 [cited 2016 Jul 21]. Available from: https://health.adelaide.edu.au/pros/docs/presentations/diabetes-info-02.pdf

39. Ormandy P. Defining information need in health - assimilating complex theories derived from information science. Heal Expect. 2011;14(1):92–104.

40. Wilson TD. Information behaviour: an interdisciplinary perspective. Inf Process Manag [Internet]. 1997;33(4):551–72. Available from: http://linkinghub.elsevier.com/retrieve/pii/S0306457397000289

41. Meho LI, Tibbo HR. Modeling the information-seeking behavior of social scientists: Ellis's study revisited. J Am Soc Inf Sci Technol. 2003;54(6):570–87.

42. Marchionini G. Information Seeking in Electronic Environments. Bull Med Libr Assoc. 1996;9:26–60.

43. Haas L, Maryniuk M, Beck J, Cox CE, Duker P, Edwards L, Fisher EB, Hanson L, Kent D, Kolb L, McLaughlin S, Orzeck E, Piette JD, Rhinehart AS, Rothman R, Sklaroff S, Tomky D, Youssef G. National standards for diabetes self-management education and support. Diabetes Care. 2012;35(11):2393–401.

44. Anderson RM, Funnell MM. Patient empowerment: Myths and misconceptions. Patient Educ Couns [Internet]. 2010;79(3):277–82. Available from: http://dx.doi.org/10.1016/j.pec.2009.07.025

45. Celler BG, Lovell NH, Basilakis J. Using information technology to improve the management of chronic disease. Med J Aust. 2003;179(5):242–6.

46. American Diabetes Association, Standards of Medical Care in Diabetes - 2016. J Clin Appl Res Educ [Internet]. 2016;39(1):1–119. Available from: http://care.diabetesjournals.org/content/suppl/2015/12/21/39.Supplement_1.DC2/2016-Standards-of-Care.pdf

47. Peyrot M, Rubin RR. Access to Diabetes Self-management Education. Diabetes Educ [Internet]. 2008;34(1):90–7. Available from: http://tde.sagepub.com/cgi/doi/10.1177/0145721707312399

48. Funnell MM, Brown TL, Childs BP, Haas LB, Hosey GM, Jensen B, Maryniuk M, Peyrot M, Piette JD, Reader D, Siminerio LM, Weinger K, Weiss MA. National standards for diabetes self- management education. Diabetes Care. 2009;32(SUPPL. 1).

49. Fox S, Purcell K. Chronic illness and the internet. Washington DC; 2010.

50. Vilhauer RP. Perceived benefits of online support groups for women with metastatic breast cancer. Women Health [Internet]. 2009;49(5):381–404. Available from: http://www.ncbi.nlm.nih.gov/pubmed/19851944

51. Qiu B, Zhao K, Mitra P, Wu D, Caragea C, Yen J, Greer GE, Portier K. Get Online Support, Feel Better -- Sentiment Analysis and Dynamics in an Online Cancer Survivor Community. 2011 IEEE Third Int'l Conf Privacy, Secur Risk Trust 2011 IEEE Third Int'l Conf Soc Comput. 2011;274–81.

52. Shrank WH, Choudhry NK, Swanton K, Jain S, Greene JA, Harlam B, Patel KP. Variations in Structure and Content of Online Social Networks for Patients With Diabetes. JAMA Intern Med. 2011;171(17):1589–91.

53. van der Eijk M, Faber MJ, Aarts JWM, Kremer JAM, Munneke M, Bloem BR. Using online health communities to deliver patient-centered care to people with chronic conditions. J Med Internet Res [Internet]. 2013 Jun 25 [cited 2017 Oct 23];15(6):e115. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23803284

54. Neal L, Oakley K, Lindgaard G, Kaufman D, Leimeister JM, Selker T. Online health communities. In: CHI '07 extended abstracts on Human factors in computing systems - CHI '07 [Internet]. New York, New York, USA: ACM Press; 2007 [cited 2017 Oct 23]. p. 2129. Available from: http://portal.acm.org/citation.cfm?doid=1240866.1240965

55. Nath C, Huh J, Adupa AK, Jonnalagadda SR. Website Sharing in Online Health Communities: A Descriptive Analysis. J Med Internet Res [Internet]. 2016 Jan 13 [cited 2017 Oct 23];18(1):e11. Available from: http://www.ncbi.nlm.nih.gov/pubmed/26764193

56. Davison KP, Pennebaker JW, Dickerson SS. Who talks? The social psychology of illness support groups. Am Psychol. 2000;55(2):205–17.

57. Biyani P, Caragea C, Mitra P, Yen J. Identifying Emotional and Informational Support in Online Health Communities. Proc 25th Int Conf Comput Linguist COLING '14. 2014;1(1):827–36.

58. Huh J, Kwon BC, Kim S-H, Lee S, Choo J, Kim J, Choi MJ, Yi JS. Personas in online health communities. J Biomed Inform. 2016;63:212–25.

59. Introne J, Semaan B, Goggins S. A Sociotechnical Mechanism for Online Support Provision. In: Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems. San Jose, CA, USA; 2016. p. 3559–71.

60. Vlahovic TA, Wang Y-C, Kraut RE, Levine JM. Support Matching and Satisfaction in an Online Breast Cancer Support Community. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 2014. p. 1625–34.

61. Wang Y, Kraut R, Levine JM. To Stay or Leave? The Relationship of Emotional and Informational Support to Commitment in Online Health Support Groups. Proc ACM 2012 Conf Comput Support Coop Work. 2012;833–42.

62. Mamykina L, Heitkemper EM, Smaldone AM, Kukafka R, Cole-Lewis H, Davidson PG, Mynatt ED, Tobin JN, Cassells A, Goodman C, Hripcsak G. Structured scaffolding for reflection and problem solving in diabetes self-management: Qualitative study of mobile diabetes detective. J Am Med Informatics Assoc. 2016;23(1):129–36.

63. Mamykina L, Nakikj D, Elhadad N. Collective Sensemaking in Online Health Forums. Proc ACM CHI'15 Conf Hum Factors Comput Syst [Internet]. 2015;1:3217–26. Available from: http://dx.doi.org/10.1145/2702123.2702566

64. Budak C, Agrawal R. On Participation in Group Chats on Twitter. In: Proceedings of the 22nd international conference on World Wide Web - WWW '13 [Internet]. New York, New York, USA: ACM Press; 2013 [cited 2016 Sep 20]. p. 165–75. Available from: http://dl.acm.org/citation.cfm?doid=2488388.2488404

65. Wang YC, Kraut RE, Levine JM. Eliciting and receiving online support: Using computer-aided content analysis to examine the dynamics of online social support. J Med Internet Res. 2015;17(4):e99.

66. Huh J, Yetisgen-Yildiz M, Pratt W. Text classification for assisting moderators in online health communities. J Biomed Inform. 2013;46(6):998–1005.

67. Park A, Hartzler AL, Huh J, Mcdonald DW, Pratt W, Park A. Automatically Detecting Failures in Natural Language Processing Tools for Online Community Text Corresponding Author : 2015;17.

68. Kwon BC, Kim SH, Lee S, Choo J, Huh J, Yi JS. VisOHC: Designing Visual Analytics for Online Health Communities. IEEE Trans Vis Comput Graph. 2016;22(1):71–80.

69. Cody R, Lee C. Behaviors, beliefs, and intentions in skin cancer prevention. J Behav Med. 1990;13(4):373–89.

70. Beyerstein BL. Alternative medicine and common errors of reasoning. Acad Med. 2001;76(3):230–7.

71. Wright K. Social support within an on-line cancer community: an assessment of emotional support, perceptions of advantages and disadvantages, and motives for using the community from a communication perspective. J Appl Commun Res. 2002;30(3):195–209.

72. Eysenbach G, Powell J, Kuss O, Sa E-R. Empirical Studies Assessing the Quality of Health Information for Consumers A Systematic Review. JAMA [Internet]. 2002;287(20):2691–700. Available from: http://www.ncbi.nlm.nih.gov/pubmed/12020305

73. Coulter A. Evidence based patient information is important, so there needs to be a national strategy to ensure it. BMJ. 1998;317:225–6.

74. Bekker HL, Winterbottom AE, Butow P, Dillard AJ, Feldman-Stewart D, Fowler FJ, Jibaja-Weiss ML, Shaffer VA, Volk RJ. Do personal stories make patient decision aids more effective? A critical review of theory and evidence. BMC Med Inform Decis Mak [Internet]. 2013;13 Suppl 2:S9. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=4044102&tool=pmcentrez&ren

dertype=abstract

75. Weitzman E, Kelemen S, Quinn M, Eggleston E, Mandl K. Participatory Surveillance of Hypoglycemia and Harms in an Online Social Network. JAMA Intern Med. 2013;173(5):345–51.

76. Huh J, Pratt W. Weaving Clinical Expertise to Online Health Communities. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '14. New York, NY, USA: ACM; 2014. p. 1355–64.

77. Dikkers MF, Dunning T, Savage S. Information needs of family carers of people with diabetes at the end of life: a literature review. J Palliat Med [Internet]. 2013;16(12):1617–23. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24219846%5Cnhttp://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0265?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%3Dpubmed&

78. Weymann N, Härter M, Dirmaier J. Information and decision support needs in patients with type 2 diabetes. Health Informatics J [Internet]. 2014;52:1460458214534090-. Available from: http://jhi.sagepub.com/content/early/2014/06/08/1460458214534090.abstract

79. Mullan RJ, Montori VM, Shah ND, Christianson TJH, Bryant SC, Guyatt GH, Perestelo-Perez LI, Stroebel RJ, Yawn BP, Yapuncich V, Breslin MA, Pencille L, Smith SA. The diabetes mellitus medication choice decision aid: a randomized trial. Arch Intern Med. 2009;169(17):1560–8.

80. Montori VM, Leung teresa W, Thomson C, Chung J, Capes S, Smith S. Choice of Risk Representation to Enable Diabetes Decision-Making [Internet]. Diabetes Pro. 2004 [cited 2017 Aug 1]. Available from: http://professional.diabetes.org/abstract/choice-risk-representation-enable-diabetes-decision-making

81. Thorne S, Paterson B, Russell C, Schultz A. Complementary/alternative medicine in chronic illness as informed self-care decision making. Int J Nurs Stud. 2002;39(7):671–83.

82. Paterson BL, Russell C, Thorne S. Critical analysis of everyday self-care decision making in chronic illness. J Adv Nurs. 2001;35(3):335–41.

83. Zhang J, Marmor R, Huh J. Towards Supporting Patient Decision-making In Online Diabetes Communities. AMIA . Annu Symp proceedings AMIA Symp [Internet]. 2017 [cited 2019 Mar 4];2017:1893–902. Available from: http://www.ncbi.nlm.nih.gov/pubmed/29854261

84. Boland L, Kryworuchko J, Saarimaki A, Lawson ML. Parental decision making involvement and decisional conflict : a descriptive study. 2017;1–8.

85. Charmaz K, Albrecht G, Fitzpatrick R, Srimshaw S. Experiencing Chronic Illness. In: Handbook of Social Studies in Health and Medicine. London, UK: Sage; 2000. p. 272–292.

86. Teevan J, Morris M, Panovich K. Factors Affecting Response Quantity, Quality, and Speed for Questions Asked Via Social Network Status Messages. Proc Int Conf Webblogs Soc Media [Internet]. 2011;630–3. Available from: http://www.aaai.org/ocs/index.php/ICWSM/ICWSM11/paper/download/2795/3219

87. Arguello J, Butler BS, Joyce L, Kraut R, Ling KS, Rose C, Wang X. Talk to Me: Foundations for Successful Individual-Group Interactions in Online Communities. In: Proceedings of the SIGCHI conference on Human Factors in computing systems - CHI '06 [Internet]. New York, New York, USA: ACM Press; 2006 [cited 2017 Oct 26]. p. 959. Available from: http://portal.acm.org/citation.cfm?doid=1124772.1124916

88. Griffiths C, Foster G, Ramsay J, Eldridge S, Taylor S. How effective are expert patient (lay led) education programmes for chronic disease? BMJ Br Med J. 2007;334(7606):1254–6.

89. Paul G, Smith SM, Whitford D, O'Kelly F, O'Dowd T. Development of a complex intervention to test the effectiveness of peer support in type 2 diabetes. BMC Health Serv Res [Internet]. 2007;7:136. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2080630&tool=pmcentrez&rendertype=abstract

90. Sillence E, Briggs P, Harris P, Fishwick L. Going online for health advice: Changes in usage and trust practices over the last five years. Interact Comput. 2007;19(3):397–406.

91. Huh J, Mcdonald DW, Hartzler A, Pratt W. Patient Moderator Interaction in Online Health Communities. In: Proceedings of American Medical Informatics Association. American Medical Informatics Association; 2013. p. 627–36.

92. Clark ML, Utz SW, Hollen P. Use of diabetes self-management instruments among rural African American populations. South Online J Nurs Res [Internet]. 2011;11(1):27p–27p 1p. Available from: http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=104871610&amp%5Cnlang=ja&site=ehost-live

93. Anderson RM, Funnell MM, Nwankwo R, Gillard M Lou, Oh M, Fitzgerald JT. Evaluating a problem-based empowerment program for African Americans with diabetes: results of a randomized controlled trial. Ethn Dis [Internet]. 2005 [cited 2017 Oct 16];15(4):671–8. Available from: http://www.ncbi.nlm.nih.gov/pubmed/16259492

94. Schmitt A, Gahr A, Hermanns N, Kulzer B, Huber J, Haak T. The Diabetes Self-Management Questionnaire (DSMQ): development and evaluation of an instrument to assess diabetes self-care activities associated with glycaemic control. Health Qual Life Outcomes. 2013 Jan;11(1):138.

95. Polonsky WH, Fisher L, Earles J, Dudl RJ, Lees J, Mullan J, Jackson RA. Assessing psychosocial distress in diabetes: development of the diabetes distress scale. Diabetes Care. 2005;28(3):626–31.

96. El Achhab Y, Nejjari C, Chikri M, Lyoussi B. Disease-specific health-related quality of life instruments among adults diabetic: A systematic review. Diabetes Res Clin Pract. 2008;80(2):171–84.

97. Magwood G, Zapka J, Jenkins C. A Review of Systematic Reviews Evaluating Diabetes Interventions: Diabetes Educ. 2008;34(2):242–65.

98. Grant RW, Cagliero E, Chueh HC, Meigs JB. Internet Use Among Primary Care Patients with Type 2 Diabetes. J Gen Intern Med. 2004;02114:470–3.

99. Grant RW, Cagliero E, Sullivan CM, Dubey AK, Estey GA, Weil EM, Gesmundo J, Nathan DM, Singer DE, Chueh HC, Meigs JB. A controlled trial of population management: diabetes mellitus: putting evidence into practice (DM-PEP). Diabetes Care [Internet]. 2004 Oct 1 [cited 2017 Oct 16];27(10):2299–305. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15451891

100. Hecht B, Teevan J, Morris MR, Liebling D. SearchBuddies: Bringing search engines into the conversation [Internet]. 2012 [cited 2017 Oct 16]. Available from: https://www.scholars.northwestern.edu/en/publications/searchbuddies-bringing-search-engines-into-the-conversation

101. Anderson RM, Funnell MM, Butler PM, Arnold MS, Fitzgerald JT, Feste CC. Patient empowerment. Results of a randomized controlled trial. Diabetes Care. 1995;18(7):943.

102. Fisher L, Glasgow RE, Mullan JT, Skaff MM, Polonsky WH. Development of a brief diabetes distress screening instrument. Ann Fam Med [Internet]. 2008 May 1 [cited 2017 Oct 16];6(3):246–52. Available from: http://www.annfammed.org/cgi/doi/10.1370/afm.842

103. Aranyi G, van Schaik P. Testing a model of user-experience with news websites. J Assoc Inf Sci Technol. 2016;67(7):1555–75.

104. Yang Z, Cai S, Zhou Z, Zhou N. Development and validation of an instrument to measure user perceived service quality of information presenting Web portals. Inf Manag [Internet]. 2005 May [cited 2017 Oct 16];42(4):575–89. Available from: http://linkinghub.elsevier.com/retrieve/pii/S0378720604000734

105. Phillips BK, Prybutok VR, Peak DA. Decision confidence, information usefulness, and information seeking intention in the presence of disconfirming information. Informing Sci. 2014;17(1):1–24.

106. Silverstri GA, Vachani A, Whitney D, Elashoff M, Smith KP, Ferguson JS, Parsons E, Mitra N, Brody J, Lenburg ME, Spira A. A Bronchial Genomic Classifier for the Diagnostic Evaluation of Lung Cancer. N Engl J Med. 2015;373:343–51.

107. American Diabetes Association. A1C and eAG. [Internet]. 2014 [cited 2017 Sep 1]. Available from: http://www.diabetes.org/living-with-diabetes/treatment-and-care/blood-glucose-control/a1c//

108. Cleveland Clinic. Vital Signs [Internet]. 2014 [cited 2017 Sep 1]. Available from: https://my.clevelandclinic.org/health/articles/vital-signs

109. HealthIT.gov. Improving Blood Pressure Control for Patients with Diabetes in 4 Community Health Centers [Internet]. 2013 [cited 2017 Sep 1]. Available from: https://www.healthit.gov/providers-professionals/improving-blood-pressure-control-patients-diabetes-4-community-health

110. Strauss A, Corbin J. Basics of Qualitative Research. Vol. 29. Sage Publications, Inc.; 2008. p. 382.

111. Shaw RJ, Johnson CM. Health Information Seeking and Social Media Use on the Internet among People with Diabetes. Online J Public Health Inform [Internet]. 2011 [cited 2017 Oct 26];3(1). Available from: http://www.ncbi.nlm.nih.gov/pubmed/23569602

112. Seidman JJ, Steinwachs D, Rubin HR. Design and testing of a tool for evaluating the quality of diabetes consumer-information Web sites. J Med Internet Res [Internet]. 2003 Nov 27 [cited 2017 Oct 26];5(4):e30. Available from: http://www.ncbi.nlm.nih.gov/pubmed/14713658

113. Fox S, Rainie L. Vital Decisions: A Pew Internet Health Report | Pew Research Center [Internet]. 2002 [cited 2017 Sep 1]. Available from: http://www.pewinternet.org/2002/05/22/vital-decisions-a-pew-internet-health-report/

114. Patel N, Savani K, Klemmer SR, Parikh TS, Dave P. Power to the Peers : Authority of Source Effects for a Voice-based Agricultural Information Service in Rural India Categories and Subject Descriptors. Inf Technol Int Dev. 2013;9(2):81–93.

115. Bekker H, Thornton JG, Airey CM, Connelly JB, Hewison J, Robinson MB, Lilleyman J, MacIntosh M, Maule AJ, Michie S, Pearman AD. Informed decision making: an annotated bibliography and systematic review. Health Technol Assess (Rockv) [Internet]. 1999;3(1):168. Available from: http://discovery.ucl.ac.uk/15902/1/15902.pdf

116. Donovan JL. Patient decision making. The missing ingredient in compliance research. Int J Technol Assess Health Care [Internet]. 1995;11(3):443–55. Available from: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=7591546

117. Tandel K. Sugar substitutes: Health controversy over perceived benefits. J Pharmacol Pharmacother. 2011;2(4):236–43.

118. Mühlhauser I, Berger M. Evidence-based patient information in diabetes. Diabet Med. 2000;17(12):823–9.

119. Paterson B, Sloan J. A phenomenological study of the decision-making experience of individuals with long-standing diabetes. Can J diabetes care. 1994;18:10–9.

120. Burke M, Joyce E, Kim T, Anand V, Kraut R. Introductions and Questions: Rhetorical Strategies that Elicit Response in Online Communities. [cited 2017 Oct 27]; Available from: http://repository.cmu.edu/hcii

121. Beenen G, Ling K, Wang X, Chang K, Frankowski D, Resnick P, Kraut RE. Using Social Psychology to Motivate Contributions to Online Communities. 2004 [cited 2017 Oct 27]; Available from: http://repository.cmu.edu/hcii

122. Ludford PJ, Cosley D, Frankowski D, Terveen L. Think different: increasing online community participation using uniqueness and group dissimilarity. In: Proceedings of the 2004 conference on Human factors in computing systems - CHI '04 [Internet]. New York, New York, USA: ACM Press; 2004 [cited 2017 Oct 27]. p. 631–8. Available from:

http://portal.acm.org/citation.cfm?doid=985692.985772

123. Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. Psychol Rev. 1977;84(2):191–215.

124. Van Dinther M, Dochy F, Segers M. Factors affecting students' self-efficacy in higher education. Vol. 6, Educational Research Review. 2011. p. 95–108.

125. Hersh WR, Weiner MG, Embi PJ, Logan JR, Payne PR, Bernstam EV, Lehmann HP, Hripcsak G, Hartzog TH, Cimino JJ, Saltz JH. Caveats for the use of operational electronic health record data in comparative effectiveness research. Med Care [Internet]. 2013 Aug [cited 2017 Oct 26];51(8 Suppl 3):S30-7. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23774517

126. Weiskopf NG, Weng C. Methods and dimensions of electronic health record data quality assessment: enabling reuse for clinical research. J Am Med Informatics Assoc [Internet]. 2013 Jan 1 [cited 2017 Oct 26];20(1):144–51. Available from: https://academic.oup.com/jamia/article-lookup/doi/10.1136/amiajnl-2011-000681

127. Weiner MG, Embi PJ. Toward Reuse of Clinical Data for Research and Quality Improvement: The End of the Beginning? Ann Intern Med [Internet]. 2009 Sep 1 [cited 2017 Oct 26];151(5):359. Available from: http://annals.org/article.aspx?doi=10.7326/0003-4819-151-5-200909010-00141

128. Mussweiler T, Posten AC. Relatively certain! Comparative thinking reduces uncertainty. Cognition. 2012;122(2):236–40.