ABSTRACT

Title of Dissertation: “IT’S TOO EXHAUSTING GOOGLING 50 THINGS!”: RECOMMENDATIONS FOR THE LOW-FIDELITY DESIGN OF A CROWDSOURCED HEALTH INFORMATION SYSTEM WITH LOCAL HEALTH-RELATED RESOURCES FOR INDIVIDUALS WHO HAVE CHRONIC HEALTH CONDITIONS

Gagan Jindal, Doctor of Philosophy, 2020

Dissertation directed by: Dr. Beth St. Jean, Associate Professor
College of Information Studies

Individuals who have chronic health conditions often encounter considerable barriers when trying to find out about local resources in their communities (e.g. libraries, senior centers, fitness classes, nutrition services, faith-based services, support groups, etc.) that can help them better manage their health. In this dissertation, I outline a series of three studies investigating the acceptability and optimal content and design of an online health information system to streamline this information-seeking process with a crowdsourced repository of information of local health resources for this population. I initially conducted 15 in-depth semi-structured interviews to assess the strategies used, and the challenges faced, by these individuals in their attempts to identify these types of local resources in their communities (Chapter 2). The evidence from this first study suggested the potential for the uptake of a novel online health

information system that will rely on users to crowdsource and maintain an up-to-date repository of information on relevant local health resources. Based on the results of my first study, I conducted a second study using a card-sorting method to determine the system functions and features, as well as the types of information, individuals who have chronic health conditions felt they would need in this type of system to find a useful local resource and then determine if that local resource would be useful for them (Chapter 3). Based on the results of this card-sorting study, I developed a series of low-fidelity wireframes representing the system features and functions and types of content my study 2 participants wished to see in the proposed crowdsourced health information system (CHIS). I then further refined these low-fidelity wireframes drawing on the findings from my third study in which I garnered direct feedback on the initial wireframes from individuals who have chronic health conditions in a series of participatory design sessions, enabling me to finalize the design recommendations for the proposed CHIS (Chapter 4). Finally, I conclude (Chapter 5) with an overview of the overarching contribution of this research, illuminating a crucial unmet information need and proposing an actionable strategy to better meet this need. I also propose opportunities for future research to further improve the uptake of the proposed CHIS.

“IT’S TOO EXHAUSTING GOOGLING 50 THINGS!”: RECOMMENDATIONS FOR THE LOW-FIDELITY DESIGN OF A CROWDSOURCED HEALTH INFORMATION SYSTEM (CHIS) WITH LOCAL HEALTH-RELATED RESOURCES FOR INDIVIDUALS WHO HAVE CHRONIC HEALTH CONDITIONS

by

Gagan Jindal

Dissertation submitted to the Faculty of the Graduate School of the
University of Maryland, College Park, in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2020

Advisory Committee:
  Professor Beth St. Jean, Ph.D., Chair
  Professor Paul Jaeger, Ph.D.
  Professor Kari Kraus, Ph.D.
  Professor Amanda Lazar, Ph.D.
  Professor Shannon Jette, Ph.D.

Dedication

To my parents, Surendar Jindal and Tripta Jindal, who have loved me, cared for me, and sacrificed so much for me, to give me so many incredible opportunities in learning and in life.

Acknowledgements

I would first like to express my sincere gratitude to my advisor, Dr. Beth St. Jean, whose immeasurable support during my time in this doctoral program, made the research presented in this dissertation possible. I am incredibly grateful for her consistent enthusiasm and kindness throughout this demanding process. Her instruction and guidance over these past four years have prepared me to confidently take advantage of new opportunities in my future as a skilled qualitative researcher. I would also like to thank the other members of my committee – Professors Paul Jaeger, Kari Kraus, Amanda Lazar, and Shannon Jette for their valuable time and advice. Their assistance throughout this dissertation was critical to grounding the theory, methodology, and implementation of this work. Additionally, I would like to extend my deepest appreciation to the 56 individuals who agreed to participate in my dissertation research for their willingness to share their time and experiences with me. Finally, I would like to thank all of my family and friends for their encouragement and belief in me as I conducted this research.

Table of Contents

Chapter 1: Introduction

The central focus of this research is the information behavior of adults who have chronic health conditions. Specifically, this work investigates this population's information needs and seeking related to identifying local health-related resources (e.g., community centers, libraries, faith-based services, support groups, local businesses, etc.) that can help them to manage their health, with the aim of developing a strategy to better meet this information need. This dissertation consisted of three interconnected studies, including (1) in-depth, semi-structured interviews (N = 15); (2) an online, card-sorting study (N = 31); and (3) participatory design sessions (N = 10).

The interview study (Chapter 2) in this dissertation sought to assess the existing strategies that individuals who have chronic health conditions use to find information on local resources and the successes and challenges they have encountered in this process. This initial study also examined whether this population would be willing to crowdsource information on local resources in an online health information system that would serve as an online repository. The results of the initial interview study indicated that participants would be amenable to using a crowdsourced health information system (CHIS) to share information on local health-related resources; however, it also became apparent that the design of the proposed system, as well as the types of information it housed, would be critical to its uptake.

Therefore, drawing on the previous study, I conducted an online, card-sorting study (Chapter 3) with another group of adults who have chronic health conditions to assess the ideal system features and functions and types of information on local resources for the proposed CHIS in order to ensure the system's usability and usefulness for potential users. The cards representing the types of information and the various system feature and functions were developed based directly on input from participants during the interview study. After completing the card-sorting study, I drew on my findings from this second study to develop an initial set of five low-fidelity paper wireframes that represented the proposed system, incorporating the types of information and system functions and features that participants had indicated would be the most valuable for them.

For my third study (Chapter 4), I conducted ten participatory design sessions with individuals who have chronic health conditions in order to finalize the design of the low-fidelity paper wireframes representing the proposed CHIS. The participatory design sessions allowed me to probe participants and discuss the necessary changes to the design of the system in the context of each participant's own personal experiences managing their chronic health conditions. The results of this study informed the revisions to each of the initial low-fidelity, paper wireframes representing the proposed CHIS and the final design recommendations for the system.

Each study in my dissertation research was designed to carefully build on the results of the previous study, iteratively informing and improving the design recommendations for the ideal low-fidelity design of the proposed CHIS. The findings from this study provide evidence that individuals who have chronic health conditions want (and can benefit from) information on local health-related resources, but that they often encounter challenges in finding this type of information. This research contributes an actionable strategy (grounded in the results of direct collaboration with this population) to meet this information need and optimize their ability to seek out this information through the proposed CHIS. This research also highlights this population's need for information on local health-related resources and a better mode of delivery. Relevant stakeholders in the healthcare and technology sectors may also be able to benefit this population by further leveraging my findings. Drawing on an exploratory study involving 15 semi-structured in-depth interviews with individuals who have chronic health conditions, this study investigates their experiences searching for information on local resources to manage their health more effectively. The findings revealed important benefits and challenges of the various strategies these individuals use to find local resources, which include word of mouth communication through informal social networks, online exploratory searches, and social media use. This study also assesses the potential uptake, design, and implementation of an online health information system that would allow these individuals to crowdsource information on local resources in their communities.

Background

Chronic illness is one of the leading causes of death and disability in the United States, with 45 percent of adults managing at least one chronic illness, and 1 in 4 Americans diagnosed with two or more chronic health conditions concurrently (Raghupathi & Raghupathi, 2018). Successfully managing one or more chronic health conditions can be a complicated, multi-step process requiring long-term maintenance. Individuals who have multiple chronic health conditions can have even more difficulty managing their health, since they are often coping with multiple complex treatment regimens. Individuals who have one or more chronic health conditions often have difficulty making the necessary lifestyle changes to manage their health without substantial instrumental support (e.g., nutritional counseling, group fitness instruction, support groups, faith-based activities, etc.). Traditional clinical care and health education are critical components of chronic illness care, but tangible and sustained support to actively make and maintain daily lifestyle changes is equally important for these individuals (Dwarswaard, Bakker, van Staa, & Boeije, 2015).

Unfortunately, it is often infeasible for healthcare professionals to provide this kind of support to individuals who have chronic health conditions due to limitations of the scope of traditional clinical care practice (Kennedy et al., 2014). Healthcare delivery in the United States tends to be highly siloed and decentralized, with providers focusing primarily on one chronic health condition, with limited communication and patient management to coordinate care and provide more holistic assistance for patients who have multiple chronic health conditions (Institute of Medicine, 2001; Koch, Wakefield, & Wakefield, 2015; Parekh, Goodman, Gordon, Koh, & HHS Interagency Workgroup on Multiple Chronic Conditions, 2011). Leveraging community resources to help individuals who have one or more chronic health conditions to manage their health may be a more practical solution. The Chronic Care Model (CCM) is an evidence-based framework to systematically improve chronic disease management by modifying six major components of health care delivery: (1) health system; (2) self-management support; (3) clinical decision support; (4) delivery system design; (5) clinical information system; and (6) community resources and policy. Specifically, the CCM emphasizes the importance of empowering patients to manage their health by mobilizing community resources to provide them with ongoing support in addition to facilitating clinically-based solutions (Improving Chronic Illness Care, 2018; Wagner, Austin, &, Von Koroff, 1996). Despite this emphasis, a systematic review of the application of the CCM to primary care settings in the United States revealed that the majority of these practices do not describe tactics for incorporating community strategies and policies into patient care. This indicates a major limitation in the application of the CCM to existing chronic illness care (Stellefson, Dipnarine, & Stopka, 2013).

Although many interventions centered around the CCM still have significant gaps, there are other types of interventions that have aimed to connect individuals who have chronic health conditions to local resources in their communities. Programming involving community resource mapping has focused on identifying and connecting individuals to local assets in the form of libraries, senior centers, faith-based services, support groups, local businesses, and more through consistently updated repositories of information (Green & Haines, 2002; Kretzmann & McKnight, 1993). Related interventions have relied on trained information professionals, such as librarians and patient navigators, to identify and recommend useful local resources for individuals who have chronic health conditions (Lopez et al., 2019; Loskutova et al., 2016; Port et al., 2015). However, despite the successes of many of these types of interventions, they can be challenging to sustain and/or expand due to resource constraints (Green & Haines, 2002; Klein, 2010).

Online interventions focused on connecting individuals to local resources can potentially circumvent some of the limitations associated with more resource-intensive programs. Tung and Peek (2015) describe several interventions that leverage technology to help individuals with diabetes access useful local resources in their communities, through programs that provide nutritional counseling, fitness services, clinical care, and more. City Health Works, for example, focuses on using mobile decision-support applications to connect patients to its community partners in East Harlem, New York based out of fitness centers, yoga studios, faith-based organizations, etc. in the area (Bachrach et al., 2014). TXT2BFiT, a mobile phone-based program based in Australia, provides opportunities for community members to access immediate options for physical activity in a community blog based on the goals they post in their comments and questions (Hebden et al., 2013). The Southeastern Diabetes Initiative, led by the Informatics Department at Duke University, offers an online diabetes-specific listing of resources related to dental care, nutrition, cooking, physical activity, food assistance, transportation, housing, etc. to patients in Cabarrus County, North Carolina (Cabarrus Wellness Coalition, 2014). These are only a few examples of a multitude of programs focused on helping individuals who have chronic health conditions make the necessary lifestyle modifications to improve their health with the help of local resources in their communities.

Despite the benefits of many of these internet-based interventions, they also have several limitations. The majority of these types of interventions tend to focus specifically on only one health condition and/or are based in only one locality, as necessitated by funding sources, staff expertise, existing partnerships with local resources, and other related factors. Additionally, even these types of successful consumer health programs must provide rigorous evidence for the cost-effectiveness of these types of interventions to enable wider scale implementation through more traditional funding outlets, such as hospitals and insurance companies. Evaluating the direct impact of these types of local resources on measurable benchmarks valuable to these types of outlets can be difficult given the complex nature of chronic illness management. Therefore, the potential for expansion is often limited and still leaves a substantial proportion of individuals who have one or more of a wide range of different types of chronic health conditions with few options to find useful information on local health resources in their communities. (Araújo-Soares, Hankonen, Presseau, Rodrigues, & Sniehotta, 2019; Miller, Lasiter, Ellis, & Buelow, 2015; Tung & Peek, 2015).

Due to the limitations of these existing interventions, programs, and tools, many individuals who have chronic health conditions have continued to rely on word of mouth (WOM) recommendations to find information on useful local resources in their communities. However, the geographic challenges around synchronous communication often limit the usefulness of this mode of information sharing. Electronic word of mouth (eWOM) can overcome some of the limitations of traditional WOM communication (Martin, 2017). Social media, in particular, has become an important space for individuals who have chronic health conditions to share details about healthcare providers and other relevant types of information (Bateman et al. 2017; Greene et al. 2011; Lober and Flowers 2011; Moorhead et al. 2013). Crowdsourcing information on local health-related resources could be a powerful tool for connecting this population with these services that can help them to manage their health (Brabham 2013). But eWOM communication has its own set of limitations, with much of the crowdsourced information on these platforms focusing only on clinical resources (e.g., hospitals) and being spread across many different online platforms (Martin, 2017, Synnot et al. 2016; Van Velsen, Beaujean, & van Gemert-Pijnen 2013). Additionally, many individuals do not trust eWOM recommendations in the same way they do WOM recommendations from their family, friends, and acquaintances (Huete-Alcocer, 2017).

As a result of the limitations of existing interventions, platforms, and methods, people who have chronic health conditions still do not have a systematic way to crowdsource trustworthy and detailed information on a diverse range of local health-related resources. This research will focus on exploring opportunities to help meet this information need to help this population better leverage highly valuable community assets to more effectively manage their chronic health conditions.

Problem Statement

Effective self-management is essential for individuals who have chronic health conditions, but adhering to and maintaining a multilayered treatment and management regimen can be exceptionally difficult (Adu, Malabu, Malau-Aduli, & Malau-Aduli, 2019). Multidisciplinary care with support from a range of health professionals and other types of community services can potentially enhance this population's ability to self-manage their health (Byers, Garth, Manley, & Chlebowy, 2016; Coleman & Newton, 2005; Dwarswaard, Bakker, van Staa, & Boeije, 2015; Jones, Crabb, Turnbull, & Oxlad, 2014). However, the ability to find and utilize these types of resources is an important part of self-management support that is unfortunately often overlooked in health promotion and education (Lorig & Holman, 2003).

Relatedly, comprehensive research into this population's needs, successes and barriers around seeking out information on a diverse range of local health-related resources to help them self-manage their health by leveraging community assets is scant. The limited insight into this information need presents a challenge for the researchers and practitioners who work with this population. The existing data is insufficient to guide the design and development of a viable intervention or tool to help individuals who have chronic health conditions to access this specific type of information.

This research attempts to address this gap by focusing specifically on the information needs of individuals who have chronic health conditions, with an emphasis on their need for information on local health-related resources in their communities that can help them to manage their health. This investigation assesses the experiences and needs of individuals who have chronic health conditions with regard to finding information on local resources in their communities and builds on this data to propose and design a technological solution to help these individuals better meet this information need. The findings from this research have the potential to help researchers and practitioners who work with this population to better understand this specific information need and an ideal design to actually implement an actionable solution (informed directly by individuals who have chronic health conditions) to fulfill this information need.

Objectives

I conducted three distinct studies for this research, and the overarching goals for this work are as follows: (1) To investigate the experiences of individuals who have chronic health conditions as they search for information on health-related local resources and to determine whether this population feels that a proposed crowdsourced health information system (CHIS) that would act as a repository for information on local resources would help them better meet this information need as compared to their existing strategies; (2) To assess the types of information and the system functions and features this population needs in order to find a useful local resource in the proposed CHIS and to propose an initial low-fidelity design for the system; and (3) To revise and finalize the design recommendations for the proposed CHIS based on direct feedback from participants who have chronic health conditions.

Research Questions

The specific overarching research questions and sub-research questions driving each study in this dissertation are:

Study 1: Assessing the value of an online repository of local resources for people who have chronic health conditions (Jindal, 2019).

RQ1: How do individuals who have chronic health conditions search for information on local health-related resources and how useful would this population find a proposed crowdsourced health information (CHIS) that would serve as a repository for this information?

1a. What strategies have individuals who have chronic health conditions used to seek out local resources in their communities to help them to manage their health conditions?;

1b. How have individuals successfully identified local resources in their communities to help them to manage their chronic health conditions?;

1c. What barriers have individuals encountered in trying to identify local resources to manage their chronic health conditions?; and

1d. How do individuals who have chronic health conditions feel about the potential usefulness of a CHIS to help them discover and share local resources in their communities?

Study 2: An online card-sorting study to inform the initial low-fidelity design of a crowdsourced health information system for individuals who have chronic health conditions seeking local health-related resources (Jindal, 2020).

RQ2: What types of information, functions and features do individuals who have chronic health conditions need in the proposed crowdsourced health information (CHIS) to make it useful for them?

2a. What types of system functions and features do individuals who have chronic health conditions need in order to find relevant resources in their local communities that will be useful for them?; and

2b. What types of information do individuals who have chronic health conditions need in order to assess whether a relevant resource in their local community will be useful for them?

Study 3: Design recommendations for a crowdsourced health information system with local health-related resources: A participatory design study.

RQ3: What is the ideal final low-fidelity design for the proposed crowdsourced health information (CHIS)?

3a. How useful do participants find the system's proposed functions and features?;

3b. How usable do participants find the system's proposed functions and features?;

3c. How useful do participants find the various types of information on each local resource in helping them to determine whether it would be relevant and useful for them in managing their chronic health condition(s)?;

3d. What changes do participants recommend to improve the content and design of the proposed system?; and

3e. How should the initial wireframes be adjusted based on the findings from the co-design sessions?

Methods

Study 1: Assessing the value of an online repository of local resources for people who have chronic health conditions.

The first study in this dissertation consisted of qualitative, in-depth, semi-structured interview sessions with 15 adults who have one or more chronic health conditions. I recruited participants using both convenience and snowball sampling by sending out an email explaining the details of the study to several University-related listservs, as well as several chronic illness-focused Meetup groups and health professionals in the Washington D.C. metropolitan area. I also requested that recipients forward the recruitment email to any other potentially interested individuals. I conducted the interviews both in-person and remotely by phone, Skype, and Google Hangouts. Incorporating remote modes of communication allowed me to recruit a more diverse sample for the study. The interviews took place over eight months, lasting between 25 and 58 minutes and averaging 43 minutes.

Before each interview, I also collected basic demographic data and background information about participants' computer/smartphone/Internet access and use. Each participant then responded to a series of questions regarding their strategies and experiences searching for information on health-related local resources and the successes and barriers they encountered in this process. After describing their own experiences searching for local resources, participants were asked to describe any idealized technologies, tools, features, etc. (whether they currently existed or not) that would enable them to find this information more easily and whether they felt a crowdsourced health information system (CHIS) might potentially improve the process. After completing the interviews, I had approximately 10 hours and 30 minutes of audio recording, which I had transcribed. I then reviewed, coded and analyzed the interviews using a general inductive approach to understand the common themes that emerged from the data to assess the strategies, successes, and barriers participants described with regard to finding information on local resources and the potential value of a proposed CHIS.

Study 2: An online card-sorting study to inform the initial low-fidelity design of a crowdsourced health information system for individuals who have chronic health conditions seeking local health-related resources.

I conducted an online, closed card-sorting using Qualtrics for the second study in this dissertation research. I asked participants to rank possible types of information and system functions and features to inform the design recommendation for a proposed CHIS that would serve as a repository of information on health-related local resources. The cards I developed for this card-sorting study were based on the types of information and system functions and features participants from my interview study indicated would be useful for them. Participants were recruited using convenience sampling with an email that was sent out through several University-related listservs. Recipients were also asked to forward the recruitment email to other potential participants.

A total of 31 participants completed the online card-sorting study. After completing the background questionnaire, participants responded to two decks of cards. The first deck included a range of possible system functions and features (e.g., keyword search, filters, etc.) for the proposed CHIS, and the second deck included several possible types of information (e.g., location, cost, reviews, ratings, etc.) on a local resource that could be included in the design of the proposed CHIS. Participants sorted the cards in each of the decks into one of five categories – very useful, somewhat useful, neutral, not very useful, or not at all useful. I also allowed participants to fill in "Other" (fill-in-the-blank) cards to recommend any additional novel types of information, functions, and/or features for the proposed CHIS.

To analyze the data collected, Qualtrics was used to run a results matrix to determine the number of times each card was sorted into each category. I used the results to design the first five initial low-fidelity wireframes for the proposed CHIS: (1) landing page; (2) adding a local resource; (3) rating and reviewing a local resource; (4) filtering search results; and (5) user profile. I included a system feature or function in the design of each wireframe if the majority of participants (more that 50 percent) indicated that it was either very useful or somewhat useful to them in the card-sorting study. Similarly, I included a type of information in the design of each wireframe if the majority (more than 50 percent) of participants indicated it would be useful to them. Only six participants suggested any additional "Other" system functions and features and/or types of information, so it was not possible to make any additions to the wireframes based on these responses.

Study 3: Design recommendations for a crowdsourced health information system (CHIS) with local health-related resources for individuals who have chronic health conditions: A participatory design study.

The third (and last) study in this dissertation was a participatory design study with 10 adult participants who have one or more chronic health conditions. Participants were recruited through an email sent out through several University-related listservs. Also, recipients of this email were asked to forward it to other potential participants who might be interested in the study. Individuals who met the inclusion criteria (i.e., adults 18 years and older who had at least one chronic health condition and had searched for local resources to manage their health) were scheduled for an in-person, one-on-one participatory design session where they were asked to give their feedback on the five low-fidelity wireframes representing the proposed CHIS (initially designed in the previous card-sorting study). I gave participants a brief description of each paper wireframe and asked them to discuss (and critique) how useful and usable they felt the system functions, features, and types of information would be for them based on their own experiences managing their chronic health conditions.

Participants were encouraged to write, sketch, draw, cut, and add to the wireframes to elucidate their thoughts throughout the participatory design sessions. They also received empty smartphone outlines to give them the freedom to describe their needs beyond the existing designs. After completing the participatory design sessions, I had about 11 hours and 11 minutes of audio recording transcribed. I reviewed, coded and analyzed the transcripts and design products from the sessions. Then, I revised and finalized the five low-fidelity wireframes representing the proposed CHIS and made my final design recommendations based on the major themes that emerged from the data, keeping in mind the respective relevance, feasibility, and appropriateness for a first iteration design of an information system.

Theoretical Orientation

Information foraging theory, which is originally rooted in optimal foraging theory from the field of behavioral ecology, provides a framework to predict and understand how individuals strategize and adapt to seek and handle information, particularly in today’s environment of information overload. As information is now largely readily available, the challenge has become how to direct individuals’ attention to the sources and information that are most relevant and valuable to them.

Information foraging theory is a natural fit for this study in that it also focuses on understanding individuals' information behavior and applying this understanding to the design and development of new technologies that can potentially improve individuals' interactions with information (Pirolli, 2009). Pirolli and Card (1999) applied a biological understanding of hunting and feeding strategies to information behavior. They posited that individuals make a cost-benefit assessment, weighing the potential gains from continuing to search for information in an "information patch" (e.g., a website) against the amount of time they will have to invest in that specific information patch. Generally, in optimal foraging theory, the energy acquired from a food source should be greater than the energy expended to procure that food source. Similarly, in information foraging theory, individuals must determine the usefulness (or potential value) of staying in an information patch against the amount of time it will take to extract that information. This theory explains why individuals do not want to endlessly scroll through their search options or click on every link they might be presented in a search query. Rather, an individual will try to get as much useful information as possible in the shortest amount of time (Budiu, 2019).

The exponential amount of information on the internet can make it infeasible for an individual to make a completely accurate estimate about the true value of every potential information patch. The information overload encountered in this process means it is incredibly difficult for an individual to effectively assess every possible information patch from the limited cues they initially have on each website. These initial cues are usually only a remote representation (e.g., link label, summary text, image) of each website (Budiu, 2020). Pirolli and Card (1999) describe the concept of an “information scent,” which refers to how an individual might use these cues (and any prior knowledge about an information source) as a guide to reach a promising information patch. These individuals will use “information scent” to gauge the potential value of an information source with limited context. However, information scent is often imperfect, and individuals rarely follow a linear trajectory directly to a high-value information source.

Drawing on information foraging theory for this work, this dissertation posits that it is possible to optimize the information seeking process for individuals who have chronic health conditions to help them effectively and efficiently meet their need for information on local resources that can help them to manage their health. This research demonstrates that participants often have difficulty “scenting” useful information patches with local resources. The proposed crowdsourced health information system (CHIS) described in this research presents an opportunity to create an enhanced information patch through careful design, which links information on local resources into one common repository. The information patch proposed in this dissertation would reduce the time users need to spend foraging between-patch (i.e., searching several different websites or information systems for the same information), and allow them to focus their limited time and attention on a single, specialized information system. Furthermore, the types of information, functions, and/or features in this proposed CHIS will improve users’ ability to “scent” potentially valuable local resources in their communities by providing highly customized cues designed specifically based on the previous experiences of members of this population as they searched for this type of information. Therefore, the time spent foraging within-patch (i.e., searching a single website or system for useful information) would also be reduced for potential system users.

Nielsen (2003) explains that Pirolli and Card's (1999) information foraging theory emphasizes that an information "predator" is generally dually focused on an "easy catch" and a "nutritious meal." Achieving the highest calorie count with minimum effort is an ideal situation for the optimal diet. Relatedly, the low-fidelity design of the proposed CHIS resulting from this research focuses on ensuring that future users of the system will have access to highly "nutritious" information, as it will include information on local resources that other users with chronic health conditions have used and have found sufficiently valuable to expend their effort to add it to the system. The design of the system also focuses on ensuring an "easy catch" by ensuring the "scent" to useful local resources is strong. The proposed CHIS has the necessary system functions and features to help users quickly find a local resource, as well as the types of information (or cues) they need to quickly assess whether a particular local resource will be useful for them. The needs of the modern informavore (i.e., an individual who seeks and assesses information, with the goal of gathering and acting on information that will enable them to optimally adapt to their environment) are central to the design of the proposed CHIS described in this research.

Significance

This research illuminates and describes a crucial unmet information need among individuals with chronic health conditions, who often lack awareness of both clinical and non-clinical resources located in their communities that can help them to better manage their health. Further, this research provides an actionable solution to meet this information need by informing the low-fidelity design of a crowdsourced health information system (CHIS) to streamline this population’s access to this type of information. Overall, my findings indicate that individuals who have chronic health conditions could substantially benefit from a system that enables them to retrieve and share information on local resources in their communities to help them more effectively manage their health. However, my interview study revealed that participants often rely more heavily on word of mouth for this information because they encounter substantial difficulty finding this information on the Internet. I found that participants are willing to consider new alternatives that can streamline and standardize their access to information on local health-related resources online; however, they emphasized that the proposed CHIS must be carefully designed in order to be a viable solution for them. My card-sorting study and participatory design study garnered direct feedback from participants on the ideal system functions and features and types of information the system will need to contain, in order to ensure the system’s usefulness and usability. Thus, the proposed system was designed for and with individuals who have chronic health conditions. To my knowledge, this stream of research comprises the very first set of studies that focus on exploring this particular information need among people who have chronic health conditions and working with this population to devise an optimal strategy to help fulfill this important need.

Structure of the Dissertation

The following three sections of the dissertation are comprised of my three published articles. In Chapter 2, my first study investigates the experiences of individuals who have chronic health conditions searching for information on local health-related resources and their willingness to use a proposed crowdsourced health information system (CHIS) to optimize their access to this information. The results of this semi-structured in-depth interview study were published in May 2019 in the peer-reviewed journal, *Journal of Consumer Health on the Internet*, which focuses on research at the intersection of consumer health information, patient education, and health literacy. In Chapter 3, my second study uses online card-sorting to assess how usable and useful participants find several possible types of information and system functions and features, aiming to inform the initial low-fidelity design of the proposed CHIS. The findings from this online, card-sorting study were published in April 2020 in the peer-reviewed journal, *Human Behavior and Emerging Technologies*, which focuses on the complex interactions between human behavior and emerging digital technologies. In Chapter 4, my third study employs participatory design to finalize the low-fidelity design recommendations for the proposed CHIS based on direct feedback from individuals who have chronic health conditions. The manuscript covering this last study is currently under consideration for publication in the journal, *Library Hi Tech*, which is broadly concerned with topics related technology-assisted information management and systems. Finally, in Chapter 5, I conclude this dissertation by summarizing the contributions of this work and discussing future next steps.

References

1. Adu, M.D., Malabu, U.H., Malau-Aduli, A., & Malau-Aduli, B.S. (2019). Enablers and barriers to effective diabetes self-management: A multi-national investigation. *PloS One, 14*(6), e0217771.
2. Araújo-Soares, V., Hankonen, N., Presseau, J., Rodrigues, A., & Sniehotta, F. F. (2019). Developing behavior change interventions for self-management in chronic illness: An integrative overview. *European Psychologist, 24*(1), 7-25.
3. Bachrach D, Pfister H, Lipson M, and Manatt Health Solutions. (2014). Addressing patients' social needs: an emerging business case for provider investment. The Commonwealth Fund. Retrieved from: http://www.commonwealthfund.org/~/media/files/publications/fundreport/2014/may/1749_bachrach_addressing_patients_social_needs_v2.pdf.
4. Bateman, D.R., Brady, E., Wilkerson, D., Yi, E.H., Karanam, Y., & Callahan, C.M. (2017). Comparing crowdsourcing and friendsourcing: A social media-based feasibility study to support Alzheimer disease caregivers. *JMIR Research Protocols, 6*(4), e56.
5. Brabham, D.C. 2013. *Crowdsourcing*. Cambridge, MA: The MIT Press Essential Knowledge Series.
6. Budiu, R. (2019). Information foraging: A theory of how people navigate on the web. Nielsen Norman Group. Retrieved from: https://www.nngroup.com/articles/information-foraging/

7. Budiu, R. (2020). Information scent: How users decide where to go next. Nielsen Norman Group. Retrieved from: https://www.nngroup.com/articles/information-scent/
8. Byers, D., Garth, K., Manley, D., & Chlebowy, D.O. (2016). Facilitators and barriers to type 2 diabetes self-management. *Journal of Health Disparities Research and Practice, 9*(1), 164-174.
9. Cabarrus Wellness Coalition (2014). Cabarrus County Diabetes Resource Guide. Retrieved from: https://nc-cha.civicplus.com/DocumentCenter/View/551/Diabetes-Resource-Guide_2014-Version?bidId=.
10. Coleman, M.T. & Newton, K.S. (2005). Supporting self-management in patients with chronic illness. *American Family Physician, 72*(8), 1503-1510.
11. Dwarswaard, J., Bakker, E.J., van Staa, A., & Boeije, H.R. (2016). Self-management support from the perspective of patients with a chronic condition: A thematic synthesis of qualitative studies. *Health Expectations*, *19*(2), 194-208.
12. Green, G.P. & Haines, A. (2002). *Asset Building & Community Development*. Thousand Oaks, CA: Sage Publications.
13. Greene, J.A., Choudhry, N.K., Kilabuk, E., & Shrank, W.H. (2011). Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook. *Journal of General Internal Medicine, 26*(3), 287-292.

14. Hebden, L., Cook, A.., van der Ploeg, H.P., King, L., Bauman, A., & Allman-Farinelli, M. (2014). A mobile health intervention for weight management among young adults: a pilot randomised controlled trial. *Journal of Human Nutrition and Dietetics, 27*(4):322-332.

15. Huete-Alcocer, N. (2017). A literature review of word of mouth and electronic word of mouth: Implications for consumer behavior. *Frontiers in Psychology*, *8*:1256.

16. Institute of Medicine (US) Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st Century*. Washington D.C.: National Academies Press

17. Improving Chronic Illness Care. (2018). *The Chronic Care Model*. Retrieved from http://www.improvingchroniccare.org/.

18. Jindal, G. (2019). Assessing the value of a crowdsourced health system for information on local resources for individuals who have chronic health conditions. *Journal of Consumer Health on the Internet*, *23*(2), 123-145.

19. Jindal, G. (2020) An online card-sorting study to inform the initial low-fidelity design of a crowdsourced health information system for individuals who have chronic health conditions seeking local health-related resources. *Human Behavior and Emerging Technologies, 2*(2), 128-139.

20. Jones, L., Crabb, S., Turnbull, D., & Oxlad, M. (2014). Barriers and facilitators to effective type 2 diabetes management in a rural context: a qualitative study with diabetic patients and health professionals. *Journal of Health Psychology, 19*(3):441-453.

21. Kennedy, A., Rogers, A., Chew-Graham, C., Blakeman, T., Bowen, R., Gardner, C., Lee, V., Morris, R., & Protheroe, J. (2014). Implementation of a self-management support approach (WISE) across a health system: a process evaluation explaining what did and did not work for organisations, clinicians and patients. *Implementation Science, 9*: 129
22. Klein, L.J. (2010). NLM to discontinue support of MedlinePlus Go Local. *National Library of Medicine Technical Bulletin, 373*, e18.
23. Koch, G., Wakefield, B.J., & Wakefield, D.S. (2015). Barriers and facilitators to managing multiple chronic conditions: A systematic literature review. *Western Journal of Nursing Research, 37*(4), 498-516.
24. Kretzmann, J.P. & McKnight, J.L. (1993). *Building Communities from the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets*. Chicago, IL: ACTA Publications.
25. Lober, W.B. & Flowers, J.L. (2011). Consumer empowerment in health care amid the internet and social media. *Seminars in Oncology Nursing, 27*(3), 169-182.
26. Lopez, D., Pratt-Chapman, M.L., Rohan, E.A., Sheldon, L.K., Basen-Engquist, K., Kline, R., Shulman, L.N., & Flores, E.J. (2019). Establishing effective patient navigation programs in oncology. *Supportive Care in Cancer, 27*(6), 1985-1996.
27. Lorig. K.R. & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7.

28. Loskutova, N.Y., Tsai, A.G., Fisher, E.B., LaCruz, D.M., Cherrington, A.L., Harrington, T.M., Turner, T.J., & Pace, W.D. (2016). Patient navigators connecting patients to community resources to improve diabetes outcomes. *Journal of the American Board of Family Medicine, 29*(1), 78-89.

29. Moorhead, A., Hazlett, D.E., Harrison, L., Carroll, J.K., Irwin, A., & Hoving, C. (2013). A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of Medical Internet Research, 15*(4), e85.

30. Martin, S. (2017). Word-of-mouth in the health care sector: A literature analysis of the current state of research and future perspectives. *International Review on Public and Nonprofit Marketing*, *14*(1), 35-56.

31. Miller, W.R., Lasiter, S., Bartlett Ellis, R., & Buelow, J.M. (2015). Chronic disease self-management: a hybrid concept analysis. *Nursing Outlook, 63*(2), 154-161.

32. Nielsen, J. (2003). Information foraging: Why Google makes people leave your site faster. Nielsen Norman Group. Retrieved from: https://www.nngroup.com/articles/information-foraging-leave-site/.

33. Parekh, A.K., Goodman, R.A., Gordon, C., Koh, H.K., & HHS Interagency Workgroup on Multiple Chronic Conditions. (2011). Managing multiple chronic conditions: A strategic framework for improving health outcomes and quality of life. *Public Health Reports, 126*(4), 460-471.

34. Pirolli, P. (2009). An elementary social information foraging model. *CHI '09: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 605-614.

35. Pirolli, P. & Card, S.K. (1999). Information foraging. *Psychological Review, 106*(4), 643-675.

36. Port, K.A., Ayers, A., Crocker, W., Hart, A., Mosavel, M., & Rafie, C. (2015). Community perceptions and utilization of a consumer health center. *Journal of the Medical Library Association, 103*(1), 35-39.

37. Raghupathi, W., & Raghupathi, V. (2018). An empirical study of chronic diseases in the United States: A visual analytics approach. *International Journal of Environmental Research and Public Health, 15*(3), 431.

38. Stellefson, M., Dipnarine, K., & Stopka, C. (2013). The Chronic Care Model and diabetes management in US primary care settings: A systematic review. *Preventing Chronic Disease*, *10*, E26.

39. Synnot, A.J., Hill, S.J., Garner, K.A., Summers, M.P., Filippini, G., Osborne, R.H., Shapland, S.D.P., Colombo, C. & Mosconi, P. (2016). Online health information seeking: How people with multiple sclerosis find, assess and integrate treatment information to manage their health. *Health Expectations*, *19*(3), 727-737.

40. Tung, E.L. & Peek, M.E. (2015). Linking community resources in diabetes care: A role for technology? *Current Diabetes Reports, 15*(7), 614.

41. Van Velsen, L., Beaujean, D.J., & van Gemert-Pijnen, J.E. (2013). Why mobile health app overload drives us crazy, and how to restore the sanity. *BMC Medical Informatics and Decision Making, 13*, 23.
42. Wagner, E.H., Austin, B.T., & Von Korff, M. (1996). Improving outcomes in chronic illness. *Managed Care Quarterly*, *4*(2), 12-25.

Chapter 2: Assessing the value of an online repository of local resources for people who have chronic health conditions

This article (Chapter 2) was originally published in the *Journal of Consumer Health on the Internet*. This postprint version of the article has retained the same content, citations, and formatting of the original journal article. Please cite Chapter 2 as follows: Jindal, G. (2019). Assessing the value of an online repository of local resources for people who have chronic health conditions. *Journal of Consumer Health on the Internet, 23*(2), 123-145. Available: https://www.tandfonline.com/doi/pdf/10.1080/15398285.2019.1611171

Abstract

Drawing on an exploratory study involving 15 semi-structured in-depth interviews with individuals who have chronic health conditions, this study investigates their experiences searching for information on local resources to manage their health more effectively. The findings revealed important benefits and challenges of the various strategies these individuals use to find local resources, which include word of mouth communication through informal social networks, online exploratory searches, and social media use. This study also assesses the potential uptake, design, and implementation of an online health information system that would allow these individuals to crowdsource information on local resources in their communities.

Keywords: Chronic illness, community resources, information seeking, user research

Introduction

Online health information-seeking has become increasingly prevalent as more individuals gain access to the Internet. However, despite the increased access to, and seeking of, online health information, individuals who have chronic health conditions still have difficulty finding information online about useful local resources that can help them more effectively manage their health. This article describes an investigation into how individuals with chronic health conditions are currently looking for health information about relevant local resources and the challenges they are encountering in this process. The purpose of this study is to determine whether a crowdsourced health system that provides this type of information could potentially be a valuable resource for this population.

According to the Pew Research Center, approximately 87% of the U.S. population has access to the Internet, and 72% of these Internet users have searched for health information online. Interestingly, 26% of users who have searched the Internet for health information say they have, "…read or watched someone else's experience about health or medical issues in the last 12 months" (Fox and Duggan 2013). Although users continue to have concerns around the credibility of health information on the Internet, it has still become the primary source of health information for many patients, surpassing even healthcare providers (Haluza et al. 2017).

Health information on the Internet can encompass a wide range of sources, including evidence-based and curated information from governmental health websites, nonprofit organizations, and academic institutions. However, individuals are also increasingly finding social media to be a valuable source of health information. A systematic review on the uses, benefits, and limitations of social media for health communication revealed that although health information from social media has several limitations related to credibility, validity, and quality, it can also be a useful source of more contextual, tailored information. Health information from social media provides individuals with the opportunity to share and learn from each other's lived experiences and to transfer knowledge on useful resources that can help one to manage various health conditions (Moorhead et al. 2013).

Social media applications that generate health information based on information crowdsourced by users have, in particular, become a growing trend. Crowdsourcing is also being applied to other disaster relief efforts (Gao, Barbier, and Goolsby 2011; Yates and Paquette 2011), health and medical science (Armstrong et al. 2012; Ranard et al. 2014), public health (Brabham et al. 2014), clinical practice (Sims et al. 2016), and physician rating services (Holliday et al. 2017), among other consumer health applications (Tung and Peek 2015). However, these crowdsourced health applications are often designed specifically for the specialized needs of one population, location, health condition, event and/or context. Although components of these applications may be useful to a wider user base, their broader impact may still be limited.

A crowdsourced online health system that would allow individuals who have chronic health conditions to search for information on a diverse range of resources in their local communities may have the potential to add value on a larger scale. However, before proposing or developing a new system, it is essential to understand prospective users' illness-related experiences, as well as their information needs and information-related preferences. To this end, I conducted 15 semi-structured interviews with individuals who have chronic health conditions, aiming to address the following research questions (RQ):

RQ1: What strategies have individuals who have chronic conditions used to seek out local resources in their communities to help them to manage their health conditions?;

RQ2: How have individuals successfully identified local resources in their communities to help them to manage their chronic health conditions?;

RQ3: What barriers have individuals encountered in trying to identify local resources to manage their chronic health conditions?; and

RQ4: How do individuals who have chronic conditions feel about the potential usefulness of an online crowdsourced health information system to help them discover and share local resources in their communities?

Background

I assessed a subset of the current literature (using relevant databases such as PubMed, Google Scholar, ACM Digital Library, and Library & Information Science Source) across these four central topics in order to review the current state of the field on: (1) online health information seeking; (2) health information in social media; (3) crowdsourcing health information; and (4) searching for health information on local resources.

Online health information seeking

Individuals' motives for actively seeking out health information online can range from a desire for wellness information on health promotion and activities for maintaining a healthy lifestyle to more disease- and illness-oriented information on diagnoses, therapies, treatments, etc. (Weaver et al. 2010). The health information that individuals discover online can range from highly credible, peer reviewed, and professionally developed content from government, non-profit, and educational sources to patient-generated health information in the form of blogs and other types of social media (Tan and Goonawardene 2017). Health information seeking through social media, in particular, has rapidly increased, despite concerns around the credibility of patient-generated health information. According to the Pew Research Center, only 5% of Americans reported using at least one social media site in 2005. However, by 2016 that number had grown to 69% (Smith 2017). The increasing number of social media users has also led to the proliferation of health information on various social media outlets. Facebook, Twitter, and other social media sites have become popular sources of health information (Moorhead et al. 2013). Individuals seem to be finding this type of health information on social media useful, as a PricewaterhouseCoopers (PwC), Health Research Institute (2012) survey reported participants indicated that information from social media would impact many of their healthcare decisions, such as how they would manage a chronic health condition (41%), choosing a doctor (41%), and their approach to diet, exercise, or stress management (42%). Younger users ages 18–24 are even more likely to share health information on social media, particularly if they are in poor health, so the number of individuals using social media for health information may increase further as these younger users age (PricewaterhouseCoopers (PwC), Health Research Institute 2012).

Health information in social media

Social media has become an important resource for individuals who have chronic conditions. These individuals have become increasingly willing to share information about their health conditions and management strategies with others online through various social media outlets (Shaw and Johnson 2011; Taggart et al. 2015; Yonker et al. 2015). These individuals are crowdsourcing health information online through social media by providing and garnering both emotional and informational support from other individuals who have similar chronic health conditions. They are actively crowdsourcing their knowledge, experiences, and opinions through social media on diagnoses, treatments, healthcare providers, and a multitude of other relevant topics (Bateman et al. 2017; Greene et al. 2011; Lober and Flowers 2011; Moorhead et al. 2013).

Crowdsourcing health information

Brabham (2013, 45) describes this type of crowdsourcing as "knowledge discovery and management." He explains that individuals who have knowledge on a specialized area of interest are often best suited to collect and organize information related to that topic in a kind of online "common repository" (Brabham 2013, 45). Individuals who have chronic health conditions seem to do just this through a wide range of social media platforms, as they seek out and share highly personalized health information to more effectively manage their health. However, despite the powerfulness of this mode of information sharing and retrieval, the fragmentation of health information on the Internet, especially across many different types of social media platforms, can make it difficult for individuals to find useful information when they need it most (Synnot et al. 2016; Van Velsen, Beaujean, and van Gemert-Pijnen 2013). Having the right information at the right time is critical for individuals who have chronic conditions in order for them to effectively manage their health (Mills and Davidson 2002; St. Jean 2012). However, without an easily searchable, common repository for health information, finding the right information at the right time on the Internet can be a difficult prospect.

Searching for health information on local resources

Community asset linkage can be a powerful resource to assist individuals to manage chronic health conditions more effectively. Although the concept of community asset linkage in the context of health has varied in research and practice, it can be broadly defined as the process of connecting individuals with resources located in their communities that can provide them with some benefit in terms of managing a specific condition or their overall health. Kretzmann and McKnight (1993) originally formalized a similar concept called asset-based community development, creating a detailed roadmap for local communities to identify and harness their own communities' assets for their residents' benefit. Kretzmann and McKnight (1993) define community assets across five key areas: local residents; local voluntary associations, clubs, and networks; local institutions; physical assets; and economic assets. These assets can encompass libraries, parks, health centers, senior centers, recreation clubs, nutrition services, faith-based services, support groups, transportation options, local businesses, and a number of other types of resources. These authors stressed that identifying and mapping these resources in a community is critical to strengthening communities and creating opportunities for local residents (Kretzmann and McKnight 1993). However, resource mapping can be an intensive process, requiring significant, sustained commitment, effort, and funding (Green and Haines 2002). Despite the promising results of community asset mapping, these types of interventions remain relatively underdeveloped in most communities. For example, the National Library of Medicine was unable to continue providing support for their MedlinePlus Go Local (Go Local) initiative, which focused on connecting users to local health services in their communities through Medline Plus and their regional libraries, due to high cost of staffing and manually maintaining a collection of health services listings and associated details (e.g., users' reviews, hours, fees, etc.) (Klein 2010).

Other types of interventions focused on community asset linkage have focused on directly connecting individuals who have chronic conditions to skilled health information professionals, such as patient navigators or librarians. These programs are often highly effective, but in order for these types of programs to be successful, professionals must be knowledgeable about the availability of relevant local resources in the community. Therefore, these interventions still require an audit of the relevant organizations and services within a community, meaning these interventions are still subject to the same issues around the sustainability of maintaining an updated, common repository of community assets without indefinite funding (Loskutova et al. 2016; Ports et al. 2015).

Tung and Peek (2015) summarize and assess several innovative interventions that have incorporated technology to connect patients with community assets. These interventions include projects such as FoodRx and ExerciseRx which allow physicians to provide food and exercise prescriptions to patients based on partnerships with local nutrition and fitness resources (Peek et al. 2014). In another intervention, Cities for Life (a diabetes management program) and the University of

Alabama’s Diabetes Research and Training Center, jointly maintain MyDiabetesConnect, a regularly updated database with local resources on nutrition, fitness, clinical care, and other support for individuals with diabetes. Community partners and members can also add new resources to the database to help to maintain a repository of assets that incorporates new and evolving resources (Cotterez et al. 2013).

These interventions successfully leverage new technologies to connect individuals who have chronic conditions to local resources in innovative ways. However, most of these interventions are still highly specialized. Individuals who have chronic health conditions can often only access the information on local resources in their communities on a limited subset of health conditions, locations, type of support (e.g., fitness, exercise, etc.), and so on within one these types of applications or interventions.

The limitations of existing interventions and technologies may explain why many individuals who have chronic health conditions still rely heavily on word of mouth (WOM) communications and physician recommendations of local resources (such as specialists) rather than going online. The complexities of finding and assessing health information online and determining the credibility and trustworthy of online sources can still be a difficult prospect for many users (Martin 2017; Tu and Lauer 2008; Yahanda et al. 2016). However, there may be new opportunities to improve users’ experiences searching for information online for local resources in their communities.

Crowdsourcing technology can potentially offer a more efficient solution to connect residents to a wider array of local resources in their communities. Crowdsourcing is already a common phenomenon across many popular platforms (Brabham 2013), including Yelp, Google Reviews, ZocDoc, Vitals, HealthGrades, and several other related platforms. However, the information individuals with chronic conditions need on relevant local health resources is often fragmented across these types of online platforms (Synnot et al. 2016; Van Velsen, Beaujean, and van Gemert-Pijnen 2013). A common, online repository for sharing information on local health resources specific to managing chronic health conditions in a single platform may potentially improve the accessibility of this type of health information.

Although there is now an extensive body of literature on people's online health information seeking, there have been very few studies that have specifically investigated the experiences of individuals who have chronic conditions in searching for local resources to help them manage their health and the effectiveness of the various information seeking strategies they employ. In order to help to fill this gap, this qualitative study assessed population's information seeking strategies and the barriers they encounter in trying to find local resources, ultimately aiming to assess whether this type of information can be more effectively shared through other methods, such as through a crowdsourced online health information system.

Methods

I conducted semi-structured, in-depth interviews with 15 individuals who have chronic conditions, exploring their experiences around seeking out health information on local resources to help them to manage their chronic conditions. I also asked participants whether they would find an online health information system that allowed them to crowdsource local health resources valuable.

Recruitment

Participants were recruited primarily through an online advertisement, which was initially sent out through a University-related listserv, which includes student, staff, faculty, and alumnae members. The online advertisement was also sent to group administrators of chronic illness-focused Meetup groups through the social networking website's messaging function. In addition, the ad was e-mailed to several health professionals in the Washington D.C. metropolitan area, with a request that they share the ad with their patients.

The online ad described the study and invited individuals who are at least 18 years of age and who have at least one chronic health condition to participate in a one-hour in-person, phone, or Skype interview. Snowball sampling was also used – recipients of the online ad were asked to forward the e-mail to other people who might fit the study criteria and be interested in participating in the study.

Potential participants were directed to a linked screening questionnaire from the online ad. The screening questionnaire asked potential participants to indicate whether they had one or more chronic condition(s) and if they had ever searched for local resources in their communities, such as exercise classes, nutritionists, and support groups, that might help them in managing their conditions. Potential participants who responded affirmatively to both questions were sent an email that welcomed them to participate in an interview. The term "local resources" was deliberately left open-ended for the purposes of this study, encompassing more traditional healthcare resources (e.g., physicians, physical therapists, psychologists, etc.) to more unique local resources (e.g., specialty grocery stores, farmers' markets, holistic services, etc.). Participants were able to self-define this term throughout the course of each interview in order to collect a comprehensive representation of their experiences around managing a diverse range of chronic health conditions. I avoided imposing artificial boundaries around the term since participants' needs are often unique to their own contexts/situations and I hoped to explore all aspects of their successes and challenges in searching for information on local resources.

The inclusion criteria for this study was also broad given the exploratory nature of this research. Although a convenience, snowball sample was used for this work, limiting the diversity of the recruited participants, adults with any type of chronic health condition were asked to participate in the study. Participants were provided with several examples of chronic health conditions (e.g., type I diabetes, type II diabetes, arthritis, obesity, hypertension, cancer, etc.) in the initial screening questionnaire for the study, but participants with any self-reported chronic health condition(s) were invited to participate.

Data collection

Semi-structured interviews were conducted with 15 individuals who met the screening criteria for the study, including eleven telephone, two Skype, and two in-person interviews. The interviews ranged in length from 25 to 58 min, averaging 43 min. Before beginning each interview, I briefly described the study and reviewed the consent form with the participant. They were then asked to sign and date the paper or emailed consent form. I asked each participant to begin by providing some basic demographic data and background information about their computer/smartphone/ Internet access and use. Each participant was then asked to respond to a series of questions based on a prepared interview guide regarding their experiences searching for information on local resources in their communities to manage their health. Specifically, participants were asked to describe the strategies they used to seek out local resources in their communities and to expand on how they successfully identified those local resources and the barriers they felt had impeded them from finding local resources.

After describing their own experiences searching for local resources, participants were asked to describe an ideal technology or system that would better enable them to find this type of information. Participants were not directed to describe any particular type of technology (e.g. website, mobile application, review service, online community, etc.) during this portion of the interview. The goal was to allow them to imagine their ideal scenarios, rather than having them focus primarily on what they felt was feasible based on their own experiences with using existing technologies. However, participants were asked to describe specific features, functions, or workflows they felt would be most helpful in their ideal system based on their prior successes and challenges with finding information on local resources. Crowdsourcing information on community resources was subsequently posited as a potential solution to participants to gauge their openness to, and interest in, the idea.

The interviews were conducted between September 2017 and April 2018, after Institutional Review Board (IRB) approval was obtained from the researcher's university. The IRB reviewed and approved the study justification, protocol, consent form, recruitment materials, interview guide, and all other relevant components. A signed consent form was received from each participant before beginning the interview.

Data analysis

After completing all interviews, I had approximately 10 hours and 30 minutes of audio recording, in total. The audio recordings were transcribed by a transcription service company. I then reviewed, coded and analyzed each interview using a thematic analysis with a general inductive approach (Braun and Clarke 2006). The questions in the interview guide were subcategorized to connect to each of the research questions for this study in order to ensure participants' responses garnered during the interviews produced the necessary data to meet the goals of this research. I analyzed participants' responses to each subset of interview questions in order to code their responses into subcategories specifically in relation to each research question. I produced four sets of initial set of codes based on each of the research questions for this study: (1) strategies participants described using to find information on local resources; (2) their successful strategies; (3) the barriers they encountered; and (4) the potential usefulness of an online crowdsourced health information system. I collated and sorted these codes into an initial set of themes and associated underlying sub-themes (in relation to each of the research questions) that I identified from the data. I reviewed and collapsed these themes and sub-themes based on the prevalence and the meaningfulness of the recurring connections made by the participants in the data. I further refined and finalized these themes based on their relevance to the narrative of this research and discuss them more explicitly under each research question in the findings of this work.

Results

A total of 15 people participated in an interview session for this study. The majority of participants were women (n = 13; 86.7%) and identified as Caucasian (n = 8; 53.3%). Other participants identified as African-American (n = 2; 13.3%), Asian or Asian Indian (n = 3; 20%), or mixed-race/ethnicity (n = 2; 13.3%). The average age of participants was 38, with participants falling between the ages of 20 and 65. Nine (60%) of the participants hold a Master's degree, four (26.6%) participants have a Bachelor's degree, one participant (6.7%) has a doctorate, and one participant (6.7%) is currently enrolled in a Bachelor's degree program. The majority (n = 9; 60%) work in professional occupations, such as data analysis, nursing, accounting, and management. Five participants (33.3%) are also undergraduate students or graduate students in degree programs related to library science, information science, human-centered design, etc. One participant (6.7%) identified as a "homemaker," but had also completed a Bachelor's degree program in Nursing. All participants have Internet access and own and regularly use personal computers and smartphones both for work and/or at home. Participants described managing one or more chronic conditions, including chronic depression, anxiety, hypertension, arthritis, prediabetes, diabetes, cancer, and autoimmune disease. Most participants described managing two or more chronic health conditions at one time.

RQ1: What strategies have individuals who have chronic conditions used to seek out local resources in their communities to help them to manage their health conditions?

Many participants described relying on their informal social networks to find information on relevant local resources in their communities. The information they received from family, friends, acquaintances, and other connections through educational, work, religious, or community settings was often obtained serendipitously in an unplanned or disorganized way. I01 described, "My girlfriend went to go see a physical therapist, and the physical therapist asked her if she had any stress in her life. She mentioned that I was going through chemotherapy, and it was like, 'Oh, well, you should hear about Ulman' [The Ulman Cancer Fund for Young Adults – Cancer to 5K]." I03 similarly explained, "…my mom was actually…frantically just begging everyone she knew, every doctor she knew, she works in a hospital, to help me and to figure out what to do. It was through the grapevine she had a coworker who had a niece that had a lot of chronic health conditions and she had gone to this doctor and then passed along the information to me…"

Participants who relied on these WOM recommendations from their informal networks were unable to search for these local resources in a systematic way. However, their informal networks often suggested highly personalized local resources, tailored specifically to participants' chronic health needs. I02 explained, "My family [told me]… their former minister … actually became a yoga teacher with a huge focus on…making yoga accessible and inclusive to everyone and…effective for people with…physical limitations. So then I had this person that I had…a trusted figure in my community…that I started taking yoga classes from…"

The majority of participants also indicated they had conducted simple exploratory searches for local resources by entering generalized terms relating to their condition and geographic location in popular web search engines. I03 described, "I literally just Googled it. I just Googled Lyme support group of Michigan…I wanted to go to an actual group to meet other people, so I found the one that was closest to me…" I07 also explained, "I go to Google and I put in 'Richmond farmers' markets' or I might put in 'West End Richmond farmers' markets'." Participants subsequently sifted through the pages of search results yielded from their exploratory searches until they were able to find a relevant resource. Participants who were unable to find relevant local resources sometimes began a new exploratory search with different search terms or decided to stop searching online for an unspecified period of time.

Some participants described finding information on local resources in their communities through more targeted searches on specific websites and social networking sites. Participants mentioned using their insurance companies' websites to more actively locate in-network healthcare providers in their areas. Other participants described unexpectedly finding relevant information on local resources while using social networking sites such as Reddit and Facebook to search for other types of information on their chronic health conditions.

Older participants relied more heavily on an awareness of their surroundings to search for local resources. I07 mentioned, "There's another farmers market there down the street, and I found out about that one 'cause they put these posters up, like those signs along the side of the road. And we saw it. We go there from time to time." Older participants were also more likely to locate local resources advertised in other sources besides informal social networks and online content, such as television commercials and written materials. I06 mentioned finding her primary care physician (PCP) in this way, "They sent around a flyer. Because I didn't know anybody, so they had sent out a flyer, I said, 'Oh, I'll check them out,' and I went." I07 also described finding a local resource when, "…you may see an advertisement, or you might see a commercial."

RQ2: How have individuals successfully identified local resources in their communities to help them to manage their chronic health conditions?

Informal social networks seemed to be the most successful strategy for most participants to find useful local resources to help them manage their health conditions. Participants described how their friends, family, and other connections seemed to have a greater awareness of the types of local resources that might be most beneficial for them to manage their chronic health conditions, given their general understanding of the participant's chronic health conditions. Individuals in participants' extended social networks were also able to quickly identify useful resources for participants through targeted discussions around participants' needs and constraints. I01 explained, "Because it was word of mouth, the language that I got was very tailored to what I was listening for…" I13 also described how helpful it was to have a close friend who also experienced severe migraines recommend campus resources she herself had found extremely useful. I13 explained, "I would definitely say that the recommendations and the advice from friends was much more helpful than what I was doing solo, online searching…" The individuals in participants' social networks were often able to adapt their recommendations to participants' highly specific criteria (but frequently vague requests) for information on local resources in their communities based on their own experiences and their knowledge of more obscure community assets.

Many participants strongly felt they were unlikely to have found many of the local resources that were most useful to them through any other means besides WOM communications through their informal social networks. I03 described, "I don't think I would have ever found this doctor without my mom having gone and asked people." I01 similarly mentioned feeling that is it was unlikely he would have found Ulman, the most helpful local resource for him, by simply conducting online exploratory searches. He was initially unaware of the targeted keywords he should use in relation to his chronic health condition to begin searching for the right resources. I01 explained, "I'm very educated now on what to look for, but I definitely wasn't in the beginning." I09 relatedly described: "I ended up picking a gym that's part of our parks and rec. There is a webpage that says that they do that monthly training…but it's buried on the page. I never would have figured it out if someone hadn't said it and then I looked it up on my own and called." Another participant also described how not having a diagnosis initially made it very difficult for her to search for local resources online using only her symptoms as keywords.

However, some participants did manage to find useful information about local resources online through their exploratory searches; however, this required that the websites they discovered include sufficient detail. I02 described, "I think that [local resource] came from just like a Google search of mindfulness class in my area, and I chose that one because I really liked what the instructor had put on his website and his kind of philosophy about things. He was really specific about talking about making things accessible and comfortable for any physical or mental limitations you may have. Really addressing that specifically versus just throwing out a buzz word like gentle." I05 similarly explained, "I just looked online…and they had all their psychiatrists that were accepting new patients, and so I read about each one of them." The participants who described experiencing difficulty finding local resources online often mentioned having the opposite experience – the websites they found were too generic to be helpful. These participants were unable to determine whether the resources they found online could relieve and/or accommodate their chronic health conditions based on the limited information available on the websites.

Participants also described using a combination approach to find local resources in their communities. Participants would use WOM recommendations from individuals in their social networks as a launching point to search for more information on those types of resources online. One participant (112), in particular, described originally searching for Ayurvedic treatments online. However, she realized naturopathic treatments were a better fit for treating her arthritic pain after her sister recommended visiting a specific naturopathic center. She explained, "Once my sister told me about naturopathy, I googled few naturopathy hospitals…then did thorough research, and made the list of what I am looking for into them as far as weather is concerned, budget is concerned, sanitary conditions, and my symptoms."

RQ3: What barriers have individuals encountered in trying to identify local resources to manage their chronic health conditions?

Most participants mentioned they received only minimal, if any, information on local resources to manage their chronic health conditions from their healthcare providers. The majority of participants said their providers recommended altering their routines in some way, often in relation to their dietary and fitness habits, to improve their health. However, their healthcare providers' recommendations were often nonspecific, with limited discussion around how to or where to find local resources to help participants' make the necessary changes to improve their health. Participants' healthcare providers seemed to primarily focus on managing their care from a clinical standpoint. I06 mentioned, "I guess it would've been nice if doctors had said, 'hey, why don't you check this out? I want you to do this', but none of them did." I07 similarly described, "Nobody has really recommended, 'Hey, go to some type of health program or some type of nutritionist.'" One participant (I05) even described how she felt her PCP actively avoided connecting her to relevant local resources in the form of healthcare specialists in her area. She explained, "Plus my PCP…I think they are pressured by the network to not send people to specialists unless they have to." Another participant (I07) even doubted whether he would even benefit from his healthcare providers' recommendations, since he was managing his care more effectively on his own.

The local resources healthcare providers did recommend to participants were often limited or ineffective in some respects. Some healthcare providers seemed to focus mainly on recommending resources only available through their own hospitals or clinical settings. Other participants felt the local resources their healthcare providers recommended were not useful given their current stage in managing their chronic health conditions. I05 explained, “Well, my PCP said she could send me to a nutritionist in our area, or I know [inaudible] Center has these classes about cholesterol and diabetes, and all that. I was like okay, my problem is not that I don’t know these things, it’s the following them that’s the problem. I know the research…It’s like I don’t have the motivation necessarily sometimes.” Cultural barriers also created issues for some participants. I12 described, “He [interviewee’s doctor] gave me few names for dieticians, where I can go and consult about my diet. But then I was getting into another issue with that because I am Indian, and I don’t eat American food and those people were American.” The local resources recommended to participants were often not personalized enough to provide any real value for them.

Participants with rarer chronic health conditions or conditions less prevalent in their informal social networks were also more likely to have difficulty finding relevant local resources through WOM communications. I09 described, “[It’s] a little trickier, because it's easy around here to find somebody who has asthma or pre-diabetes, it's a lot harder to find someone who has CP [cerebral palsy].” I13 also explained that as a young college student with back pain she, “…didn't have as many friends or close acquaintances…who saw a PT [physical therapist] or knew anyone…that saw a PT…It didn't really play as much role in my decision because I didn’t know anyone in the first place.”

Some participants described having success using exploratory searches to find local resources online; however, other participants described having significant difficulty using search engines to find useful local resources in their communities. Information overload was a common barrier described by participants. I02 described, "I think if you have something in mind, like yoga, that helps a little bit, but even then, there's lots of information, but I think if you just Google straight up like, arthritis resources or mental health resources. That's even more information to sift through." I06 also mentioned, "It's too exhausting, Googling, like 50 things."

Additionally, even when participants were able to find a local resource online that could potentially help them manage their chronic health conditions more effectively, they were unable to determine if the resource they had located would be useful based on the limited information on the website. Outdated and incomplete information on these websites frustrated many participants. They were unable to determine whether the local resources they had identified would be useful based on their specific needs. Therefore, they had to expend significant energy and time calling and/or trying out these resources, frequently only to find that they would not be a good fit for a number of reasons, such as financial, physical, or timing barriers. I03 explained, "Yeah, I went to a nutritionist for a while…It was way too expensive. I liked what she had to say and I liked the plans that she put me on, but…I could not afford to keep going to her…I tried Yoga classes, but with my joints being the way they are, it was just too hard and I'm just too exhausted after work." I08 similarly described, "I also looked at yoga… for POTS [Postural Orthostatic Tachycardia Syndrome]… but it's really hard to find a yoga class that actually would be mild, or that would have the right conditions at the right time of day." I05 also mentioned, "I need an endocrinologist, so I looked in the department of endocrinology to see all their physicians there…but I don’t remember that anyone specifically mentioned thyroid issue…it’s not always clear if it's accepting new patients sometimes. It's not always updated.”

RQ4: How do individuals who have chronic health conditions feel about the potential usefulness of an online crowdsourced health information system to help them discover and share local resources in their communities?

Despite the success many participants had finding useful local resources through their informal social networks and sometimes through general online exploratory searches, the barriers they encountered often overshadowed their successful experiences. Most participants still found it extremely burdensome to find new local resources in their communities. The process was so difficult, some participants continued to use healthcare providers and other types of local resources even if they were not ideal or too expensive. 105 described, “I’m actually moving to a new insurance now and she’s not on the insurance. I’m considering keeping going to her, even though she’s not accepting that insurance. Just paying her, because it’s so hard to move, to find someone new.” The majority of participants did seem to think there could be some value in a health information system that would allow them to discover and share information about local resources more easily. I08 explained, “A network of professionals, I think would be nice…somebody who knows about this condition…very supportive, and can give you a lot of guidance…I think that would’ve been ideal.” Most participants had difficulty describing how exactly they would like this online health information system to perform, but when probed they were able to describe certain features and functions they would find useful in any such system.

Testimonials were overwhelmingly the most important feature almost every participant described during their interviews. Participants wanted detailed information from other individuals with similar chronic conditions about specific aspects of local resources they found most valuable. I02 explained, “So like, if you’re just looking at like Facebook review or Google review, it's all very abstract into just like ‘oh, this was fantastic’…but never really any details. So if…people really describe…what their daily struggles are like and really getting into the nitty gritty of how things were and how the resource helped and that kind of thing…Somebody who knows what you’re going through versus the really, kind of bland, could be anyone, ‘This was great,’ or ‘This was terrible.’” I03 similarly mentioned, “It would be nice after diagnosis being able to go on and search for resources and having the first things popping up being those testimonials of other people who have Lyme disease, their information and their advice or contact information or something like that rather than just Googling it.” One participant felt that basic rating systems from existing online applications were unhelpful in terms of the information she actually needed to decide whether a local resource would have any value for her.

Participants also emphasized any such online health information system would need to be extremely usable and provide useful information quickly in order for them to recognize the utility of the system. They highlighted the importance of having information on local resources that is regularly updated and highly detailed in one consistent location online. I06 mentioned specifically, “Yeah, it’s just like, who has time to Google 50,000 things, you know, just won't. Yeah, so that would be cool to just press a button and get what you want." Participants explained they would want as much information as possible on each local resource in this type of system, including contact information, locations, credentialing, clinical philosophies, costs, insurances accepted, appointment times, availability, experience working with individuals with their chronic conditions, independent testimonials, and more. They felt this could potentially reduce the burden of conducting multiple, fruitless exploratory searches and using multiple, fragmented, and/or outdated sources of information online to find useful local resources to manage their chronic health conditions.

However, it is important to note, some participants were skeptical as to whether any online health information system could provide them with all of the information they needed and be sufficiently useful that they would actively use it. Other participants questioned whether a new online health information system would provide credible information or if it would simply become another online system with fragmented or out of date information on local resources in their communities. I07 explained that although he uses Yelp and Google to search for reviews on different local resources, he finds it necessary to use multiple sources: "I wanna hear what others have to say. I just don't go to one spot and just land there. I don't trust anybody that much, so I'm a skeptic." Establishing trust in the quality of the online information similar to the trust participants have in their informal social networks was also a major prerequisite participants' insisted upon if they were going to use any such new online health information system. I13 explained, "I can do so much [online] searching, but I never really know the true story…My friends obviously…I trust them. I feel like they wouldn’t lead me down the wrong path.”

Discussion

The findings from this exploratory study revealed that individuals who have chronic health conditions still rely primarily on WOM communications through their informal social networks to find information on relevant local resources in their communities. This is consistent with the results of previous research indicating individuals often rely on WOM recommendations for physicians and hospitals (Martin 2017; Yahanda et al. 2016). Participants felt this form of information provision was highly personalized, and thus, especially useful to them. Their informal social networks often recommended local resources meant to directly address the specific symptoms, limitations, and/or challenges participants regularly confronted while managing their chronic health conditions. Participants reported that it would have been unlikely they would have found the same types of local resources on their own through any other method, including using the Internet, since they would not have known how to construct their online keyword queries appropriately.

Despite the vast amount of health information available on the Internet, participants still seem to have substantial difficulty locating online information about local resources that can help them more effectively manage their chronic health conditions. Participants often experience information overload after conducting exploratory searches for local resources. They attempt to limit their exploratory searches using more specific keyword queries related to their chronic health conditions, symptoms, locations, etc.; however, the results are often still too overwhelming. Reviewing every search result is unfeasible, but even filtering through a portion of the results can become impractical. Local resources that can meet participants' unique health needs are often not easily identifiable by quickly scanning the search results. Even participants who report taking the additional time to sift through the results of their exploratory searches in more depth do not seem to be more likely to find useful local resources. Participants who report discovering online information about relevant local resources seem to only identify these resources because they serendipitously find a website early enough in the process before becoming too fatigued. Additionally, the website must also happen to have enough detailed information for them to recognize its value in light of their condition and current situation. This second factor only increased the unlikelihood of finding a relevant local resource through an online exploratory search.

Echoing the findings of previous work, the fragmentation of the information across multiple platforms and websites can also make it extremely burdensome to find local resources online (Synnot et al. 2016; Van Velsen, Beaujean, and van Gemert-Pijnen 2013). Some participants reviewed several social media sites and other types of websites, as well as mobile applications, before coming across even one helpful local resource. Investing so much time and effort into finding such limited, if any, information on local resources can be unsustainable. Individuals who have chronic health conditions are usually already managing several other aspects of their care. The difficulty associated with locating information online can make finding useful local resources a low priority, even given the potential opportunity to achieve better health outcomes.

Participants acknowledged the fatigue they experienced searching for information on local resources due to information overload and the fragmentation of the information online. Most of them agreed a streamlined method for finding local resources could potentially be beneficial, perhaps in the form of an online health information system. Brabham (2013) defines a similar type common repository of information in his work.

However, participants emphasized that this online health information system would need to be consistently updated and contain highly detailed information on each local resource in order for it to be truly useful for them. Their requests are potentially compatible with an online health information system that relies on users to find and share information on local resources they have found to be helpful.

The data from this exploratory study suggest that a crowdsourced online health information system that relies on a modular design may be ideal. The flexibility to add new and existing local resources into a common information repository is obviously a critical function, as Cotterez et al. (2013) describe in their interventions design. However, participants seem to need different types of information on each local resource. Providing users with the flexibility to add and update specific aspects of each local resource will be crucial. Individuals will need to be able to add, update, and search for information on credentialing, availability, testimonials, and other relevant details related to a resource's ability to tailor their services to individuals with different types of chronic health conditions. Existing online resources seem to provide components of this type of information on local resources, but force users to sift through multiple sites and applications to find the information they need.

Participants also seemed to convey that the discoverability of local resources will be an essential feature in any online health information system. Compiling local resources under specific chronic health conditions may be useful initially for organizing content. However, users may also need an option to tag local resources with specific keywords to increase the probability that other individuals with the same chronic conditions can find the local resources that are the best match for their needs. Users with the same chronic health condition are likely well-positioned to create keyword tags that others with the same chronic health condition are more likely to use while searching for a local resource. Additional research with potential users may reveal other solutions to improve the discoverability of local resources in an online health information system.

Populating this type of online health information system is difficult since users need to be sufficiently engaged with the system to consistently add and update local resources. However, if a sufficient number of users found value in the system, it could potentially connect individuals who have chronic conditions with numerous valuable local resources in their communities much more quickly and easily than existing systems. A systematic method for connecting individuals to local resources may allow users to circumvent (or at least supplement) the serendipitous discovery process through informal networks that most participants in this study relied heavily on.

Although the serendipitous discovery of local resources through informal social networks is a valuable form of information provision, it does present some major limitations for certain individuals. Participants with rarer health conditions, such as cerebral palsy, had much more difficulty finding individuals in their informal social networks who could offer information on useful local resources. Individuals in these participants' social networks were less likely to be able to draw on their own experiences and they had more limited exposure to others with similar chronic health conditions, reducing the value and extent of the information they could provide to participants.

Additionally, the individuals who participated in this study are likely highly computer literate considering their education attainment levels and their professional occupations. They represent a privileged subset of the population based on their demographic characteristics. These participants' successful experiences locating useful local resources through their informal social networks may have been partly related to their cultural capital. The participants in this study were often able to clearly articulate their unique health needs and reach out for assistance from an equally highly educated and literate network of professional family, friends, and acquaintances. Several participants even mentioned having professional experience in a healthcare environment themselves or connections to family members or friends who worked or had previously worked in a healthcare environment. These types of social connections may have made it more likely that they would identify information on local resources through WOM communications. An online health information system may potentially democratize this process of discovery for individuals who do not have the same level of cultural capital and/or digital health literacy.

Limitations

This study has several limitations. The findings from this study are not generalizable beyond this group of 15 participants, given the small size and biased nature of this sample. Regarding the latter, the individuals who chose to participate in this study were initially recruited through a University-related listserv. Therefore, the individuals who were contacted for participation may have a higher level of digital literacy and education than the general population. The participants in this study may also be more likely to actively seek out local resources to manage their chronic health conditions. Overall, however, my in-depth interviews provided significant insights on the strategies used and the challenges encountered by people who have a chronic health condition as they look for local resources in their community that can help them to maintain or improve their health. Additionally, the findings suggest a potential opportunity to improve provision of this type of information through an online health information technology that allows individuals to crowdsource information on local resources in their communities.

Conclusion

This study revealed that people who have a chronic health condition frequently rely on WOM communications with their informal social networks to find a wide array of useful local resources. They also conduct general online exploratory searches and use social media applications to find this type of information. However, participants in this study encountered numerous barriers when using online strategies to find information on local resources. They often experienced information overload and a frequently insurmountable fragmentation of information online. Additionally, the details provided on local resources' websites, social media sites, and other applications were often too general to be useful for participants who sought to quickly and easily identify whether the local resources would be helpful. Participants often had substantial success locating highly valuable local resources through their informal social networks. However, this strategy may have been primarily successful due to participants' significant cultural capital.

The findings suggest that an online health information system that would allow users who have chronic health conditions to crowdsource information on local resources in their communities could potentially be valuable. Participants in this study made several suggestions regarding the features and functions, such as testimonials and discoverability, an online health information system would need to incorporate to be useful for them. However, additional research on this topic (such as a survey study with a larger and more diverse sample) will need to be conducted to gather more data on the design and development of an ideal online health information system that will enable individuals who have chronic health conditions to crowdsource information on local resources.

References

1. Armstrong, A. W., S. Cheeney, J. Wu, C. T. Harskamp, and C.W. Schupp. 2012. "Harnessing the Power of Crowds: Crowdsourcing as a Novel Research Method for Evaluation of Acne Treatments." *American Journal of Clinical Dermatology* 13 (6):405–16.
2. Bateman, D. R., E. Brady, D. Wilkerson, et al. 2017. "Comparing Crowdsourcing and Friendsourcing: A Social Media-Based Feasibility Study

to Support Alzheimer Disease Caregivers." *JMIR Research Protocols* 6 (4):e56.

3. Brabham, D. C., K. M. Ribisl, T. R. Kirchner, and J. M. Bernhardt. 2014. "Crowdsourcing Applications for Public Health." *American Journal of Preventive Medicine* 46 (2):179–187.
4. Brabham, D.C. 2013. *Crowdsourcing*. Cambridge, MA: The MIT Press Essential Knowledge Series.
5. Braun, V. and V. Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3 (2):77–101.
6. Cotterez, A., N. Durant, A. Agne, and A. Cherrington. 2013. "Internet Interventions to Support Lifestyle Modification for Diabetes Management: A Systematic Review of the Evidence." *Journal of Diabetes and its Complications* 28 (2):243–251.
7. Fox, S. and M. Duggan. 2013. *Health Online 2013*. Washington, DC: Pew Research Center.
8. Gao, H., G. Barbier, and R. Goolsby. 2011. "Harnessing the Crowdsourcing Power of Social Media for Disaster Relief." *IEEE Intelligent Systems* 26 (3):10–14.
9. Green, G. P. and A. L. Haines. 2002. *Asset Building & Community Development*. Thousand Oaks, CA: Sage Publications).
10. Greene, J. A., N. K. Choudhry, E. Kilabuk, and W. H. Shrank. 2011. "Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of

Communication with Facebook.” *Journal of General Internal Medicine* 26 (3):287–92.

11. Haluza, D., M. Naszay, A. Stockinger, and D. Jungwirth. 2017. “Digital Natives Versus Digital Immigrants: Influence of Online Health Information Seeking on the Doctor-Patient Relationship.” *Health Communication* 32 (11):1342–49.
12. Holliday, A. M., A. Kachalia, G. S. Meyer, and T. D. Sequist. 2017. “Physician and Patient Views on Public Physician Rating Websites: A Cross-Sectional Study.” Journal of General Internal Medicine 32 (6):626–31.
13. Klein, L. J. 2010. NLM® to Discontinue Support of MedlinePlus® Go Local. *National Library of Medicine Technical Bulletin* 373:e18.
14. Kretzmann, J. P. and J. L. McKnight. 1993. *Building Communities from the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets*. Chicago, IL: ACTA Publications.
15. Lober, W. B. and J. L. Flowers, 2011. “Consumer Empowerment in Health Care Amid the Internet and Social Media.” *Seminars in Oncology Nursing* 27 (3):169–82.
16. Loskutova, N. Y., A. G. Tsai, E. B. Fisher, et al. 2016. “Patient Navigators Connecting Patients to Community Resources to Improve Diabetes Outcomes.” Journal of the American Board of Family Members 29 (1):78–89.
17. Martin, S. 2017. “Word-of-Mouth in the Health Care Sector: A Literature Analysis of the Current State of Research and Future Perspectives.” *International Review on Public and Nonprofit Marketing* 14 (1):35–56.

18. Mills, M. E., and R. Davidson. 2002. “Cancer Patients’ Sources of Information: Use and Quality Issues.” *Psycho-Oncology* 11 (5):371–378.
19. Moorhead, S. A., D. E. Hazlett, L. Harrison, et al. 2013. “A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communication.” *Journal of Medical Internet Research* 15 (4):e85.
20. Peek, M. E., M. J. Ferguson, T. P. Roberson, and M. H. Chin. 2014. “Putting Theory into Practice: A Case Study of Diabetes-Related Behavioral Change Interventions on Chicago's South Side.” *Health Promotion Practice* 15 (2 Suppl):40S–50S.
21. Ports, K. A., A. Ayers, W. Crocker, et al. 2015. “Community Perceptions and Utilization of a Consumer Health Center.” *Journal of the Medical Library Association* 103 (1):35–39.
22. PricewaterhouseCoopers (PwC), Health Research Institute. 2012. Social media “likes” healthcare: From marketing to social business.
23. Ranard, B. L., Y. P. Ha, Z. F. Meisel, et al. 2014. “Crowdsourcing – Harnessing the Masses to Advance Health and Medicine, a Systematic Review.” *Journal of General Internal Medicine* 29 (1):187–203.
24. Shaw R. J. and C. M. Johnson. 2011. “Health Information Seeking and Social Media Use on the Internet among People with Diabetes.” *Online Journal of Public Health Informatics* 3 (1). doi: 10. 5210/ojphi.v3i1.3561.

25. Sims, M. H., M. Fagnano, J. S. Halterman, and M. W. Halterman. 2016. “Provider Impressions of the Use of a Mobile Crowdsourcing App in Medical Practice.” *Health Informatics Journal* 22 (2):221–231.
26. Smith, A. 2017. “Record Shares of Americans Now Own Smartphones, Have Home Broadband.” In Washington, DC: Pew Research Center.
27. St. Jean, B. 2012. “‘I just don't know what I don't know!’: A Longitudinal Investigation of the Perceived Usefulness of Information to People with Type 2 Diabetes.” *Proceedings of the Association for Information Science and Technology* 49 (1):1–10.
28. Synnot, A. J., S. J. Hill, K. A. Garner, et al. 2016. “Online Health Information Seeking: How People with Multiple Sclerosis Find, Assess and Integrate Treatment Information to Manage Their Health.” *Health Expectations* 19 (3):727–737.
29. Taggart, T., M. E. Grewe, D. F. Conserve, C. Gliwa, and M. R. Isler. 2015. “Social Media and HIV: A Systematic Review of Uses of Social Media in HIV Communication.” Journal of Medical Internet Research 17 (11):e248.
30. Tan, S. S. and N. Goonawardene. 2017. “Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review.” *Journal of Medical Internet Research* 19 (1):e9.
31. Tu, H. T. and J. Lauer. 2008. “Word of Mouth and Physician Referrals Still Drive Health Care Provider Choice.” *Health System Change Research Brief* 9:1–8.

32. Tung, E. L. and M. E. Peek. 2015. “Linking Community Resources in Diabetes Care: A Role for Technology?” *Current Diabetes Reports* 15 (7):614.

33. van Velsen, L., D. Beaujean, and J. van Gemert-Pijnen. 2013. “Why Mobile Health App Overload Drives Us Crazy, and How to Restore the Sanity.” *BMC Medical Informatics and Decision Making* 13 (1):23–27.

34. Weaver, III, J. B., D. Mays, S. S. Weaver, et al. 2010. “Health Information–Seeking Behaviors, Health Indicators, and Health Risks,” *American Journal of Public Health* 100 (8): 1520–1525.

35. Yahanda, A. T., K. J. Lafaro, G. Spolverato, and T. M. Pawlik. (2016). “A Systematic Review of the Factors that Patients Use to Choose Their Surgeon.” *World Journal of Surgery* 40 (1):45–55.

36. Yates, D. and S. Paquette. 2011. “Emergency Knowledge Management and Social Media Technologies: A Case Study of the 2010 Haitian Earthquake.” *International Journal of Information Management* 31 (1):6–13.

37. Yonker, L. M., S. Zan, C. V. Scirica, K. Jethwani, and T. B. Kinane. 2015. “Friending” Teens: Systematic Review of Social Media in Adolescent and Young Adult Health Care.” *Journal of Medical Internet Research* 17 (1):e4.

Chapter 3: An online card-sorting study to inform the initial low-fidelity design of a crowdsourced health information system for individuals who have chronic health conditions seeking local health-related resources

This article (Chapter 3) was originally published in *Human Behavior and Emerging Technologies*. This postprint version of the article has retained the same content, citations, and formatting of the original journal article. Please cite Chapter 3 as follows: Jindal, G. (2020). An online card-sorting study to inform the initial low-fidelity design of a crowdsourced health information system for individuals who have chronic health conditions seeking local health-related resources. *Human Behavior and Emerging Technologies, 2*(2), 128-139. Available: https://onlinelibrary.wiley.com/doi/full/10.1002/hbe2.186

Abstract

Individuals who have chronic health conditions often have difficulty finding useful local resources (e.g., senior centers, support groups, fitness classes) online. A crowdsourced health information system (CHIS) that would allow individuals to easily share and access detailed, credible information on a wide array of local resources is a potential solution. An online, closed card-sorting study was carried out with 31 participants who have chronic health conditions to assess their perceptions about the usefulness of a range of hypothesized types of information on local resources (e.g., reviews, ratings) and system functions and features (e.g., keyword search, filters) for the proposed CHIS. The results of the study indicated participants are interested in using the proposed CHIS if the local resources are easily discoverable (through the use of many different types of system functions and features), with highly detailed information available for each local resource, so they can quickly determine its value for them in managing their health. If designed appropriately, the proposed system could be a useful tool to help people take advantage of local resources to manage their health.

Keywords: Chronic health; chronic illness; chronic condition; crowdsourcing; community resources; local resources; health resources; health information system; crowdsourced health information system; provider reviews

Introduction

Word of mouth (WOM) communication is a powerful mode of health information provision. A nationally representative survey of U.S. adults revealed that 85 percent of respondents reported that WOM recommendations from family or friends were a very important or at least somewhat important factor when choosing their physician (Hanauer, Zheng, Singer, Gebremariam, & Davis, 2014). Similar studies have also demonstrated the importance of WOM recommendations when choosing hospitals (de Cruppé & Geraedts, 2017; Martin, 2017); primary care physicians (Tu & Lauer, 2008); surgeons (Yahanda, Lafaro, Spolverato, & Pawlik, 2016); cancer specialists (Jiang et al., 2017); and other types of healthcare providers and resources (McCaughey, McGhan, Walsh, Rathert, & Belue, 2014; Pettigrew & Durrance, 2001; Shreffler-Grant, Weinert, Nichols, & Ide, 2005). Individuals can draw out highly experiential insights from their family, friends and acquaintances around their satisfaction and dissatisfaction on a wide array of points of care, such as cost, clinical competencies, staff members' interpersonal skills, and more (Martin, 2017).

Electronic word of mouth (eWOM) communication is also becoming an increasingly popular form of online health information provision. The concept of eWOM generally refers to consumer-generated content posted and viewed on social networking sites (SNSs) to provide and garner emotional and information support from other individuals (Liang & Scammon, 2011). eWOM communication may help individuals overcome the geographic and synchronous communication limitations of traditional WOM recommendations for hospitals and healthcare providers (Martin, 2017). However, eWOM recommendations may not have the same level of reliability and credibility as recommendations individuals receive from their family members, friends, and other individuals in their co-located informal social networks (Huete-Alcocer, 2017).

Family, friends, and other acquaintances can perform a certain amount of uncertainty absorption (March & Simon, 1958) in person-to-person communication with individuals in their social networks when they provide WOM recommendations for relevant resources in their local communities. March and Simon (1958) originally formalized the concept of uncertainty absorption (the process by which one person absorbs the uncertainty of information for another person by providing them with just the information they believe will be the most relevant and useful for them) in their seminal work on organizational management. However, their findings have highly relevant applications in the context of information provision regarding healthcare resources through WOM recommendations. Synchronous dialogue can allow an individual's family, friends, and acquaintances to perform a certain amount of tailoring of their recommendations of relevant resources, as they can draw not only on their own experiences and knowledge of the specific elements of a particular health resource but also on their knowledge of the individual's preferences, needs, situation, etc. However, recipients of such information must have confidence in people in their informal social networks and their ability to understand their needs and provide just the most relevant information back to them in order to comfortably forego reviewing each resource themselves directly. This process of uncertainty absorption through WOM communication can possibly limit the amount of information overload individuals experience while conducting exploratory searches on the Internet or SNSs to find information on relevant resources located in their communities that can help them to manage their health (Jindal, 2019).

The dialogic nature of uncertainty absorption through WOM recommendations may be difficult to replicate in an online environment. However, the quality, relevance, and comprehensiveness of the information individuals receive solely through WOM communication can be constrained, as each individual is entirely dependent on the composition of their social network. Martin (2017) found that the importance of WOM as an information source decreases for individuals with lower levels of education. This may indicate that individuals in higher socioeconomic groups may have access to more (and/or more relevant and useful) information from their social networks. Finding opportunities to democratize the provision of information on local resources that enable individuals to manage their health more effectively, such as group exercise classes, nutrition services, and behavioral health providers, is essential. Although, the nuances of patient-provider interactions can be difficult to impart through eWOM, individuals still desire detailed, experiential information on medical services.

Consumers seem willing to use online health information systems to share and find information about relevant resources that can help them to manage their health, such as physician evaluation SNSs, despite their uncertainty regarding the trustworthiness of the information on existing online platforms (Jindal, 2019; Lin & Lin, 2018). Online information systems, such as Yelp, that allow patients to crowdsource information on their experiences in healthcare settings can offer individuals a nuanced portrayal of a wide array of relevant metrics on healthcare providers and hospitals. Individuals may be able to find narrative information on healthcare providers' and hospitals' billing procedures; staff empathy, compassion, and communication skills in clinical settings; practice and hospital efficiency; and many other factors that can be difficult to learn about elsewhere (Kilaru et al., 2016; Ranard et al., 2016). Although individuals value recommendations from their own social networks, providers' reputations on physician-rating websites can still significantly sway individuals' decisions around choosing a healthcare provider (Hanauer, Zheng, Singer, Gebremariam, & Davis, 2014).

Despite the benefits of existing online platforms centered around providing eWOM recommendations through reviews and/or ratings, many of these platforms still have substantial limitations. Kordzadeh (2018) found major inconsistencies in the patient satisfaction scores for physicians published on the hospitals' websites compared to the scores posted on physician-rating websites, such as RateMDs, HealthGrades, Vitals, and Google Reviews, with hospital websites reporting significantly higher mean ratings. The value of independent physician-rating websites has also been limited due to the skewed number of positive reviews (Gao, McCullough, Agarwal, & Jha, 2012; Hanauer, Zheng, Singer, Gebremariam, & Davis, 2014; Kadry, Chu, Kadry, Gammas, & Macario, 2011; Pasternak & Scherger, 2009), the lack of detailed information around patients' interactions with physicians on these sites, and the cumbersome search mechanisms provided for finding physicians online (Lagu, Hannon, Rothberg, & Lindenauer, 2010; Pettigrew & Durrance, 2001).

The majority of these eWOM online platforms also tend to focus heavily on providing information exclusively about physicians, hospitals, and/or other types of clinical care (Martin, 2017). Online platforms that provide information systematically in the form of user ratings and/or reviews on other types of relevant resources in individuals' local communities, such as libraries, parks, health centers, senior centers, recreation clubs, nutrition services, faith-based services, support groups, and local businesses, seem to be far less common (Jindal, 2019). The absence of information on other types of local resources that can help one to manage their health is a major limitation, particularly for individuals who have one or more chronic health conditions. These individuals, in particular, may require additional assistance from a broader range of healthcare professionals and nonclinical resources to successfully self-manage their health (Bazata, Robinson, Fox, Grandy, & SHIELD Study Group, 2008; Diabetes Prevention Program Research Group, 2002).

Self-management of chronic health conditions through lifestyle intervention is essential to improving these individuals' health outcomes. However, changing personal behaviors to support the day-to-day management of chronic health conditions can be difficult for many individuals to implement. Although many people who have chronic health conditions do have the knowledge, skills, and/or intention to manage their health, they are often unable to translate them into real behavior change. This population may even receive the health education they need to manage their chronic health conditions, but effective health promotion to help them actually implement their knowledge, skills, and intention into action throughout their daily lives is often more elusive (Adams, 2010; Fastring, Mayfield-Johnson, & Madison, 2017; Ryan, 2009). Healthcare providers in a clinical care context often do not have the bandwidth to provide this kind of health promotion to help this population enact and maintain the necessary behavior changes to manage their health (Kennedy et al., 2013). Health promotion is a multifaceted concept that involves not only helping individuals with chronic health conditions develop the personal agency to improve their health outcomes, but also strengthening community action and creating supportive environments for these individuals beyond a clinical care context (Kumar & Preetha, 2012).

Instrumental support provided by clinical and nonclinical local resources in this population's communities can be an effective way to empower them to enact the necessary behavior changes within the context of their daily lives to better manage their health. The Chronic Care Model, which defines the essential elements for a healthcare system to promote successful chronic disease care, specifically identifies mobilizing community resources to meet the needs of patients as one of six major structural changes necessary to improve care for patients with a chronic disease (Barr et al., 2003). Mobilizing different types of local resources in these individuals' local communities through an online health information system could serve the dual purpose of helping this population to take personal agency to manage their health and to create a supportive community environment for themselves. Individuals with chronic health conditions could develop a support network by attending regular fitness classes, nutrition workshops, support groups, clubs, faith-based services, and offerings by many other types of local resources that can support them as they make changes in their day-to-day lives.

Assembling information about local health-related resources into an online health information system to help individuals access the tangible, social support that already exists within their communities may also be a practical and sustainable health promotion strategy to support behavior change. These types of clinical and nonclinical local resources are valuable community assets that frequently exist independently, without support from unstable funding from a governmental, nonprofit, research, or charitable source. Therefore, an online health information system that focuses on providing this population with this type of information can circumvent the geographic and funding limitations that can affect the implementation and long-term impact of more traditional interventions focused on connecting individuals to local community assets. However, such resources, though they may, in fact, exist, are often very difficult for people to learn about.

Crowdsourcing, a term originally defined in Howe's 2006 Wired article, is a problem-solving model that relies on the collective intelligence of online communities to meet some kind of explicit goal (Brabham, 2013). This open exchange of information from a bottom-up perspective, relying on individuals who have chronic health conditions (in this case) to proactively share knowledge for their mutual benefit, could potentially be a strategy to make information on local resources inexpensively and sustainably accessible for this population. Brabham (2013) describes this specific kind of crowdsourcing as "knowledge discovery and management," in which a crowd finds and collects information and deposits it into a "common location and format" (p. 45). Crowdsourcing information in this way can face many challenges, especially around user engagement in these types of online communities, but it also presents a low-barrier opportunity for individuals who have chronic health conditions to strategically and systematically share and discover information in a standardized format (Brabham, 2013; Butler, Sproull, Kiesler, & Kraut, 2002). Crowdsourcing is already being applied to a number of health-related areas related to patient education, research, advocacy, diagnosis, recruitment, etc. (Swan, 2012 & Wazny, 2018). However, a crowdsourced platform to streamline this population's access to information on local health-related resources to help them self-manage their health does not yet exist.

Therefore, this research focuses on collecting the information-related perceptions of people who have chronic health conditions to inform the design and development of a new type of proposed crowdsourced health information system (CHIS). The proposed CHIS will enable individuals to manage their health more effectively by providing an opportunity for them to share and access detailed, credible information on a wider array of relevant resources available in their local communities. The proposed CHIS will also focus on leveraging the process of uncertainty absorption from traditional WOM communication to help individuals not only finding relevant resources in their local communities, but also determining whether those resources will be useful for them. However, before this new type of crowdsourced health information system can be designed, it is critical to first identify the specific system functions and the types of information about each local resource individuals need in order to find a relevant resource and determine whether it will be valuable for them. A crowdsourced health information system that can potentially simulate some aspects of uncertainty absorption from more traditional WOM communication will likely be highly valuable for individuals who have chronic health conditions. To prepare for designing the proposed system, I performed a closed card sorting exercise with individuals who have chronic health conditions in order to investigate the following research questions:

1. What types of system functions and features do individuals who have chronic health conditions need in order to find relevant resources in their local communities that will be useful for them?
2. What types of information do individuals who have chronic health conditions need in order to assess whether a relevant resource in their local communities will be useful for them?

Methods

Card-sorting is a highly useful methodology for informing the design of online health information systems. Typically, this method is often used to inform the information architecture of online information systems (Kurniawan & Zaphiris, 2003; Wentzel, Müller, Beerlage-de Jong, & van Gemert-Pijnen, 2016) However, card-sorting has also been employed in a broader context within healthcare. Although not always specifically related to the design of online health information systems, researchers have used card-sorting to assess participants' preferred sources of health information (St. Jean, 2014); preferred roles in treatment-related decision-making (Bilodeau & Degner, 1996; Hack, Degner, & Dyck, 1994); and personal strengths in managing their health (Mirkovic et al., 2016). The diversity in the applications of this method suggests its value in understanding the needs and preferences of individuals who have chronic health conditions, even beyond addressing information architecture. Therefore, a closed card-sorting activity was conducted to identify the specific system functions and features, as well as the types of information content, that people with a chronic health condition would find the most useful when trying to find and assess the potential relevance and usefulness of local resources in their communities that can help them to manage their health.

Recruitment

Participants were initially recruited for the online card-sorting study using convenience sampling – an e-mail was sent out through several University-related listservs, which include student, staff, faculty, and alumnae members. Snowball sampling was also used – potential participants who received the recruitment e-mail were asked to forward the e-mail to other people who might be interested in participating in the study. The recruitment e-mail described the eligibility criteria (must be at least 18 years of age and have one or more chronic health conditions), as well as the purpose and methods of the card-sorting study. Interested individuals were asked to click on a URL at the end of the recruitment email in order to complete a screening questionnaire. This questionnaire asked potential participants their age, whether they had one or more chronic health condition(s), and if they had ever searched for relevant resources within their local communities that could help them to more effectively manage their health, such as physicians, physical therapists, support groups, recreation centers, etc. Potential participants who met the eligibility criteria and who reported that they had searched for health-related resources within their communities were then directed to an introductory screen, which asked whether they would still like to participate in the study. Potential participants who affirmed their continued interest in the study were then asked to read and electronically sign an informed consent form on the next screen. After electronically signing the consent form, participants were directed to the background questionnaire and then the card-sorting activity.

Data Collection

Participants completed a background questionnaire requesting basic demographic information, as well as details on their computer/smartphone/Internet access and use and their health-related information seeking behaviors. After completing the background questionnaire, participants were directed to instructions for the card sorting activity. The instructions explained that there were two decks of cards that they would be asked to sort into a set of closed categories. For each of the decks, participants sorted the cards into five categories – very useful, somewhat useful, neutral, not very useful, or not at all useful. Using the first deck (Table 1), participants assessed the usefulness of a range of hypothesized system functions and features for the proposed system, indicating how useful each feature or function would be in helping them to more easily locate relevant resources in their local communities. The second deck (Table 2) included several types of information on resources in local communities that people could use to assess whether the resource would actually be valuable for them in their own personal efforts to manage a chronic health condition.

Table 1. Deck 1 for Card-Sorting Exercise: System Functions/Features

Deck 1: System Functions/Features
1. Find a local resource for a specific health condition (e.g., diabetes; arthritis; sciatica).
2. Add a local resource to the system based on a specific health condition (e.g., diabetes).
3. Add keyword tags to a local resource (e.g., physical therapy; yoga; symptoms).
4. Filter results of local resources with keywords (e.g., yoga; back pain)
5. Rate the usefulness of a local resource.
6. Filter results of local resources based on others' ratings of their usefulness (e.g., only show local resources with a usefulness rating of 4 stars or above).
7. Rate local resources based on how customized they are for various health conditions (e.g., how much is this yoga class tailored for individuals with arthritis).
8. Filter results based on the ratings of how customized they are for various health conditions (e.g. only show local resources with a customized rating of 4 stars or above).
9. Add a free-text review of a local resource.
10. Filter results of local resources based on the number of reviews.
11. Filter reviews/testimonials for a local resource by other users'/reviewers' health conditions (e.g., only show reviews for a local resource posted by users with diabetes).
12. Filter by other users'/reviewers' demographic characteristics (e.g., only show reviews posted by reviewers over the age of 65).
13. Filter by the distance/location.
14. Filter by insurance types accepted.
15. Add a cost rating for a local resource (e.g., \$, \$\$, \$\$\$, etc.).
16. Filter by cost rating.
Other: [Fill in the blank].

Table 2. Deck 2 for Card-Sorting Exercise: Types of Information on Local Resources

Deck 2: Types of Information on Local Resources
1. Type of local resource (e.g., Medical provider, support group, class, etc.).
2. Short description of local resource (e.g., Senior water arthritis exercise class).
3. Location of resource (e.g., Oak Marr Community Center).
4. Physical address of resource (e.g., 3200 Willow Lane Road).

5. Cost of resource (e.g., $6 drop-in fee; $100 for 8-week class).
6. Cost rating of a resource (e.g. $, $$, $$$, etc.).
7. Insurance details (e.g., types of insurances accepted).
8. Link to official website with more information.
9. Contact information.
10. Credentials (e.g., Doctor of Physical Therapy, Registered Dietician, etc.).
11. Ratings of how useful a local resource is from other users.
12. Reviews of a local resource from other users.
13. Strengths of a local resource based on the experiences of other users.
14. Weaknesses of a local resource based on the experiences of other users.
15. Ratings of how much a local resource is customized to meet the needs of people with a particular chronic health condition.
16. Description of how much a local resource is tailored to meet the needs of people with a particular chronic health condition.
17. Users'/Reviewers' specific health conditions.
18. Users'/Reviewers' demographic information (e.g., age).
19. Description of users' interactions with the local resource (e.g., number of visits, experiences with staff members, billing issues, etc.).
Other: [Fill in the blank]

The cards for this activity were developed based on a previous interview study I conducted with 15 participants who have chronic health conditions (Jindal, 2019). Participants shared their experiences searching for information on local resources to manage their chronic health conditions, and described the strategies they used to find this information and the challenges and barriers they encountered in this process. The findings from this earlier study revealed that participants would be willing to use the type of proposed CHIS described in this study, but it would need to be carefully designed to address many of the shortcomings that participants had encountered in their previous attempts to find information on local resources. The cards in this study represent just the system features and functions and types of information that participants indicated would be useful in some way or that seemed like they might address some of the information seeking-related challenges and barriers the participants had encountered in the past. Although the cards do not represent every possible type of information or system feature or function that could potentially be included in the proposed CHIS, they are based directly on the experiences of 15 people who are members of the target population for this system and on their perceptions regarding the specific system features and functions and types of information that would be most important to them.

Participants were not limited to the functions/features/information types listed on the cards provided; they were encouraged to add an unlimited number of their own cards to each deck using the fill-in-the-blank “Other” cards that were also provided. Prior to recruiting participants for this study, the card-sorting activity was administered to three pilot participants to assess whether the content of each card was clear and understandable. Based on their feedback, some necessary adjustments were made to the wording of the cards before the finalized decks were administered for this study.

Qualtrics, online survey software, was used to remotely administer the card-sorting activity to participants from February through March 2019. The Institutional Review Board at the author’s University reviewed and approved all study materials prior to participant recruitment.

Data Analysis

A total of 31 participants completed the study. To analyze the data collected, Qualtrics was used to run a results matrix, which shows the number of times each card was sorted into each of the pre-determined categories for this closed card-sorting activity– very useful, somewhat useful, neutral, not very useful, or not at all useful.

The resulting matrix summarized the number of times each system feature and function and each type of information were sorted into the very useful or somewhat useful categories versus the neutral, not very useful, or not at all useful categories. For the purposes of this study, if the majority of participants indicated a system feature or function was very useful or somewhat useful, I concluded that potential users would find that system feature or function helpful in terms of enabling them to find a relevant resource in their local communities. Similarly, if the majority of participants felt that a type of information was very useful or somewhat useful, I concluded that type of information would be helpful for potential users in determining whether a resource would be useful for them in managing their chronic health condition. Additionally, I also reviewed the cards participants added through the Other (fill-in-the-blank) option in the card-sorting activity. It was not possible to determine if the majority of participants would find those system features or functions or types of information very useful or somewhat useful in a crowdsourced health information system. However, all "Other" cards were carefully reviewed and assessed to identify any major patterns that might emerge from the data. Any related functions, features, or types of information that several participants independently indicated would be useful were deemed to be important to include in the design of the proposed crowdsourced health information system.

Results

A total of 31 people completed the background questionnaire and card-sorting activity for this study. The majority of participants were women (n = 25; 80.6%) and identified as Caucasian (n = 22; 70.9%). The other participants identified as Asian (n

= 4; 12.9%), Black or African-American (n = 2; 6.5%), or multiracial (n = 3; 9.7%). The average age of participants was 39, with all participants falling between the ages of 20 and 71. Most participants were well-educated, holding a graduate or professional degree (n = 17; 54.8%), some graduate or professional degree (n = 4; 12.9%), or a Bachelor's degree (n = 6; 19.4%). The majority (n = 29; 93.5%) also reported that they work in professional occupations, such as education, information technology, information sciences, publishing, research, and management. All participants have access to the Internet and own and regularly use personal computers, tablets, and/or smartphones. Smartphone use was ubiquitous, with all participants reporting accessing the Internet on their smartphones very frequently (n = 28; 90.3%) or frequently (n = 3; 9.7%). Many participants also indicated they accessed the Internet on laptops very frequently (n = 19; 61.3%) or frequently (n = 6; 19.4%). Participants spent an average of seven hours per day on the Internet. More specifically, the majority of participants reported using their smartphones to look for health information very frequently (n = 8; 25.8%), frequently (n = 12; 38.7%), or sometimes (n = 6; 19.4%).

Participants described managing a diverse range of chronic health conditions, such as chronic depression, anxiety, hypertension, fibromyalgia, arthritis, diabetes, sickle cell anemia, and asthma. The majority of participants (n = 25; 80.7%) described managing two or more chronic health conditions at one time. However, most participants felt they were coping somewhat well (n = 18; 58.1%) or very well (n = 5; 16.1%) with these chronic health conditions. Nevertheless, almost all participants felt their chronic health conditions impacted their life either an extreme amount (n = 5; 16.1%), very much (n = 9; 29.0%), or a moderate amount (n = 12; 38.7%).

Most participants felt it was extremely important (n = 4; 12.9%), very important (n = 12; 38.7%), or moderately important (n = 10, 32.3%) to find local resources to help them manage their chronic health conditions. However, nearly all participants generally reported looking for such resources relatively rarely – either a few times over the past year (n = 20; 64.5%) or a few times per month (n = 9; 29.0%). This may be related to the finding that only about a third of participants were either somewhat satisfied (n = 10; 32.3%) or very satisfied (n = 1; 3.2%) with the information they were able to find on local resources. The rest of the participants were either neutral (n = 11; 35.5%), somewhat unsatisfied (n = 7; 22.6%), or very unsatisfied (n = 2; 6.5%) with the information they had found on local resources to manage their health.

Participants felt that a crowdsourced health information system would need to have 14 of the 16 proposed system functions/features from the first deck (Table 1) in order for the system to be useful for them. The majority (16 participants or more) indicated that each of these 14 system functions/features would be very useful or somewhat useful. However, more than half of the participants did not feel that being able to filter results of local resources based on the number of reviews or based on other users'/reviewers' demographic characteristics (e.g., only show reviews posted by reviewers over the age of 65) would be useful. Table 3 has a full description of participants' ratings for each of the proposed system functions and features.

With regard to types of information, participants felt that a crowdsourced health information system would need to have 18 of the 19 types of information mentioned in the second deck (Table 2) in order for the system to be useful for them. The majority (16 participants or more) indicated that each of these 18 system functions/features would be very useful or somewhat useful. However, the majority of participants did not indicate that the user/reviewer's demographic information (e.g., age) would be useful, which is consistent with participants' responses to the first deck. Table 4 has a full description of participants' ratings for each type of information on local resources.

Only six participants used the "Other" cards to suggest additional system functions and features and/or types of information they would like to see in the proposed health information system, so it was not possible to assess any patterns in the data based on their responses. However, participants recommended several interesting options to expand on the design of the proposed system in the future, including a recommendation system for other local resources based on one's previous selections, distance to public transportation, and information on accessibility accommodations.

Table 3: System Functions and Features (Deck 1)

Deck 1: System Functions/ Features	**Very Useful**	**Somewhat Useful**	**Neutral**	**Not Very Useful**	**Not At All Useful**	**% Very + Somewhat Useful (>50%?)**
Find a local resource for a specific health condition (e.g., diabetes; arthritis; sciatica).	25 (80.6%)	6 (19.4%)	0	0	0	100.0% (Yes)

Deck 1: System Functions/ Features	**Very Useful**	**Somewhat Useful**	**Neutral**	**Not Very Useful**	**Not At All Useful**	**% Very + Somewhat Useful (>50%?)**
Add a local resource to the system based on a specific health condition (e.g., diabetes).	13 (41.9%)	11 (35.5%)	6 (19.4%)	1 (3.2%)	0	77.4% (Yes)
Add keyword tags to a local resource (e.g., physical therapy; yoga; symptoms).	14 (45.2%)	9 (29.0%)	6 (19.4%)	2 (6.5%)	0	74.2% (Yes)
Filter results of local resources with keywords (e.g., yoga; back pain)	18 (58.1%)	9 (29.0%)	3 (9.7%)	1 (3.2%)	0	87.1% (Yes)
Rate the usefulness of a local resource.	17 (54.8%)	9 (29.0%)	3 (9.7%)	1 (3.2%)	1 (3.2%)	83.8% (Yes)
Filter results of local resources based on others' ratings of their usefulness (e.g., only show local resources with a usefulness rating of 4 stars or above).	18 (58.1%)	8 (25.8%)	2 (6.5%)	3 (9.7%)	0	83.9% (Yes)
Rate local resources based on how customized they are for various health conditions (e.g., how much is this	9 (29.0%)	16 (51.6%)	4 (13.0%)	2 (6.5%)	0	80.6% (Yes)

Deck 1: System Functions/ Features	**Very Useful**	**Somewhat Useful**	**Neutral**	**Not Very Useful**	**Not At All Useful**	**% Very + Somewhat Useful (>50%?)**
yoga class tailored for individuals with arthritis).						
Filter results based on the ratings of how customized they are for various health conditions (e.g. only show local resources with a customized rating of 4 stars or above).	9 (29.0%)	9 (29.0%)	9 (29.0%)	4 (13.0%)	0	58.0% (Yes)
Add a free-text review of a local resource.	9 (29.0%)	7 (22.6%)	7 (22.6%)	7 (22.6%)	1 (3.2%)	51.6% (Yes)
Filter results of local resources based on the number of reviews.	5 (16.1%)	9 (29.0%)	9 (29.0%)	5 (16.1%)	3 (9.7%)	45.1% (No)
Filter reviews/testimonials for a local resource by other users'/reviewers' health conditions (e.g., only show reviews for a local resource posted by users with diabetes).	14 (45.2%)	6 (19.4%)	6 (19.4%)	5 (16.1%)	0	64.6% (Yes)
Filter by other users'/reviewers' demographic	2 (6.5%)	8 (25.8%)	11 (35.5%)	5 (16.1%)	5 (16.1%)	32.3% (No)

Deck 1: System Functions/ Features	**Very Useful**	**Somewhat Useful**	**Neutral**	**Not Very Useful**	**Not At All Useful**	**% Very + Somewhat Useful (>50%?)**
characteristics (e.g., only show reviews posted by reviewers over the age of 65).						
Filter by the distance/location.	22 (71.0%)	8 (25.8%)	1 (3.2%)	0	0	96.8% (Yes)
Filter by insurance types accepted.	22 (71.0%)	8 (25.8%)	0	1 (3.2%)	0	96.8% (Yes)
Add a cost rating for a local resource (e.g., $, $$, $$$, etc.).	11 (35.5%)	16 (51.6%)	3 (9.7%)	1 (3.2%)	0	87.1% (Yes)
Filter by cost rating.	10 (32.3%)	12 (38.7%)	7 (22.6%)	2 (6.5%)	0	71.0% (Yes)

Table 4: Types of Information on Local Resources (Deck 2)

Deck 2: Types of Information on Local Resources	**Very Useful**	**Somewhat Useful**	**Neutral**	**Not Very Useful**	**Very Useful**	**% Very + Somewhat Useful (>50%?)**
Type of local resource (e.g., Medical provider, support group, class, etc.).	28 (90.3%)	3 (9.7%)	0	0	0	100.0% (Yes)
Short description of local resource (e.g., Senior water arthritis exercise class).	25 (80.6%)	6 (19.4%)	0	0	0	100.0% (Yes)

Deck 2: Types of Information on Local Resources	**Very Useful**	**Somewhat Useful**	**Neutral**	**Not Very Useful**	**Very Useful**	**% Very + Somewhat Useful (>50%?)**
Location of resource (e.g., Oak Marr Community Center).	27 (87.1%)	2 (6.5%)	1 (3.2%)	1 (3.2%)	0	93.6% (Yes)
Physical address of resource (e.g., 3200 Willow Lane Road).	27 (87.1%)	3 (9.7%)	1 (3.2%)	0	0	96.8% (Yes)
Cost of resource (e.g., $6 drop-in fee; $100 for 8-week class).	24 (77.4%)	7 (22.6%)	0	0	0	100.0% (Yes)
Cost rating of a resource (e.g. $, $$, $$$, etc.).	9 (29.0%)	18 (58.1%)	2 (6.5%)	2 (6.5%)	0	87.1% (Yes)
Insurance details (e.g., types of insurances accepted).	21 (67.7%)	7 (22.6%)	2 (6.5%)	1 (3.2%)	0	90.3% (Yes)
Link to official website with more information.	26 (83.9%)	5 (16.1%)	0	0	0	100.0% (Yes)
Contact information.	22 (71.0%)	5 (16.1%)	3 (9.7%)	0	1 (3.2%)	87.1% (Yes)
Credentials (e.g., Doctor of Physical Therapy, Registered Dietician, etc.).	13 (41.9%)	10 (32.3%)	5 (16.1%)	2 (6.5%)	1 (3.2%)	74.2% (Yes)
Ratings of how useful a	15 (48.4%)	8 (25.8%)	4 (13.0%)	3 (9.7%)	1 (3.2%)	74.2% (Yes)

Deck 2: Types of Information on Local Resources	Very Useful	Somewhat Useful	Neutral	Not Very Useful	Very Useful	% Very + Somewhat Useful (>50%?)
local resource is from other users.						
Reviews of a local resource from other users.	13 (41.9%)	13 (41.9%)	3 (9.7%)	2 (6.5%)	0	83.8% (Yes)
Strengths of a local resource based on the experiences of other users.	6 (19.4%)	15 (48.4%)	8 (25.8%)	0	2 (6.5%)	67.8% (Yes)
Weaknesses of a local resource based on the experiences of other users.	5 (16.1%)	13 (41.9%)	9 (29.0%)	2 (6.5%)	2 (6.5%)	58.0% (Yes)
Ratings of how much a local resource is customized to meet the needs of people with a particular chronic health condition.	8 (25.8%)	13 (41.9%)	7 (22.6%)	3 (9.7%)	0	67.7% (Yes)
Description of how much a local resource is tailored to meet the needs of people with a particular chronic health condition.	15 (48.4%)	6 (19.4%)	7 (22.6%)	3 (9.7%)	0	67.8% (Yes)
Users'/Reviewers' specific	15 (48.4%)	8 (25.8%)	5 (16.1%)	2 (6.5%)	1 (3.2%)	74.2% (Yes)

Deck 2: Types of Information on Local Resources	**Very Useful**	**Somewhat Useful**	**Neutral**	**Not Very Useful**	**Very Useful**	**% Very + Somewhat Useful (>50%?)**
health conditions.						
Users'/Reviewers' demographic information (e.g., age).	5 (16.1%)	7 (22.6%)	13 (41.9%)	4 (13.0%)	2 (6.5%)	38.7% (No)
Description of users' interactions with the local resource (e.g., number of visits, experiences with staff members, billing issues, etc.).	8 (25.8%)	8 (25.8%)	9 (29.0%)	5 (16.1%)	1 (3.2%)	51.6% (Yes)

Design Implications

The results demonstrate that participants are interested in using a crowdsourced health information system to find information on local resources that can help them better manage their chronic health conditions. However, each local resource must be easily discoverable (through the use of several types of system functions and features), with detailed information provided on each local resource. Based on the results of this card-sorting activity, I created five low-fidelity paper prototypes (Landing Page, Adding a Local Resource, Rating and Reviewing a Local Resource, Filtering Search Results, and Profile) that represent the proposed system features and functions and types of information that participants indicated they would find most useful. I chose to design this proposed system as a mobile prototype since most of the participants in the study indicated they regularly use their smartphones to search for online health information. Therefore, a smartphone application will likely be the best format to deliver information on local resources to many of the individuals who have chronic health conditions.

Most participants indicated that the ability to easily find a local resource based on a specific health condition is an essential function of the proposed system. The first low-fidelity wireframe (Figure 1: Landing Page) demonstrates a simple option for intended users to begin their search by selecting their health condition from a prepopulated list displayed on the landing page. Users would also have the option to simply use the "Search" field on the landing page to search for local resources using keywords. For example, if a user cannot (or does not want to) select their health condition from the prepopulated list of health conditions, they could enter their health condition in the "Search" field instead. Alternatively, a user could also search for a local resource based on a symptom (e.g., back pain). All local resources that have been tagged by other users with the keyword(s) entered into the "Search" field (e.g., hypothyroidism) would then be displayed. Users would be able to enter multiple keywords into the "Search" field or select multiple health conditions from the prepopulated list on the landing page; however, only local resources tagged with all of those selected conditions or keywords would be displayed. Results would likely be based on a user's current location (after receiving permission to enable location services through the application), assuming an alternative location is not provided by the user.

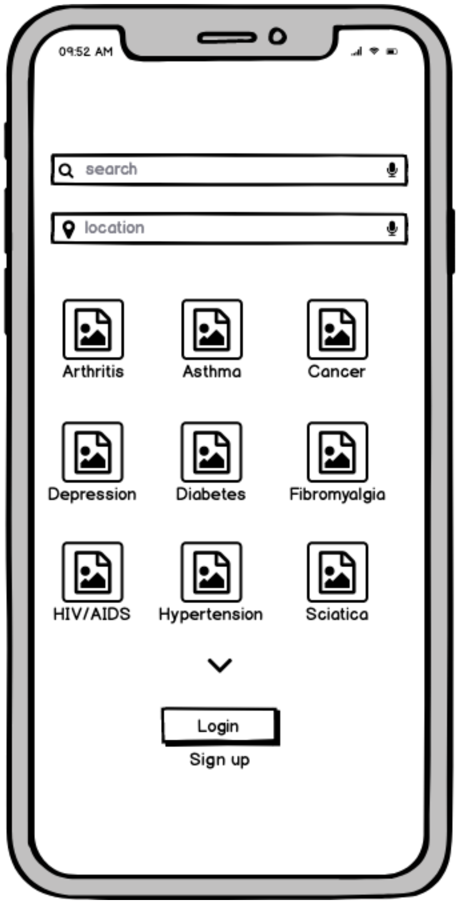


Figure 1: Landing Page

Adding a local resource is another critical function of the proposed system. Users could be able to quickly and easily add a local resource to the system to encourage substantial input to populate the system. However, a user must also add enough detail to make the information on the local resource valuable to other potential users. Participants in this study indicated the types of information they felt would be most valuable to them in deciding if a local resource could potentially be helpful to them in managing their chronic health conditions. The second low-fidelity wireframe (Figure 2: Adding a Local Resource) illustrates how a user would add these points of information to create a local resource in the system. In order to simplify the process, users would not be required to rate and review the local resource when they initially add it to the system. However, a reminder method would likely need to be in place to ask the user to rate and review the resource at a later time in order to promote the population of useful information into the system. Redundancy management would also be an essential component of this process to ensure that the same resource is not entered into the system multiple times in different ways. This issue would need to be addressed at a later point in the design and development of this system.

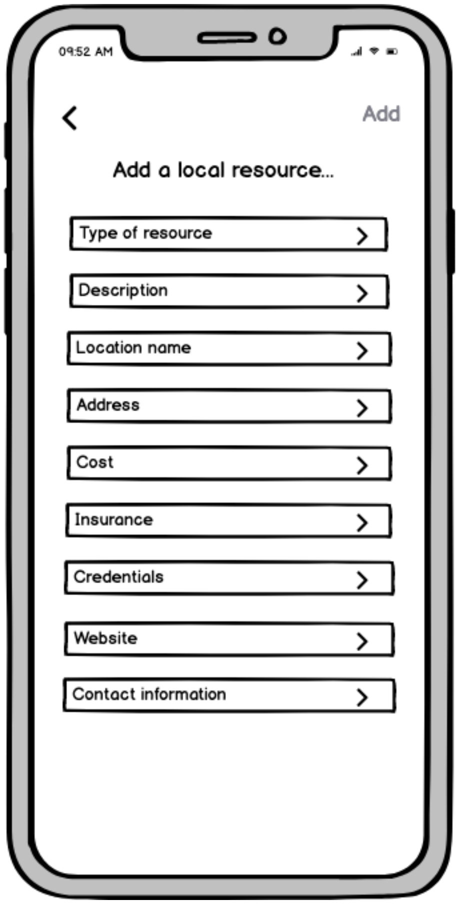


Figure 2: Adding a Local Resource

Rating and reviews in the proposed system represent another valuable form of information for potential users. Participants (and potential users) want credible and personalized details on local resources from other individuals who understand their unique needs around managing specific chronic health conditions. The strengths, weaknesses, customization strategies, and other types of information participants indicated would be useful to them can be valuable information for potential users endeavoring to choose a local resource that will meet their needs, without investing a substantial amount of time and effort in the process. The third low-fidelity wireframe (Figure 3: Rating and Reviewing a Local Resource) illustrates how users can rate and review a local resource, providing the types of information participants indicated would be most useful.

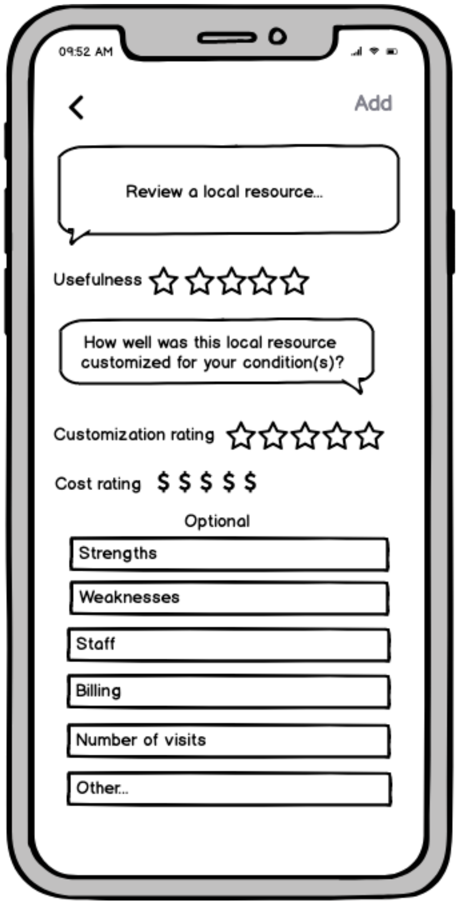


Figure 3: Rating and Reviewing a Local Resource

The fourth low-fidelity wireframe (Figure 4: Filtering Search Results) shows options for potential users to filter their search results, enabling them to avoid information overload. Potential users should be able to easily select and/or remove one or more filters to increase the discoverability of the local resources likely to be the most relevant to them. This wireframe encompasses the categories participants indicated would be most useful for them when filtering their search results in the system. Participants will not be able to precisely describe what they need in a local resource as well as they might be able to through an offline WOM exchange, so filtering is a critical tool to help users quickly refine and narrow their search results.

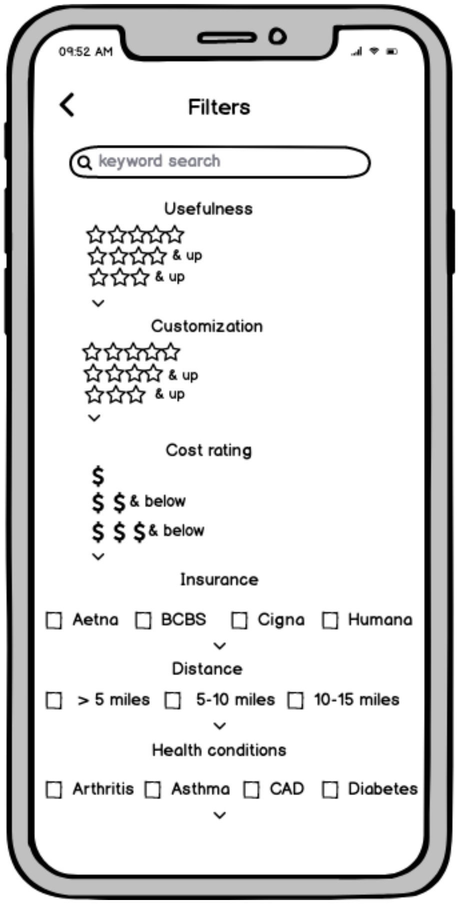


Figure 4: Filtering Search Results

The last low-fidelity wireframe (Figure 5: Profile) illustrates the profile that new users would create when signing up for an account in the system, although this would not be a requirement to use the system. The profile will include a username, password reset function, and the option to enter some general demographic information (e.g., age and gender). Most importantly, users will also be asked to select any chronic health conditions they are currently managing. This will allow users to filter by these characteristics as well as to search for local resources that individuals with the same or similar chronic health conditions have found helpful.

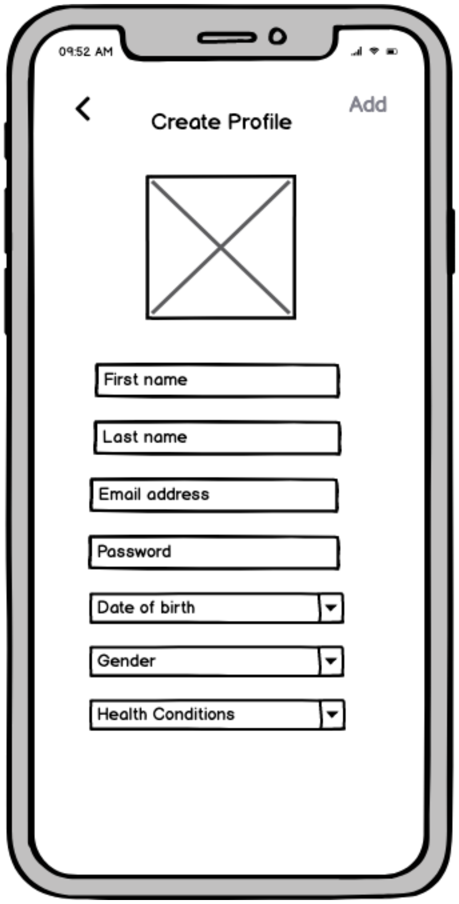


Figure 5: Profile

Limitations

This study has several limitations. The remote nature of this study provided access to a larger and more diverse sample of participants; however, a moderator was not present to answer participants' questions or provide clarifications on each of the cards. Therefore, participants' interpretations of the cards in the study remain unclear. As a result, the findings of this study may be biased because participants may have varying interpretations the meaning of one or more cards in the card-sorting activity. Additionally, the lack of a moderator made it unfeasible to probe participants further and draw out additional information on *why* they felt certain system functions/features and types of information would be most useful in a crowdsourced health information system.

The findings from this study are also not generalizable beyond this group of 31 participants, given the small sample size. Further, the small sample size of this study means that it is not possible to conduct a statistical analysis on the data, since the results would have a high margin of error, limiting the credibility of any statistical findings. However, the data from this card-sorting study is meant to inform the initial low-fidelity design of the proposed CHIS, rather than to generalize the results to all individuals who have chronic health conditions. Nielson (2004) explains that card-sorting studies generally have diminishing returns in terms of valuable insights for the information architecture of a system after testing 30 participants. Therefore, I also plan to continue iterating on the design of this proposed CHIS further with additional qualitative research to ensure the design is ideal for the target population of this system.

Lastly, the individuals who chose to participate in this study were initially recruited through a University-related listserv. Therefore, the sample is likely biased due to the nature of this convenience/snowball sample. Individuals who were contacted for participation likely have a higher level of digital literacy and education than the general population. The participants in this study may also be more likely to actively seek out local resources to manage their chronic health conditions as a result. However, people with chronic health conditions who have lower digital health literacy and less cultural capital than the participants in this study may have an even lower likelihood of being able to find relevant and potentially useful local resources in their communities, whether online or through WOM communications. A usable and detailed crowdsourced health information system as proposed herein may potentially further democratize this process of discovery for individuals who do not have the same level of cultural capital and digital health literacy as the participants in this study.

Future Research

This card-sorting study facilitated the initial low-fidelity design of a proposed CHIS with information on local health-related resources for individuals who have health chronic health conditions. The results of this study may lead to the development of a highly useful tool to help people to become aware of and able to take advantage of resources in their local communities that can enable them to better manage their chronic health conditions. However, additional qualitative research to ensure the system is as useful and usable as possible could be helpful to ensure the potential uptake of this system by the target population. I plan to conduct participatory design sessions with this same population in the future to garner direct, moderated input from participants on each of the five low-fidelity paper prototypes (Landing Page, Adding a Local Resource, Rating and Reviewing a Local Resource, Filtering Search Results, and User Profile) I developed based on the findings from this study. This next step in my research will allow me to engage directly with potential users of this type of system and probe them to ensure that the design of the proposed CHIS fully meets their needs and then make any subsequent changes, as necessary.

References

1. Adams R. J. (2010). Improving health outcomes with better patient understanding and education. *Risk Manag. Healthc. Policy, 3*, 61–72. http://doi.org/10.2147/RMHP.S7500
2. Barr, V.J., Robinson, S., Marin-Link, B., Underhill, L., Dotts, A., Ravensdale, D., & Salivaras, S. (2003). The expanded Chronic Care Model: An integration of concepts and strategies from population health promotion and the Chronic Care Model. *Hosp. Q., 7*(1), 73-82. http://dx.doi.org/10.12927/hcq.2003.16763
3. Bazata, D.D., Robinson, J.G., Fox, K.M., Grandy, S., & SHIELD Study Group. (2008). Affecting behavior change in individuals with diabetes: Findings from the Study to Help Improve Early Evaluation and Management of Risk Factors Leading to Diabetes (SHIELD). *Diabetes Educ., 34*(6), 1025-1036. https://doi.org/10.1177/0145721708325767
4. Bilodeau, B.A. & Degner, L.F. (1996). Information needs, sources of information, and decisional roles in women with breast cancer. *Oncol. Nurs. Forum., 23*(4), 691-696.
5. Brabham, D.C. (2013). *Crowdsourcing*. Cambridge, MA: The MIT Press Essential Knowledge Series.

6. Butler, B., Sproull, L., Kiesler, S., & Kraut, R. (2002). “Community effort in online groups: who does the work and why,” in *Leadership at a Distance*, S. Weisband, L. Atwater (eds.), Lawrence Erlbaum Publishers, Mahwah, NJ, p. 171-194.
7. De Cruppé, W. & Geraedts, M. (2017). Hospital choice in Germany from the patient’s perspective: A cross-sectional study. *BMC Health Services Research, 17*, 720. https://doi.org/10.1186/s12913-017-2712-3
8. Fastring, D., Mayfield-Johnson, S., & Madison, J. (2017). Evaluation of a health education intervention to improve knowledge, skills, behavioral intentions and resources associated with preventable determinants of infant mortality. *Divers. Equal. Health Care, 14*(6), 290–295.
9. Gao, G.G., McCullough, J.S., Agarwal, R., & Jha, A.K. (2012). A changing landscape of physician quality reporting: Analysis of patients’ online ratings of their physicians over a 5-year period. *J. Int. Med. Res., 14*(1), e38. https://doi.org/10.2196/jmir.2003
10. Hack, T.F., Degner, L.F. & Dyck, D.G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Soc. Sci. Med., 39*(2), 279-289. https://doi.org/10.1016/0277-9536(94)90336-0
11. Hanauer, D.A., Zheng, K., Singer, D.C., Gebremariam, A., & Davis, M.M. (2014). Public awareness, perception, and use of online physician rating sites. *JAMA*, *311*(7), 734-735. https://doi.org/10.1001/jama.2013.283194

12. Huete-Alcocer, N. (2017). A literature review of word of mouth and electronic word of mouth: Implications for consumer behavior. *Front Psychol., 8*:1256. https://doi.org/10.3389/fpsyg.2017.01256
13. Jiang, T., Stillson, C.H., Pollack, C.E., Crossette, L., Ross, M., Radhakrishnan, A., & Grande, D. (2017). How men with prostate cancer choose specialists: A qualitative study. *JABFM, 30*(2), 220-229. https://doi.org/10.3122/jabfm.2017.02.160163
14. Jindal, G. (2019). Assessing the value of an online repository of local resources for people who have chronic health conditions. *J. Consum. Health Internet*, *23*(2), 123-145. https://doi.org/10.1080/15398285.2019.1611171
15. Kadry, B., Chu, L.F., Kadry, B., Gammas, D., & Macario, A. (2011). Analysis of 4999 online physician ratings indicates that most patients give physicians a favorable rating. *J. Int. Med. Res.,13*(4), e95. https://doi.org/10.2196/jmir.1960
16. Kennedy, A., Bower, P., Reeves, D., Blakeman, T., Bowen, R., Chew-Graham, C., Eden, M., et al. (2013). Implementation of self management support for long term conditions in routine primary care settings: Cluster randomised controlled trial. *BMJ, 346*: f2882. https://doi.org/10.1136/bmj.f2882
17. Kilaru, A.S., Meisel, Z.F., Paciotti, B., Ha, Y.P., Smith, R.J., Ranard, B.L., & Merchant, R.M. (2016). What do patients say about emergency departments in online reviews? A qualitative study. *BMJ Quality & Safety, 25*(1), 14-24. http://dx.doi.org/10.1136/bmjqs-2015-004035

18. Kordzadeh, N. (2018). Physician ratings published on healthcare organizations' websites: Are they biased? *HICSS-51*, 3347-3354. https://doi.org/10.24251/hicss.2018.424
19. Kurniawan, S.H. & Zaphiris, P. (2003). Web health information architecture for older users. *IT&Society, 1*(3), 42-63.
20. Kumar, S. & Preetha, G. (2012). Health promotion: An effective tool for global health. *Indian J. Community Med.*, *37*(1), 5–12. https://doi.org/10.4103/0970-0218.94009
21. Lagu, T., Hannon, N.S., Rothberg, M.B., & Lindenauer, P.K. (2010). Patients' evaluations of health care providers in the era of social networking: An analysis of physician-rating websites. *J. Gen. Intern. Med., 25*(9), 942–946. https://doi.org/10.1007/s11606-010-1383-0
22. Liang, B. & Scammon, D.L. (2011). E-Word-of-Mouth on health social networking sites: An opportunity for tailored health communication. *J. Consumer Behav., 10*(6), 322-331. https://doi.org/10.1002/cb.378
23. Lin, S.H. & Lin, T.M.Y. (2018). Demand for online platforms for medical word-of-mouth. *J. Int. Med. Res., 46*(5), 1910-1918. https://doi.org/10.1177/0300060518757899
24. March, J.G. & Simon, H.A. (1958). *Organizations*. Cambridge, Massachusetts: Wiley-Blackwell.
25. Martin, S. (2017). Word-of-mouth in the health care sector: A literature analysis of the current state of research and future perspectives. *Int. Rev.*

Public Nonprofit Mark., 14(1), 35-56. https://doi.org/10.1007/s12208-016-0154-y

26. McCaughey, D., McGhan, G., Walsh, E.M., Rathert, C., & Belue, R. (2014). The relationship of positive work environments and workplace injury: Evidence from the National Nursing Assistant Survey. *Health Care Management Review*, *39*(1), 75–88. https://doi.org/10.1097/HMR.0b013e3182860919
27. Mirkovic, J., Kristjansdottir, O.B., Stenberg, U., Krogseth, T., Stange, K.C., & Ruland, C.M. (2016). Patient insights into the design of technology to support a strengths-based approach to health care. *JMIR Research Protocols, 5*(3), e175. https://doi.org/10.2196/resprot.5906
28. Nielsen, J. (2004, July 18). Card sorting: How many users to test. *Nielsen Norman Group*. Retrieved from: https://www.nngroup.com/articles/card-sorting-how-many-users-to-test/.
29. Pasternak, A. & Scherger, J.E. (2009). Online reviews of physicians: What are your patients posting about you? *Fam. Pract. Manag., 16*(3), 9-11.
30. Pettigrew, K.E. & Durrance, J.C. (2001). Public use of digital community information systems: Findings from a recent study with implications for system design. *JCDL'01*, 136-143. https://doi.org/10.1145/379437.379470
31. Ranard, B.L., Werner, R.M., Antanavicius, T., Schwartz, H.A., Smith, R.J., Meisel, Z.F., Asch, D.A., Ungar, L.H., & Merchant, R.M. (2016). Yelp reviews of hospital care can supplement and inform traditional surveys of the

patient experience of care. *Health Aff., 35*(4), 697-705. https://doi.org/10.1377/hlthaff.2015.1030

32. Ryan, P. (2009). Integrated Theory of Health Behavior Change: Background and intervention development. *Clin Nurse Spec., 23*(3): 161–172. https://doi.org/10.1097/NUR.0b013e3181a42373
33. Shreffler-Grant, J., Weinert, C., Nichols, E., & Ide. B. (2005). Complementary therapy use among older rural adults. *Public Health Nursing*, 22(4), 323–331. https://doi.org/10.1111/j.0737-1209.2005.220407.x
34. St. Jean, B. (2014). Devising and implementing a card-sorting technique for a longitudinal investigation of the information behavior of people with type 2 diabetes. *Library & Information Science Research, 36*(1), 16-26. https://doi.org/10.1016/j.lisr.2013.10.002
35. Swan M. (2012). Crowdsourced health research studies: an important emerging complement to clinical trials in the public health research ecosystem. *J. Med. Internet. Res.,14*(2), e46. https://doi.org/10.2196/jmir.1988
36. The Diabetes Prevention Program (DPP) Research Group. (2002). The Diabetes Prevention Program (DPP): Description of lifestyle intervention. *Diabetes Care, 25*(12), 2165-2171. https://doi.org/10.2337/diacare.25.12.2165
37. Tu, H.T. & Lauer, J.R. (2008). Word of mouth and physician referrals still drive health care provider choice. *Res. Brief., 9*:1-8.
38. Wazny K. (2018). Applications of crowdsourcing in health: An overview. *J. Glob. Health, 8*(1), 010502. https://doi.org/10.7189/jogh.08.010502

39. Wentzel, M.J., Müller, F., Beerlage-de Jong, N., & van Gemert-Pijnen, J.E.W.C. (2016). Card sorting to evaluate the robustness of the information architecture of a protocol website. *Int. J. Med. Inform., 86*, 71-81. https://doi.org/10.1016/j.ijmedinf.2015.12.003

40. Yahanda, A.T., Lafaro, K.J., Spolverato, G., & Pawlik, T.M. (2016). A systematic review of the factors that patients use to choose their surgeon. *World J. Surg., 40*(1), 45-55. https://doi.org/10.1007/s00268-015-3246-7

Chapter 4: Design recommendations for a crowdsourced health information system with local health-related resources: A participatory design study

This article (Chapter 4) is under review by the *Library Hi Tech*. This version of the article has retained the same content, citations, and formatting as the manuscript currently under review.

Abstract

Methodology: Participatory design sessions were conducted with ten individuals who have chronic health conditions to garner their feedback on five low-fidelity, paper wireframes representing a proposed crowdsourced health information system (CHIS). Purpose: Individuals who have chronic health conditions often need support to make the necessary lifestyle changes to successfully manage their health. Local health-related resources in these individuals' communities can provide an important form of instrumental support. However, obtaining information on local resources that may be personally useful can be difficult. Crowdsourcing information on local resources using a new, proposed CHIS is a possible strategy to meet this information need. The aim of this study was to draw on direct input from individuals who have chronic health conditions to inform the ideal, low-fidelity design of the proposed CHIS. Findings: Participants found significant value in many of the proposed system functions and features and types of content in the each of the wireframes. They also made suggestions for several changes and adjustments to each of the wireframes, thereby enabling the researcher to optimize the usability and usefulness of the proposed CHIS for potential user.

Originality/value: The findings from this study help to inform the optimal design of the proposed CHIS. The proposed system will enable individuals who have chronic health conditions to more systematically find and share information on local health-related resources.

Keywords: Chronic illness; chronic health condition; community resource; information need; information seeking; user research; participatory design; consumer health information

Introduction

Self-management support is a critical component of effective chronic illness care. Individuals who have chronic health conditions often require intensive, instrumental support to make sustainable long-term lifestyle changes to improve and maintain their health. Practical strategies to manage the complex components of their care can be essential to this process (Jeon et al., 2010; Taylor et al., 2014). However, the existing health care delivery system in the United States is primarily centered on the treatment of acute health conditions, rather than on educating patients about prevention and the actions necessary for long-term management of a chronic health condition (Institute of Medicine, 2001).

The Chronic Care Model (CCM), formulated to provide strategies to address the inadequate care individuals who have chronic health conditions receive through the health care delivery system, is comprised of six major elements: (1) community resources and policies; (2) the health system organization of care; (3) self-management support; (4) delivery system design; (5) decision support; and (6) clinical information systems (Improving Chronic Illness Care, 2018; Wagner et al., 1996). This model specifically emphasizes the importance of connecting individuals who have chronic health conditions with useful local health-related resources located in their own communities that can help them to more effectively manage their health. Several interventions have already emphasized the benefits of the application of the CCM to interventions tailored for people who have various chronic health conditions, including diabetes, cardiovascular disease, cancer, etc. Many of these interventions demonstrated an improvement in participants' quality of care and their health outcomes (Coleman et al., 2009; McCorkle et al., 2011; Stellefson et al., 2013).

Despite the successes of these applications of the CCM, the prevalence of fee-for-service payment models restricts the potential for widespread adoption of these types of interventions within many healthcare delivery systems (Bodenheimer et al., 2002). Although the passage of the Patient Protection and Affordable Care Act (ACA) in 2010 offered some new value-based payment models for health care delivery systems to improve their chronic illness care for patients (Clarke et al., 2017), broader implementation still remains limited, especially within a contentious and shifting political environment. Healthcare providers currently have a limited ability to assist patients with effectively managing a chronic illness, particularly within the confines of existing healthcare delivery systems, despite innovative approaches based on the CCM.

Consumer health technologies offer new opportunities to apply the CCM to chronic illness care (Gee et al., 2015; Siminerio, 2010). However, despite the proliferation of these new technologies, individuals who have chronic health conditions still rely heavily on word of mouth to obtain information on useful resources in their local communities that can help them to better manage their health (Martin, 2017). Existing consumer health technologies are still limited in their ability to provide targeted information on relevant local resources. Several online consumer health interventions have attempted to provide information on useful local resources within geographic communities; however, they often face problems with sustainability, and the quality and detail of the information they offer is insufficient and/or fragmented (Huete-Alcocer, 2017; Jindal, 2019; Pettigrew and Durrance, 2001; Synnot et al., 2016; Van Velsen et al., 2013).

Some existing research indicates that individuals who have chronic health conditions are interested in using consumer health information systems that would enable them to crowdsource information regarding relevant local resources (e.g. community health centers, fitness classes, support groups, etc.) in their communities that can help them to manage their health (Jindal, 2019; Lagu et al., 2010; Pettigrew and Durrance, 2001). However, the design and content of this type of crowdsourced health information system (CHIS) would be critical to its potential adoption and use because the exchange of information through computer-mediated environments lacks the socioemotional and verbal cues that can provide additional context to better enable users to decide whether a local resource will be useful for them (Markham, 2005). This type of CHIS would need to have the necessary functions and features to allow potential users who have chronic health conditions to successfully identify relevant resources in their communities. Complementarily, users would also need specific types of information on each resource in order to accurately assess whether it will be useful for them (Jindal, 2019; Lagu et al., 2010; Pettigrew and Durrance, 2001).

Building on this prior research, I conducted a card-sorting study (Jindal, 2020) to investigate the ideal design for this type of CHIS. I assessed participants' perceptions regarding the usefulness of a range of types of information on local resources (e.g., location, cost, reviews, ratings, etc.) and various system functions and features (e.g., keyword search, filters, etc.) in order to inform the low-fidelity design for a proposed CHIS. Based on the results of this card-sorting study, I developed a set of five paper-based wireframes representing the proposed CHIS with information on relevant local resources for individuals who have chronic health conditions. These wireframes for the proposed CHIS include (1) the landing (home) page; (2) adding a local resource; (3) rating and reviewing a local resource; (4) filtering search results; and (5) user profile page.

This prior study was an important starting point for the design of the proposed CHIS, but it was conducted entirely online (Jindal, 2020). The card-sorting study lacked sufficient explanatory depth and detail to translate participants' varied and subjective experiences managing their chronic health conditions into the final low-fidelity design of the proposed CHIS. Therefore, I leveraged the wireframes developed based on the findings from this earlier card-sorting study, to conduct this study focused on garnering direct feedback from representative users of the proposed CHIS. I conducted a participatory design study with 10 participants who have chronic health conditions. I specifically investigated the following research questions: (1) How useful do participants find the system's proposed functions and features?; (2)

How usable do participants find the system’s proposed features and functions?; (3) How useful do participants find the various types of information on each local resource in helping them to determine whether it would be relevant and useful for them in managing their chronic health condition?; (4) What changes do participants recommend to improve the content and design of the proposed system?; and (5) How should the initial wireframes be adjusted based on the findings from the co-design sessions? The goal of these participatory design sessions was to improve upon the original wireframes from the card-sorting study through additional user testing. The revised wireframes based on the results of this study are shown in the Discussion section.

Methods

Co-designing with representative users can be highly beneficial in the development of an online information system, as participants can share critical insights into the content and the design of a system as “experts of their experience” (Sanders and Stappers, 2013, p. 24). In a traditional usability study, participants generally complete a set of predetermined tasks to assess the usability of an existing system. However, this study aimed to reach a broader understanding of participants’ insights regarding the design of the system through an interactive participatory design process. Participants were meant to be active co-creators in this research. Similar research has demonstrated the benefits of this more collaborative and creative exchange of ideas to identify new design possibilities from a “context-sensitive” perspective (Mirkovic et al., 2018).

The initial set of low-fidelity paper-based wireframes I used for this study, based on my earlier work (Jindal, 2020), represent screens in a proposed CHIS with the functions and features deemed necessary by participants from the previous study to find and share information on local resources in their communities to manage their health. For this study, participants were asked to share their observations as they reacted to each paper wireframe and make or draw suggestions for additions and/or alterations based on their own experiences managing their chronic health conditions.

Recruitment

Participants were recruited for one-on-one participatory design sessions through an e-mail sent out through several University-related listservs, which include student, staff, faculty, and alumnae members. Snowball sampling was also used, as potential participants who received the recruitment e-mail were asked to forward the e-mail to others who might be interested. The recruitment e-mail described the participatory design study in more detail, outlining the purpose and the methods. The inclusion criteria for this study required participants to be at least 18 years old and to have at least one chronic health condition. Individuals who were interested in participating in the study were required to attend the session in-person, given the nature of the study, which involved co-designing with paper materials. Potential participants were directed to a screening questionnaire from the recruitment e-mail to ensure they met the inclusion criteria. Individuals who met the inclusion criteria were subsequently contacted and scheduled for an in-person, one-on-one participatory design session at the researcher’s University. Prior to beginning the actual study, two professionals in the human-centered design field were asked to serve as expert reviewers and to inform the researcher as they finalized the procedures for the study. The structure and content of the sessions were then adjusted based on the feedback received from these expert reviewers. After these adjustments were made, the actual study began.

Participatory Design Sessions

At the beginning of each co-design session, the participant was briefed on the purpose and procedures for the participatory design session and asked to sign an informed consent form. Each participant was provided with a toolkit (which included multicolored pens, pencils, markers, paper, sticky notes, scissors, tape, etc.) to help them generate ideas and elaborate on their thoughts throughout the process. However, use of the toolkit was optional; participants who felt more comfortable simply describing their reactions to the wireframes and/or directly providing their suggestions for changes were not required to use the toolkit.

Each participant also received a copy of each paper wireframe to encourage them to write, sketch, draw, cut, and add to the wireframes. I briefly described the functions, features, and content of each paper wireframe to the participant. The use of paper copies of each wireframe aimed to help circumvent any hesitation participants might have had in assessing the design of the proposed system through a more formalized click-through prototype with the wireframes. However, the researcher explained that the low-fidelity wireframes were meant to serve only as a guide.

Participants were not required to react to the wireframes if they preferred to suggest a completely different type of design for the proposed CHIS during the session. In order to promote more open-ended feedback, participants also received paper with an empty smartphone outline (see Figure 1). Participants were assured that the proposed CHIS as described to them is still in an early, malleable stage of development, open to changes based on their suggestions and alternative interpretations of the current wireframes based on their own experiences managing their chronic health conditions.

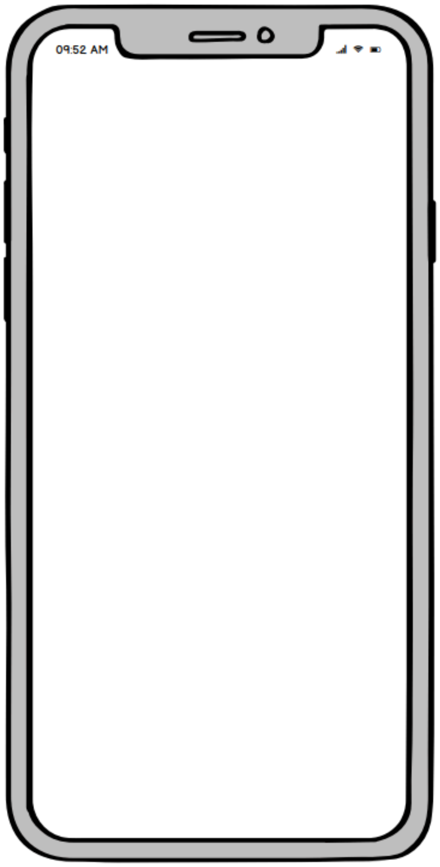


Figure 1: Empty Smartphone Outline

Data Analysis

Each co-design session was audio-recorded in order to collect all relevant data from each session, particularly those resulting in limited design product. After the participatory design sessions were completed, the audio-recordings were transcribed.

Approximately 11 hours and 11 minutes of audio recording were collected, in total. Sessions lasted between 46 and 78 minutes, averaging just over one hour.

The transcriptions and participants' design products were analyzed after all ten sessions were completed in order to assess the complete data set simultaneously. I reviewed, coded and analyzed the transcripts and design product from each participatory design session using thematic analysis with a general inductive approach (Braun and Clarke, 2006). I produced five initial sets of codes based on participants' reactions to each of the five low-fidelity wireframes I had developed to represent the proposed CHIS for this study: (1) the landing (home) page; (2) adding a local resource; (3) rating and reviewing a local resource; (4) filtering search results; and (5) user profile page. I developed this initial set of codes based on the themes and associated underlying sub-themes that arose during my analysis of participants' reactions to each of the wireframes. The majority of these themes and sub-themes focused on positive aspects of the existing features/functions/information types shown in the wireframes, negative aspects of the existing features/functions/ information types shown in the wireframes, opportunities for adjustments to the existing features/functions/information types, and new ideas for features/functions/ information types in the proposed system. I reviewed and collapsed these themes and sub-themes based on the prevalence and the significance of the recurring connections I identified across participants. I further refined and finalized these themes based on their relevance, feasibility of implementation, and the appropriateness for a first iteration design of the proposed CHIS.

Results

A total of 10 adults were recruited for one-on-one participatory design sessions. The majority of participants were women (n = 8; 80%), and the average age of participants was 29.8 (SD = 6.30), with all participants falling between the ages of 22 and 45. Participants identified as Caucasian (n = 4; 40%), South Asian (n = 2; 20%), East Asian (n = 2; 20%), Black or African-American (n = 1; 10%), or multiracial (n = 1; 10%). With regard to ethnicity, one participant (10%) identified as Hispanic or Latino. All participants were well-educated, either holding a graduate or professional degree (n = 4; 40%) or having completed some graduate or professional school (n = 6; 60%). All participants reported that they have access to the Internet and own and regularly use personal computers, tablets, and/or smartphones. Participants reported spending an average of 9 hours per day on the Internet, and all participants indicated they access the Internet on their smartphones either very frequently (n = 7; 70%) or frequently (n = 3; 30%), suggesting very active daily use of the Internet.

Participants described managing a diverse range of chronic health conditions, such as chronic depression, anxiety, attention deficit hyperactivity disorder (ADHD), rheumatoid arthritis, muscular dystrophy, narcolepsy, fibromyalgia, polycystic ovary syndrome, irritable bowel syndrome, asthma, Lyme disease, and lumbar muscle strain. The majority (n = 8; 80%) described managing two or more chronic health conditions simultaneously. Most participants felt they were coping very well (n = 1; 10%) or somewhat well (n = 6; 60%) with their chronic health conditions.

Participants reactions to wireframe #1: Landing or home page

Most participants felt that the search function in the original “Landing or home page” wireframe (see Figure 2) should rely more heavily on the heuristic principle of recognition rather than recall (Nielsen, 1994). They expected the proposed CHIS to recommend other related search terms based on their initial search on the home page. For example, if a potential user entered a symptom related to back pain, they felt the system should propose related chronic health conditions for the user to select, such as sciatica or chronic lumbar muscle strain. Additionally, participants felt the system should be able to interpret common acronyms for chronic health conditions, (e.g., “ADHD” as attention-deficit/hyperactivity disorder) and common variations or uses of different names for chronic health conditions (e.g., high blood pressure as hypertension) and make the appropriate recommendations in order to simplify the search process. I09 explained, “It can be really valuable in [a] search system…to have a way of reparsing searches to accommodate misspelled terms, common synonyms, and so forth…for consumers who may not know the correct spelling [or correct term] for everything they are looking for…on the technical end having something like…recommended alternative terms or dropdown menus…”

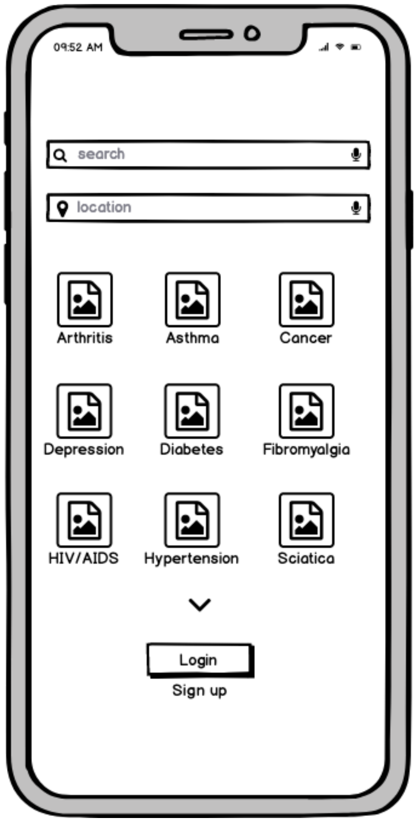


Figure 2: Wireframe #1: Landing or Home Page

Many participants also described the importance of having a personalized landing or home page in the proposed CHIS. They felt that creating an account should be optional, but the benefits of creating a user profile should be immediately emphasized to any potential user. Participants asked for personalized information on the home page to include details about relevant and new local resources in their communities that might be a good match for them based on the information they had entered into their profiles. This personalized information could be presented through unique types of map data visualizations, alerts/notifications, and/or some type of news feed to prioritize the most useful information for each user in a visually appealing way. I02 described, “Once you have all your personal information filled in and you go to the recommendations based off of conditions, symptoms, allergies, pain areas… It’s [a news feed] going to give you all those local options based on your location anyway…Zumba, tai chi, yoga, support group, whatever else.” I01 also described a desire to receive personalized results through other types of functions and features: “Getting a notification…somebody highly recommends the chiropractor for this symptom and this symptom that you have put down on your profile.” The same participant similarly recommended, “Seeing a map view of our surroundings… so just knowing it’s [local resource] so close, or knowing that it’s just like three blocks away. But instead of seeing ‘four miles’ or ‘half a mile’ [written out], you're seeing it as a map.”

Several participants also mentioned wanting the system to quickly recommend the best local resources by categorizing them according to the ideal treatment and/or management options for their particular conditions. I05 explained, “Okay, I have depression, and it [the system] brought me to this [home] screen that was like ‘here are the routes that you might want to take’.” This participant clarified that the personalized home screen should include categories for clinical resources, fitness and nutrition resources, support groups, community events, and so on since those might be potential “routes” people with depression might take to manage this condition. I03 similarly emphasized, “Yeah, with carpal tunnel…you can have physical therapy. You can have orthopedists. You can have recreation. You can have yoga. Or you can have fitness exercise… It makes sense because then you know where to look for clinical health and [where] to look for more like recreation…or like alternative therapy.”

Participants reactions to wireframe #2: Adding a local resource

The majority of participants felt that all of the types of information (e.g., type of resource, basic description, location, address, cost, insurance, etc.) represented in the original “Adding a local resource” wireframe (see Figure 3) would be useful for them. However, they also described many additional types of information that would be helpful for them in assessing whether a particular local resource would be a good fit for them in terms of managing their health.

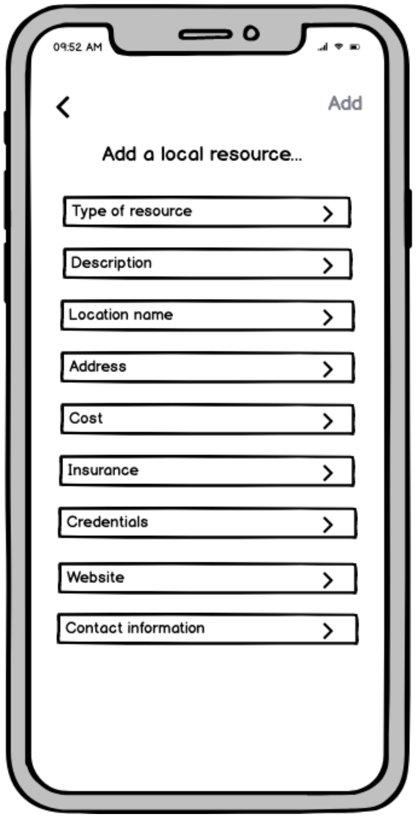


Figure 3: Wireframe #2: Adding a Local Resource

Most participants suggested including information on a local resource’s appointment availability and business hours in this wireframe. I09 explained this information would be vital for, “working people or people who need to schedule around their kid’s school schedule…or people with transportation limitations who can only get to certain places at certain times." I03 recalled how difficult it was for him to make an appointment with a specialist: "They said, 'Oh, we just do it on couple of days [a particular procedure], you have to come on these days,' [but]…the information is not available online."

Several participants also mentioned that having additional information on a local resource's (especially healthcare providers') credentialing, specialties, treatment modalities, and philosophies of care before they contacted them would be helpful. I07 explained that she wanted to know, "What are the three letters behind their name? Is it an MD? Is it a DO? Because I have a lot of family who go to DOs, but my grandmother hates DOs." I02 similarly described, "I look for…if the doctor is trained in rheumatology, but they're also trained in psoriasis...I try and find somebody in the rheumatology world as opposed to just being an arthritis person. Because then they see something and they stop and they don't look beyond that." Beyond credentialing and treatment options, participants felt it was important to have a provider who understood how to help them manage their care while also taking into account their fundamental identities. For example, I05 explained "She's [health care provider] an intersectional feminist, and that informs her practice. And I never had to explain basic parts of myself, I guess." Participants asked that the proposed CHIS also incorporate information on whether or not a local resource could offer care tailored to a diversity of treatment philosophies, particularly related to sexuality, gender identity, race, ethnicity, and other related factors.

Information related to cost was also understandably critical for most participants. They all appreciated that the wireframe incorporated information on cost and insurance more generally, but here too they asked for additional details to help them decide whether they could even afford a particular local resource. Some participants mentioned that knowing whether they could receive treatment on a sliding scale based on their income would be useful. Other participants mentioned that additional information on which insurance providers were in-network versus out-of-network would also be helpful, rather than just listing whether a local resource accepted a particular type of insurance. Furthermore, clarifying which treatments a local resource would cover under insurance and which treatments a patient would need to pay for out-of-pocket was also important for participants. I06 expressed frustration around this issue, describing that she, "…tried for a really long time to find a doctor, was on wait lists, just couldn't get anything. I now go to a doctor that's out of network…So I have to pay everything out of pocket, and I can't see her very frequently." I07 also mentioned, "I need to know it [insurance-related information about the local resource], because for me right now I do have so many chronic illnesses that I can't pay out of pocket for my healthcare; I just can't."

Almost every participant recommended that the proposed CHIS should include information related to accessibility in terms of the local resource's physical building and the parking and public transportation options (and costs) in the area around the local resource. I09 described a situation where a building's lack of accessibility prevented him from seeking care: "Okay, this [local resource] sounds like a great specialist for dealing with depression for me, but they're in fifth-floor walk-up, I cannot get there." Relatedly, some participants had difficulty accessing local resources without public transportation nearby, either because they did not have a car or due to physical limitations. I03 described, “It’s hard driving. I used to have back issues…they were really bad and it was always really hard to drive all the way…” Transportation cost was also a related issue that affected the accessibility of certain local resources for participants, especially in addition to the already high cost of their own medical care. I07 explained, “I didn’t know people were paying for parking when they went to the doctor. That really made me upset… it’s like five dollars an hour or five dollars for every two hours. It’s not cheap.”

Participants reactions to wireframe #3: Rating and reviewing a local resource

Participants felt that the detailed information in the original “Rating and reviewing a local resource” wireframe (see Figure 4) would be useful for them, but they also felt that inputting so much information might become burdensome for potential users of the proposed CHIS. They thought users might avoid rating and reviewing a local resource altogether as a result. The majority of participants recommended exploring alternatives to simplify this wireframe, while still providing guidance to potential users on how to best comment on a range of elements about a local resource. Some participants recommended using auto-populated text suggestions to help users supply additional detail when reviewing a local resource. I01 suggested, “If it was a big text box and I feel obligated to write more…sentences, whereas this could just be words [auto-populated text].” Other participants suggested collapsing certain aspects of the wireframe, such as customization, strengths, and/or weaknesses, into the initial “usefulness” review, while still providing some kind of hint text or suggestions to focus on these specific elements in order to ensure the inclusion of detailed, constructive feedback in the review.

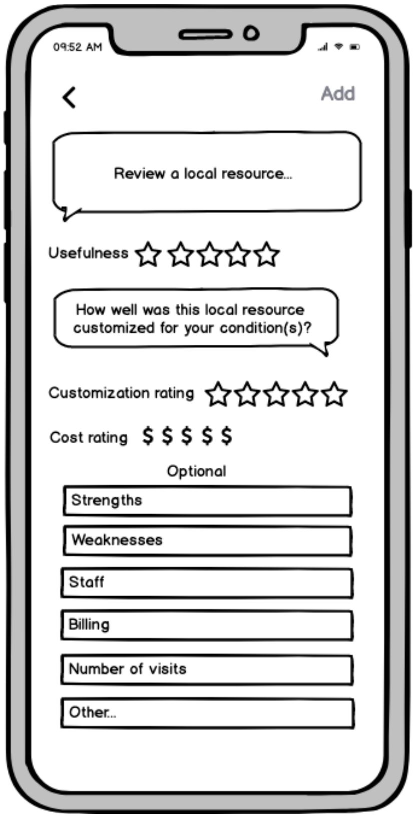


Figure 4: Wireframe #3: Rating and Reviewing a Local Resource

Participants also found the terms “usefulness” and “customization” in this wireframe confusing. They suggested either using alternative terms like “overall” review instead of “usefulness” and “personalization” instead of “customization,” or just explaining these terms in more detail with a help tooltip. I07 explained, “There might be a better word than customization, because when I think customization I’m like, ‘Have it your way,’ kind of Burger King-ish.”

The option to add information on the “strengths” and “weaknesses” of a local resource was also met with mixed reactions. Some participants felt having those prompts would help them provide more detailed information about a local resource. As I05 explained, “I probably wouldn’t think of providing that kind of information on my own. I would just say like, ‘Oh, she’s great,’ but if… it sort of prompts me to provide more information… I think that's useful.” However, other participants felt that adding the strengths and weaknesses of a local resource would be too subjective to be useful. I07 explained, “I don't really know how helpful it would be to have my strengths [on a local resource]. I think my favorite providers are my mental health providers, and the strengths that I think are strengths might be weaknesses to someone else. My therapist likes to ask me pointed questions, and they’re helpful. And I really like her and I trust her, but they’re not nice always… she’s very blunt.” I06 similarly explained, “Because I can imagine going somewhere, like a yoga class for example, like yoga puts me in more pain rather than less, I hate yoga. But sometimes I go just to get out of the house. And just because sometimes I enjoy the energy of the instructor. So, I wouldn’t say it’s useful, but I don’t want to give them bad ratings. It wasn’t a bad experience.”

Most participants did like the option to review the staff and billing separately from the actual local resource itself. Many participants described instances where they liked a local resource, but had substantial issues with the staff or billing. I07 described, “Gosh, if I would’ve realized the billing department at my doctor in Michigan would just ignore me for literally months, I would have never gone there.” Participants also suggested adding information related to the friendliness, convenience, and timeliness of a local resource. I08 described the importance of understanding the “…personality of the person. I’ve had a shoulder surgeon in the past who had no bedside manner whatsoever, but was a really good surgeon. So, it’s one of those things that’s maybe more of a subjective kind of description… It’s worth seeing him, but be aware of that…” I06 explained that in terms of the convenience and the timeliness of getting appointments and information from a local resource, "there's such a big difference between providers who've done a really good job with…appointments systems [and online portals]. Do I have to call to get an appointment, or is there a nice little online system where I can schedule my appointment? Is there a nice little online portal where I can get my results? My doctor in California had all of that, it was awesome." I03 relatedly mentioned how, "The specialist would come here [to the health center] but he would come only on specific times and… they didn't [always] know when, and then I had to visit the specialist outside of the health center."

Participants reactions to wireframe #4: Filtering search results

Most participants suggested rearranging the order of the filters in the original "Filtering search results" wireframe (see Figure 5). They recommended prioritizing health condition(s), distance, insurance, and cost, and moving review- and rating-related filters further down on the list. I04 explained, "I would mainly be concerned about insurance and distance." I07 similarly emphasized, "I obviously am always filtering by insurance, always." Participants prioritized distance and cost in their search for local resources because if a local resource was too far away from their home, did not accept their insurance, and/or was too expensive, they said they were unlikely to reach out to that local resource even if it did have a high rating and good reviews. Although, most participants preferred an affordable, nearby local resource that also had a high rating.

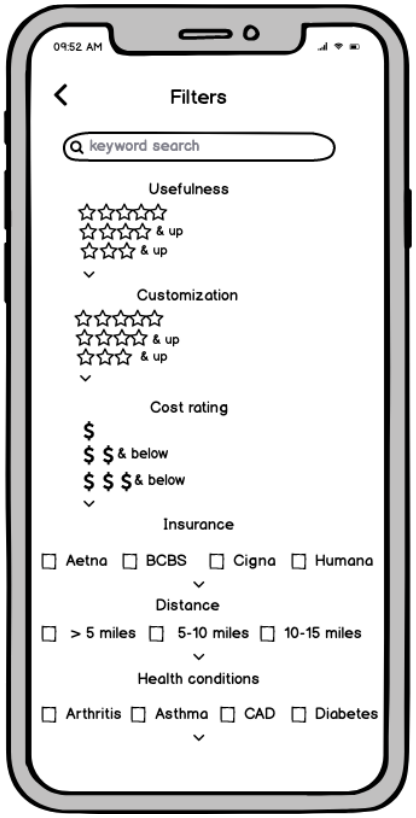


Figure 5: Wireframe #4: Filtering Search Results

The number of reviews was also an important filtering option for most participants. They felt the ratings for a local resource would only be useful if there were a substantial number of accompanying reviews. I06 explained, “I would add the number of reviews it has so far. So that way, if it’s got one star, it's got one review, I can be like, all right, not very helpful. If it has five stars, has one review, you know what I mean?” I03 similarly mentioned, “If fifty percent [of the reviews] are negative, leave this product. [If] you just have one person negative [one review], then you look into [this local resource].”

Participants also mentioned that an additional filter based on broad categories of types of local resource would be helpful, such as clinical care, alternative therapy, recreation, religious, etc. I04 explained, “I think that would be good. I mean, filtering based on if this [local resource] is medical, or is this clinical, as opposed to a support group.” I03 similarly described, “I mean it makes sense if you have it categorized… it makes sense because then you know where to look for clinical health and to look for more like recreation…Like clinical or recreation, physical or…alternative.”

A filter related to age was also important to most participants to narrow down their search results in the proposed CHIS. I08 suggested including a filter with the age-range categories, “Elderly versus adult versus pediatric.” This participant explained, “Now having had a kid, if you have a kid with a chronic health condition, you’re probably going to be looking for loads of resources, but you really need resources that are pediatric.” I09 also described the need for a similar type of filter because he described that knowing if a local resource is, “…being run through a particular university or school system…that will just help you determine whether or not this is [the] type of resource you need… If you look at a resource for depression and see that it’s through a high school, and if I’m in my forties and I see a resource in a high school, I’m probably going to conclude this is for people younger than me.”

Participants reactions to wireframe #5: User profile page

Privacy was a major concern for the majority of participants in the original “User profile page” wireframe (see Figure 6). Some participants recommended removing first name and last name fields from this wireframe and replacing it with an anonymized username, especially given the sensitive nature of the type of information they might be sharing in the proposed CHIS. I08 explained, “I basically want control over whether someone can connect me with that particular condition…so if my review came up…it was totally anonymous… A person may suffer, somehow if it gets back to their employer or something like that."

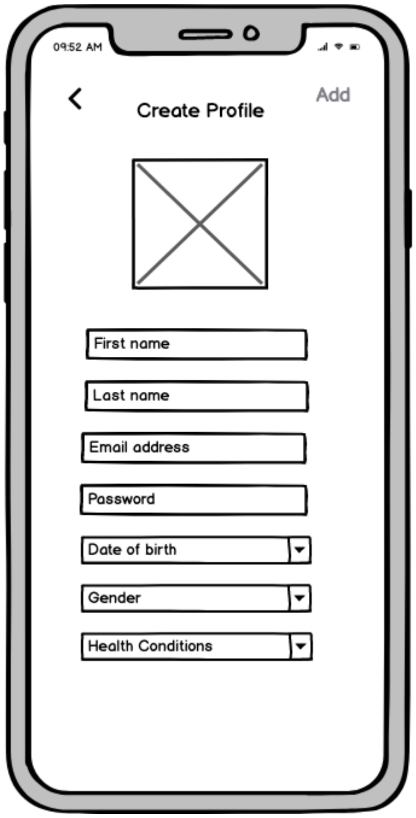


Figure 6: Wireframe #5: User Profile Page

Other participants needed reassurance that any data they entered into the proposed CHIS would be protected before they would be willing to use the system. I05 mentioned, "I would have a baseline assumption of privacy, especially since it's kind of sensitive information. I would want [the CHIS] to keep it private and not sell it or anything." I01 similarly emphasized that the system should not collect any unnecessary data from users such as phone number and texting history.

The majority of participants, however, did expect the proposed CHIS to collect enough information from them to be able to offer the personalized recommendations that they had suggested for the home page earlier in their participatory design sessions. They recommended this wireframe include an option for users to enter their location in the profile. Participants wanted the proposed CHIS to suggest local resources in areas they felt were convenient and familiar to them. I05 explained, “I don’t know how much you know about [name of a local hospital]… I went to high school not far from there…I know a bunch of people who had been in [name of a local hospital], so I was like, ‘Okay, so I know she’s a [city name] woman. She knows what she’s doing.’” Participants similarly wanted an option to enter their preferred health insurances so they only received recommendations for local resources they knew they could afford. I04 mentioned that the user profile should prioritize “… maybe distance first, insurance either second or up there… just because I think paying for this stuff is really a concern to some people.”

They also wanted the ability to enter their preferred treatment modalities and philosophies of care in their profile. I10 described wanting to receive recommendations for providers who could offer her preferred treatment method for her anxiety and depression: “There are different kinds of therapies…like CBT [Cognitive Behavioral Therapy] or other kinds of things. I think it would be helpful to say [enter into the system] that also.” Relatedly, I07 preferred to receive only recommendations for local resources with a philosophy of care that is, “…queer friendly…because that’s another big thing with being in [city name]. A lot of the people I’m talking to are also queer, and that community’s even smaller.”

Appointment availability was also critical for participants. They did not want to receive recommendations for local resources that were not accepting new clients or patients. Participants suggested adding some kind of opt-out method in the profile for personalized local resources that do not currently have openings in their schedules for new clients or patients in order to avoid any potential frustration. I06 described her exasperation: “Hopkins is big on Lyme’s…And so, I contacted them. They all had [a] waitlist. They couldn’t even put me on the waitlist, it was beyond waitlists. So that was infuriating.” Relatedly, participants requested the ability to opt-out of seeing certain local resources that do not meet accessibility guidelines. I07 mentioned, “A lot of doctors I go to should be ADA [Americans with Disabilities Act] accessible, but they aren’t unless someone opens the door for you.”

Discussion

These results demonstrate that participants found substantial value in the types of information and the functions and features represented in each of the five low-fidelity paper prototypes representing the proposed CHIS. However, they also recommended several changes and adjustments to each of the prototypes to make the system more usable and useful for them. Based on the results of the participatory design sessions, I revised the design of each of the five low-fidelity paper prototypes to reflect participants’ feedback.

Revisions to wireframe #1: Landing or home page

In the first revised low-fidelity paper prototype (Figure 7: Landing or Home Page), I made several changes to reflect participants’ desire for a personalized home page. This wireframe demonstrates several possible ways users could receive recommendations for local resources tailored to their own chronic health conditions. The home page could initially showcase resources that have recently opened in the user’s area or added to the CHIS to help alert them to new resources in their preferred locations. Recommendations for local resources by category is another useful option for users if they already have an idea of the type of local resource they would like to search for in the system, or to help give them ideas for potential treatment routes they could take to manage their chronic health conditions. This revised wireframe for the landing page also shows top-rated resources that each have at least approximately 20-25 reviews since the number of reviews (in addition to a high rating) was very important to most participants. Users may trust these top-rated recommendations from individuals who generally may confront similar challenges around managing the same types of chronic health conditions.

Figure 7: Wireframe #1: Landing or Home Page (Revised)

I've shown two distinct ways this information could be displayed on the landing page – users could have the option to search for local resources in a traditional grid view (which may feel more comfortable or familiar to some users) or they could see local resources in a map view to quickly ascertain their proximity.

Participants also mentioned that recognition rather than recall would be a critical component of the landing page. Although not shown in the wireframe, the proposed CHIS could eventually include a library of related terms in a later iteration of the system's design and development. For example, if a user entered a symptom, such as "back pain," offering recommendations to select a related chronic health condition, such as sciatica or lumbar muscle strain, may be helpful for some users to narrow their search. However, a keyword search by symptom would still be possible. Including a spell checker, especially one that can quickly autocorrect the names of many chronic health conditions (including rare ones), would obviously be essential in the first iteration of development of this proposed system.

Revisions to wireframe #2: Adding a local resource

The revised wireframe for the second low-fidelity paper prototype (Figure 8: Adding a Local Resource) reflects participants' expressed need for additional types of information on a local resource to help them decide whether it will be useful for them based on its quality, value, and accessibility. The addition of business hours and appointment availability to this wireframe will help users determine whether taking advantage of the local resource is feasible for them based on their other personal, work, and medical commitments. Incorporating specialty information into this wireframe will also hopefully help users understand a local resource's experience and background in helping people with specific chronic health conditions (and related or niche sub-areas). Philosophies of care can be a slightly more complicated type of information in this context. However, this can be a safe space for users to discuss a local resource’s ability to provide care tailored to the needs of individuals based on their sexuality, gender identity, race, ethnicity, etc. The overarching categories (e.g., clinical, nutrition, fitness, religious, alternative, etc.) and the target age/life stage (i.e., senior, adult, teen, and/or child) associated with a local resource can also be added in this revised wireframe.

Figure 8: Wireframe #2: “Adding a Local Resource (Revised)

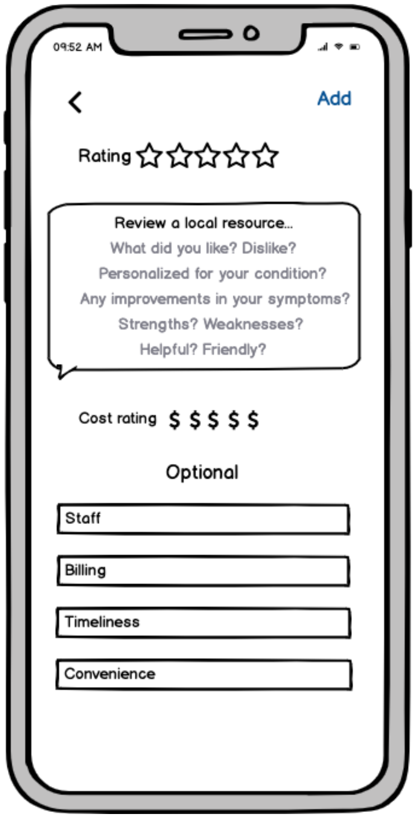
Connecting treatment modalities to cost and insurance is also critical. Participants were interested in knowing not only the types of treatments and/or services different local resources offer, but also whether each of these treatments and/or services would be covered by their insurance or if they would need to pay out of pocket. Additional information about whether treatments and/or services that are covered by insurance are in-network or out-of-network was also important for participants, who had been confused by this distinction in the past. Therefore, instead of having this information separately, users of the proposed CHIS will be able to add this type of cost and insurance information under treatment modalities.

The final addition to this second wireframe is information related to the accessibility of a local resource. This space will allow users to share whether a local resource's physical building is accessible for individuals with disabilities by providing information related to ramps, elevators, disability parking, etc. Users will also be able to input information related to the cost of parking and nearby public transportation options to help individuals determine whether a local resource is reachable based on their own transportation options.

Some of this information will be optional when a user adds a local resource to the proposed CHIS. Requiring users to add all of this information at once might be too burdensome. Therefore, additional details related to credentialing, specialties, treatments and services, philosophies of care, etc. can be entered at a later point or by other users to help distribute some of the work around adding a new local resource to the system.

Revisions to wireframe #3: Rating and reviewing a local resource

Participants recommended streamlining the design of the third wireframe (Figure 9: Rating and Reviewing a Local Resource). They felt potential users of the proposed CHIS might be so overwhelmed with the amount of information they should enter (even if the majority of it was described as optional), they might avoid rating and reviewing a local resource altogether. Therefore, this revised wireframe reflects a more minimalist design with hint text prompting users to discuss the usefulness, level of personalization (to a chronic health condition), and the strengths and weaknesses of a local resource. I've also added additional hint text for "improvement" of symptoms and the "friendliness" of a local resource since many participants indicated this would be important to them as well.



Review a local resource...
What did you like? Dislike?
Personalized for your condition?
Any improvements in your symptoms?
Strengths? Weaknesses?
Helpful? Friendly?

Figure 9: Wireframe #3: Rating and Reviewing a Local Resource (Revised)

I retained the separate sections for users to discuss the staff, billing, timeliness, and convenience of a local resource, since many of them felt these aspects of a local resource would certainly factor into their decision whether or not to use it and that these aspects were distinct from the actual quality of the local resource itself. I also removed the sections for the "number of visits" and "other" from the original wireframe to simplify the design even further and to take into account my finding that most participants did not seem to derive much additional value from these components.

Revisions to wireframe #4: Filtering search results

I revised the fourth wireframe (Figure 10: Filtering Search Results) to represent participants' highest priorities in terms of searching for a local resource in the proposed CHIS. The filters in the revised wireframe have been accordingly rearranged with insurance, distance, and cost toward the top of the screen, and review and rating-related filters moved further down. I also added additional filters to reflect the types of information participants felt they would need to make a truly informed decision around whether a local resource would be worth pursuing.

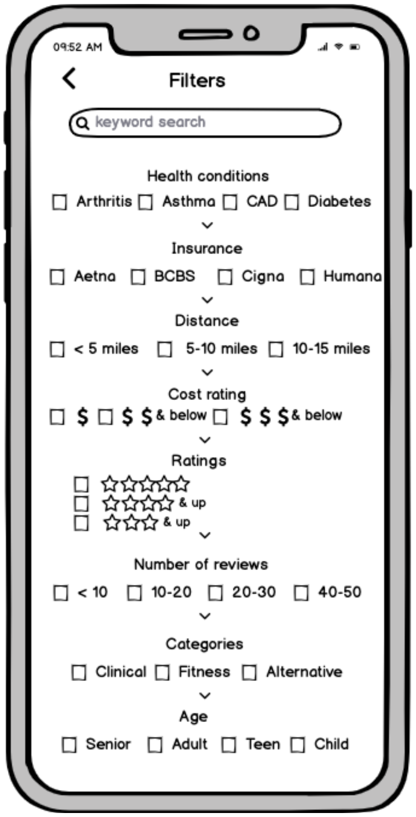


Figure 10: Wireframe #4: Filtering Search Results (Revised)

I added a filter for the number of reviews since many participants felt they would not have much faith in a local resource with only a few reviews. A new filter for broad categories related to the type of local resource (e.g., clinical care, alternative therapy, recreation, religious) has also been added to help users narrow down their search for the type of local resource they feel would be most valuable for them, given their current stage of treatment and/or management of their chronic health condition. Finally, one last new filter related to age (i.e., senior, adult, teen, or child) has been incorporated to help potential users find local resources that are tailored to their needs based on their current life stage.

Revisions to wireframe #5: User profile page

The last wireframe (Figure 11: User Profile Page) has also been adjusted to reflect participants' feedback. Privacy was a major concern for most participants, so this wireframe has been revised to allow users to enter a username, instead of their full first and last name. I have also removed gender from the profile since participants didn't express a strong interest in finding local resources based on gender. Removing this from the profile helps to avoid collecting extraneous personally identifiable information. Users could also receive some kind of system message confirming that the proposed CHIS strives to protect their privacy and does not collect any unnecessary data from their phones, such as their text messages or data regarding their internet usage, to help reassure them when they first create a profile. This revised wireframe does ask potential users to share their zip code in order to automatically provide recommendations for local resources on their landing (home) page. However, this would be optional so users uncomfortable with sharing this type of personal information could opt out.

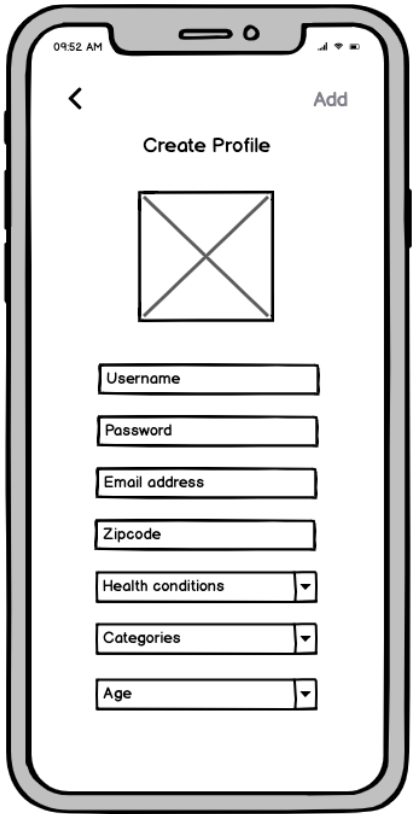


Figure 11: Wireframe #5: User Profile Page (Revised)

Participants also asked for the option to indicate their preferences for philosophies of care, treatment modalities, and accessibility in their profile. However, this might be a slightly complicated process for the first iteration of the design and development of this type of system, especially since this information is likely to be entered as free-text at the point when users add a local resource. Therefore, this is something that could potentially be explored in a future iteration of the design and development of the proposed system.

Finally, I added “Age” (life stage) and “Categories” options to the user profile, since participants emphasized the importance of these factors several times throughout the participatory design sessions. These options could be used to inform the types of recommendations users would receive on their home page and further ensure that they match each user's self-reported needs for managing their chronic health conditions. It should be possible to include this function in the first iteration of the high-fidelity design and development of this type of system, since there will be a closed-ended option for users to select both their age (i.e.; senior, adult, teen, and/or child) and the category of the resource when adding it into the system.

Limitations

This study has several limitations. As a result of both the small size of the sample and the bias created by recruiting participants through a University listserv and through snowball sampling, the findings from this study are not generalizable beyond the 10 individuals who participated. Additionally, the instructions given to participants at the beginning of the participatory design sessions, as well as the initial wireframes provided to them for comment, likely influenced their feedback and suggestions. Nevertheless, the participants in this study provided significant insight on the ideal types of information, functions, and features for the proposed CHIS based on their own unique experiences managing a range of chronic health conditions. Their feedback from the participatory design sessions will be invaluable in informing the ideal design for the system. Further testing of the revised wireframes in a high-fidelity format with larger and more diverse samples of participants is recommended as next steps for this work.

Conclusion

In conclusion, the results of this participatory design study indicate that the proposed CHIS could enable individuals who have chronic health conditions to better leverage community assets by providing them with useful information on local resources through a highly usable mobile application. The application of the design recommendations from this study can help to ensure the successful uptake of the proposed CHIS by this population in the future. In subsequent work, the revised wireframes developed in the course of this study can be used to inform the development of a high-fidelity prototype and additional user testing can be conducted to practically assess participants' willingness to populate and use the proposed CHIS.

References

1. Bodenheimer, T., Wagner, E.H., and Grumbach, K. (2002), "Improving primary care for patients with chronic illness," *Journal of the American Medical Association*, Vol. 288 No. 14, pp. 1775-1779.
2. Braun, V. and Clarke, V. (2006), "Using thematic analysis in psychology," *Qualitative Research in Psychology*, Vol. 3 No. 2, pp. 77-101.
3. Clarke, J.L., Bourn, S., Skoufalos, A., Beck, E.H., and Castillo, D.J. (2017), "An innovative approach to health care delivery for patients with chronic conditions," *Population Health Management*, Vol. 20 No. 1, pp. 23-30.
4. Coleman, K., Austin, B.T., Brach, C., and Wagner, E.H. (2009), "Evidence on the Chronic Care Model in the new millennium," *Health Affairs*, Vol. 28 No. 1, pp. 75-85.

5. Gee, P.M., Greenwood, D.A., Paterniti, D.A., Ward, D., and Miller, L.M.S. (2015), “The eHealth enhanced Chronic Care Model: A theory derivation approach,” *Journal of Medical Internet Research*, Vol. 17 No. 4, e86.
6. Huete-Alcocer, N. (2017), “A literature review of word of mouth and electronic word of mouth: Implications for consumer behavior,” *Frontiers in Psychology*, Vol. 8, 1256.
7. Improving Chronic Illness Care. (2018). *The Chronic Care Model*, available at http://www.improvingchroniccare.org/ (accessed 10 March 2019).
8. Institute of Medicine (US) Committee on Quality of Health Care in America. (2001), *Crossing the quality chasm: A new health system for the 21st Century*, National Academies Press: Washington D.C.
9. Jeon, Y.H., Jowsey, T., Yen, L., Glasgow, N.J., Essue, B., Kljakovic, M., Pearce-Brown, C., Mirzaei, M., Usherwood, T., Jan, S., Kraus, S.G., and Aspin, C. (2010), “Achieving a balanced life in the face of chronic illness,” *Australian Journal of Primary Health*, Vol. 16 No. 1, pp. 66-74.
10. Jindal, G. (2019). Assessing the value of an online repository of local resources for people who have chronic health conditions. *Journal of Consumer Health on the Internet*, Vol. 23 No. 2, pp. 123-145.
11. Jindal, G. (2020). An online card-sorting study to inform the initial low-fidelity design of a crowdsourced health information system for individuals who have chronic health conditions seeking local health-related resources. *Human Behavior and Emerging Technologies*, Vol. 2 No. 2, pp. 128-139.

12. Lagu, T., Hannon, N.S., Rothberg, M.B., and Lindenauer, P.K. (2010). Patients' evaluations of health care providers in the era of social networking: An analysis of physician-rating websites. *Journal of General Internal Medicine*, Vol. 25 No. 9, pp. 942-946.
13. Markham, A. (2005), "The politics, ethics, and methods of representation in online ethnography," in Denzin, N. & Lincoln, Y. (Eds.), *Handbook of Qualitative Research, 3rd Edition,* Sage: Thousand Oaks, California, pp. 793-820.
14. Martin, S. (2017), "Word-of-mouth in the health care sector: A literature analysis of the current state of research and future perspectives," *International Review on Public and Nonprofit Marketing*, Vol. 14 No. 1, pp. 35-56.
15. McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L. S., Lorig, K., and Wagner, E. H. (2011), "Self-management: Enabling and empowering patients living with cancer as a chronic illness," *CA: A Cancer Journal for Clinicians*, Vol. 61 No. 1, pp. 50-62.
16. Mirkovic, J., Jessen, S., Kristjansdottir, O.B., Krogseth, T., Koricho, A.T., and Ruland, C.M. (2018), "Developing technology to mobilize personal strengths in people with chronic illness: Positive codesign approach," *JMIR Formative Research*, Vol. 2 No. 1, e10774.
17. Nielsen, K. (1994), "10 usability heuristics for user interface design," available at: https://www.nngroup.com/articles/ten-usability-heuristics/ (accessed 4 January 2020).

18. Pettigrew, K.E. and Durrance, J.C. (2001), "Public use of digital community information stems: Findings from a recent study with implications for system design," in the proceedings of the 1st ACM/IEEE-CS Joint Conference on Digital Libraries in Roanoke, Virginia, 2001, Association for Computing Machinery, New York, NY, pp. 136-143.
19. Sanders, L. and Stappers, P.J. (2013), *Convivial toolbox: Generative research for the front end of design*, BIS Publishers, Amsterdam, Netherlands.
20. Siminerio, L.M. (2010), "The role of technology and the Chronic Care Model," *Journal of Diabetes Science and Technology*, Vol. 4 No. 2, pp. 470-475.
21. Stellefson, M., Dipnarine, K., & Stopka, C. (2013), "The Chronic Care Model and diabetes management in US primary care settings: A systematic review," *Preventing Chronic Disease*, Vol. 10, E26.
22. Synnot, A.J., Hill, S.J., Garner, K.A., Summers, M.P., Filippini, G., Osborne, R.H., Shapland, S.D.P., Colombo, C. and Mosconi, P. (2016), "Online health information seeking: How people with multiple sclerosis find, assess and integrate treatment information to manage their health," *Health Expectations*, Vol. 19 No. 3, pp. 727-737.
23. Taylor, S.J.C., Pinnock, H., Epiphaniou, E., Pearce, G., Parke, H.L., Schwappach, A., Purushotham, N., Jacob, S., Griffiths, C.J., Greenhalgh, T., and Sheikh, A. (2014), "A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS –

Practical systematic Review of Self-Management Support for long-term conditions," *Health Services and Delivery Research,* Vol. 2 No. 53, pp. 1-580.

24. Van Velsen, L., Beaujean, D.J., and van Gemert-Pijnen, J.E. (2013), "Why mobile health app overload drives us crazy, and how to restore the sanity," *BMC Medical Informatics & Decision Making*, Vol. 13, 23.
25. Wagner, E.H., Austin, B.T., and Von Korff, M. (1996), "Improving outcomes in chronic illness," *Managed Care Quarterly*, Vol. 4 No. 2, pp. 12-25.

Chapter 5: Conclusion

Individuals who have chronic health conditions need instrumental support to manage their health more effectively. Clinical support (e.g., physicians, psychologists, counselors, physical therapists, chiropractors) and nonclinical support (e.g., exercise classes, local businesses, support groups) can both be essential forms of instrumental support for this population. Individuals who have support from these types of local resources are much more likely to successfully manage complex regimens of care for their chronic health conditions. This dissertation research investigated how these individuals seek out information on relevant local resources in their communities and offers a possible strategy (a crowdsourced health information system (CHIS) containing information on local health-related resources) to optimize their ability to find information on local resources.

The literature (Kretzmann & McKnight, 1993; Loskutova et al. 2016; Tung & Peek, 2015) indicates that the prevailing interventions, programs, and tools to help individuals who have chronic health conditions find information on local resources in their communities have substantial limitations. Resource constraints, geographic limitations, single disease or condition focus, incomplete or outdated online information, unsystematic discovery, and other issues limit the usefulness of this population's existing strategies. However, the data these authors provide on the strategies their participants use to find information on local health-related resources and their related successes and challenges in this information-seeking process are limited. Therefore, this dissertation research first attempted to investigate how participants who have chronic health conditions presently meet this information need and whether they need (or want) new strategies to improve this information-seeking process. Based on participants' feedback and experiences managing chronic health conditions, this research then proposed early design recommendations for an actionable technology-based strategy to improve this process.

I conducted in-depth semi-structured interviews with participants who have chronic health conditions for the first study in this dissertation (Chapter 2) to investigate and understand their experiences searching for information on local resources, and the strategies they ultimately did (or did not) find successful. The results of this study indicated that participants do find information on local health-related resources online, but word of mouth (WOM) communication tends to be the most successful strategy. However, the serendipitous and unstructured nature of WOM communications can make it difficult for participants to more systematically find information on local resources when they need it to manage their health. Participants shared that they were open to a crowdsourced health information system (CHIS) that would allow them to more easily find information on local resources. But they also explained that the design of the proposed CHIS would need to address many of the shortcomings and challenges they had encountered while searching for information on local resources online in the past. The findings from this first study highlighted this unmet need for information on local resources and assessed participants' willingness to use a CHIS to seek out information on local resources to meet this information need.

The second study in this dissertation (Chapter 3) leveraged the successes and barriers participants described in the first study to assess the types of information and system functions and features that would be most useful to include in the design of the proposed CHIS. An online card-sorting study revealed that participants prefer to have several types of system functions and features to find a local resource in the proposed CHIS and many types of information to determine whether that local resource will actually be useful for them to manage a chronic health condition. Based on the results of this study, I developed design recommendations for the proposed CHIS with low-fidelity, paper wireframes for the: 1) Landing page; 2) Adding a local resource; 3) Rating and reviewing a local resource; 4) Filtering search results; and 5) Profile. The low-fidelity paper wireframes included all of the critical proposed system features and functions and types of information that participants indicated they would find most useful in the card-sorting study. Although the proposed CHIS cannot completely recreate the way these individuals may receive recommendations through WOM communication, the proposed system (if designed to be highly usable and sufficiently populated with detailed information) could be a useful tool to help people discover and take advantage of local resources in their communities that can enable them to better manage their chronic health conditions.

The third study (Chapter 4) in this dissertation focused on finalizing the design recommendations initially proposed in the second study. Although, the low-fidelity paper wireframes developed in the second study were grounded in participants' experiences managing their chronic health conditions, the participatory design sessions in the third study for this dissertation garnered direct feedback from participants on the design recommendations for the proposed CHIS. Participants assessed how useful and usable they found the proposed system features and functions and the types of information represented in the low-fidelity wireframes (initially developed at the end of the second study). Based on their feedback, I made necessary changes to each of the low-fidelity wireframes and the associated design recommendations for the proposed CHIS to help ensure its successful uptake in the future.

Limitations

The findings in this dissertation will be valuable for researchers and practitioners who work with individuals who have chronic health conditions in many different capacities through clinical health, health informatics, public health, and more. However, the research presented in this dissertation does have some additional limitations beyond those outlined in each individual study. Since the results from the first study directly informed the types of information and system functions and features that comprised the cards in the second study for this dissertation, the small size and biased nature of this convenience/snowball sample (particularly towards highly educated individuals) from the first study could have potentially impacted the results of the both the second and third study. Relatedly, the remote nature and any additional bias from the convenience/snowball sample of the second study could have also impacted the results of the third study, since each study was designed to build on the results of the previous one. However, despite these limitations, this research makes several important theoretical, practical, and methodological contributions for various stakeholders.

Theoretical Contributions

Information foraging theory, originally developed by Peter Pirolli and Stuart Card (1999), provides a unique perspective on users' information behaviors by comparing them to animals' strategies foraging for food. Pirolli and Card theorize that users seek out and consume information in a manner that would characterize them as "informavores," meaning that individuals make rational decisions about how to maximize their potential information gain by "foraging" or searching through possible sources of information, called "information patches," such as specific websites. But they also consider how to invest the least possible amount of time, similar to how animals might try to reduce their energy expenditures searching for the most nutritious meals they can find.

Pirolli (2007) provides a detailed framework demonstrating how information foraging theory can be applied to information behavior research through the method of rational analysis. They provide a mathematical strategy for researchers to calculate the relative value of certain information against the cost (or expenditure) of their effort and time spent information foraging. Their work allows researchers to mathematically predict how users' will navigate a website or a similar type of "information patch," which can provide significant insight on how to improve these types of human-computer interactions.

Researchers have drawn on information foraging theory to assess users' information behaviors within the context of a range of websites, applications, online tools, and so on. For example, this theory has been applied (and adapted) to understand professional developers' information behaviors around maintaining code

(Fleming, Scaffidi, Piorkowski, Burnett, Bellamy, Lawrence, & Kwan, 2013; Lawrance, Bellamy and Burnett, 2007; Lawrance, Burnett, Bellamy, Bogart, & Swart, 2010). McCart, Padmanabhan, and Berndt (2013) tested hypotheses driven by information foraging theory in research assessing clickstream data from small business websites. Goodwin, Cohen, and Rindflesch (2012) hypothesized how information foraging theory could inform the design of a discovery browsing system. van Houten (2009) assessed users' online video browsing behaviors, using information foraging theory as the framework for their research. But these examples are only a small sampling of the research that has been produced in relation to Pirolli and Card's (1999) information foraging theory, which has been highly influential both within human-computer interaction and information behavior research. However, much of this existing research still tends to more prescriptively apply the mathematical models developed for this theory, rather than using it in a more descriptive sense.

Very few researchers seem to have applied information foraging theory within qualitative studies. Haun and Kauffman (2002) did leverage information foraging theory for their descriptive analysis of online consumer purchase behaviors, but with the caveat that future research should apply Pirolli's (2007) mathematical models. Nabi et al. (2016) conducted a qualitative study framed by information foraging theory, focusing on the community-generated design of programming tools for developers; however, their study analysis focused heavily on a code set with concepts directly from information foraging theory that could be quantified by frequencies. Gattis (2002) combines information foraging theory and strategic planning theory to explain how new technical communicators can more efficiently locate and apply the data they need for their work, but this particular article functions more as an extended example of a possible application, rather than applied research. As demonstrated by these examples, most researchers still seem to hesitate applying information foraging theory directly to their work if they are unable to incorporate it more quantitatively.

Additionally, "proving" the applicability of information foraging theory somehow seems to be critical to most of this existing research. Applying information foraging theory without "testing" exactly how the theory fits seems to be unusual in the literature. However, I posit that researchers (and practitioners) can underpin their research, including qualitative research, with Pirolli and Card's (1999) information foraging theory without directly "testing" the theory's relevance to their work. Their theory has the potential to inform work across many disciplines much more broadly and researchers and practitioners can extend its applicability to new contexts.

The structure of my research was not conducive to directly testing information foraging theory, particularly with mathematical models, given the qualitative nature of this work, but it was still an incredibly useful framework to help inform the need for and design of the crowdsourced health information system I propose in this dissertation. I applied information foraging theory to the information behavior of individuals who have chronic health conditions in a more unrestrained sense. The work I conducted for this dissertation does not engage participants in specific tasks to measure the variables mentioned in information foraging theory, but the central concepts (e.g., foraging, scent, patches) of this theory still directly guided my investigation of the information need at the center of this research and the strategy I propose for improving the effectiveness and efficiency of this population’s information seeking processes with regard to this particular information need. For example, although the participants in these studies may not be exactly the “information predators” Pirolli and Card (1999) describe, the theory has enough flexibility to encompass how participants in my research described their need to conveniently access valuable information on local resources to manage their health. I believe this research has the potential to encourage other researchers and practitioners to apply information foraging theory in a similar, more descriptive way to their own work in the future.

Practical Contributions

This dissertation research has also resulted in important practical contributions that may be useful for researchers and practitioners conducting research on the design of systems that rely on users to crowdsource information. My findings indicated that participants seemed to view themselves alternately as contributors to or as just viewers of the proposed system. For example, the participants in my participatory design study (Chapter 4) reacted very differently to the wireframes that illustrated how a user might add a local health-related resource to the proposed system versus the wireframes that illustrated how a user might rate and review a local resource in the same system. Participants tended to think of themselves as just viewers when discussing the wireframe that demonstrated how a user might add a local resource to the system. Therefore, they interestingly seemed to press for as much additional information on the local resource as possible. They seemed to feel that the onus was on another user or another business to add the initial background information on each local resource, so it was acceptable to ask this amorphous user to include quite a bit of detail, despite how burdensome it might be for this hypothesized “other” user. Participants rarely seemed to consider themselves to be the user who would add this initial information on a local resource, which may have altered how they responded during the participatory design sessions.

In contrast, participants had the opposite reaction when considering the design of the wireframe illustrating how a user would rate and review a local resource in the proposed system. They seemed to view themselves as the contributor (i.e., reviewer) in this instance and were heavily motivated to streamline the design of this particular wireframe to make it as simple as possible for themselves to rate and review a local resource. Participants seemed to accept that they would need to forego access to certain types of information on a local resource, if it meant the reviewing process would impose a lower cognitive load on them. They were willing to make compromises to reduce the level of effort and time required to rate and review a local resource; however, they had not been willing to make such compromises around the initial addition of the local resource to the system.

This dichotomy could have major implications for how researchers and practitioners work with potential users to assess the ideal design of crowdsourced health information systems. Stakeholders working with users should be cognizant of the fact that participants may alternate between considering themselves as active contributors or as passive viewers when considering different aspects of a crowdsourced system. Crowdsourced systems will be more successful when they are dynamically populated by their users to ensure that the content remains useful and updated. It is critical to consider during the design process how you will ultimately encourage users to become and remain active contributors to the system.

Maintaining a balance between personalization and privacy is another challenge that researchers and practitioners will need to continuously consider in the design of crowdsourced information systems. Participants in this study wanted tailored recommendations personalized to their health conditions, age, location, interests, and more. However, they were also greatly concerned about sharing the types of personal information needed to make such personalized recommendations. Their hesitation is understandable, especially given the current events in the past decade and the limited regulation of data privacy in the United States (especially in comparison to the European Union). However, their desire for privacy was often in conflict with their preference for highly personalized recommendations.

The design changes I made to the home screen and user profile wireframes for the proposed system based on the results of the participatory design sessions (Chapter 4) reflect the compromises needed to balance participants' concerns around privacy and their need for personalized recommendations. I assessed participants' most important information needs with regard to health resources (e.g., health condition, location, etc.) and asked only for the personalized information I would absolutely require to be able to meet those specific information needs. I also identified alternative opportunities to provide participants with useful recommendations. For example, instead of asking for participants' date of birth (as I did in the original wireframes), I revised the wireframes to ask for users' life stage (i.e., senior, adult, teen, and/or child) instead. Participants could still receive personalized recommendations based on whether they needed information on local resources for a senior, adult, teen, or child (which was very important to participants) without providing more specific information about their age. These types of considerations became some of the most critical design decisions I made throughout this research.

Researchers and practitioners may be able use the results from this dissertation to inform their own work with users when discussing the compromises that may need to be made around privacy and personalization in the design of crowdsourced health information systems. Designers working on these types of systems will need to find opportunities to ensure that users can still receive useful recommendations to meet their information needs, even if they provide just the details they are comfortable sharing.

Methodological Contributions

The research described in this dissertation utilized three interdependent, but distinct, research methodologies. The overarching methodology I selected for each of the three studies (semi-structured interviews, card-sorting, and participatory design) drew from several different disciplines, including information studies, human-computer interaction, library science, and public health. I adapted traditional methodologies from these disciplines for this research. This dissertation exists at a nexus of several disciplines and can help to inform the work of researchers and practitioners across several domains in both academia and industry.

In my first study (Chapter 2), I investigated the existing strategies individuals who have chronic health conditions use to find information on local resources in their communities. I also examined their challenges and successes around this process, as well as their interest in crowdsourcing information on local resources into the proposed system. This initial study was traditional in that I used a semi-structured interview format, guiding participants to answer particular questions so I could answer my research questions. However, this study was unique in that my findings were also useful for guiding the design of the proposed system. Participants were very clear that the system would need to be carefully designed to address the challenges they had experienced in the past before they would consider using it. Therefore, I was able to leverage the successes and challenges they described around their existing strategies searching for information on local resources to directly inform the card-sorting study (Chapter 3). The system functions and features and types of information that I used to populate the cards for this study were based directly on the experiences of participants from the first study. Thus, this initial study played a dual role in terms of not only answering my overarching research questions, but also informing the population of the cards with specific types of information and system features and functions for the second study.

My second study, an online card-sorting study, could have been carried out more traditionally as a quantitative survey given the closed-ended nature of the options participants were provided with to sort each of the cards (i.e., very useful, somewhat useful, neutral, not very useful, or not at all useful). However, instead of focusing on statistical significance, this study asked participants to consider each type of information and system function and feature from a user experience lens. Participants evaluated the proposed system more holistically in this study and were thus able to better inform the design of the initial wireframes representing the proposed system.

My final study (Chapter 4) entailed participatory design sessions in which I asked participants to react to the initial set of wireframes developed at the end of the second study. Although, this last study was more open-ended methodologically than my two earlier studies, the structure of this study was informed by user experience research that takes into account both academic and industry considerations. Every change I had made to the initial set of wireframes was based on evidence from a comprehensive thematic analysis, but also feasible within the limitations of a first iteration design of this type of system. As a result, I was able to leverage participants' reactions into actionable revisions to the wireframes representing the proposed system.

This dissertation demonstrates how researchers and practitioners across disciplines can adapt and apply a mix of traditional research methods from other fields to suit their own research. New applications also have the potential to broaden the reach and interdisciplinarity of their work.

Future Research

There remain several areas of research that should be explored prior to the actual development of the proposed CHIS. Populating this type of proposed CHIS can be exceptionally difficult, since the majority of users in online communities tend to consume information, rather than contribute information (Preece, Nonnecke, & Andrews, 2004; Yang, Li, & Huang, 2017). Creating a critical mass of active users that are willing to contribute information based on their experiences managing their chronic health conditions to make the system useful for individuals who have chronic health conditions will be challenging. Assessing opportunities to increase and sustain engagement with the proposed CHIS will an important area for future research.

Additionally, online reviews can be highly binary, often skewing either very positive or very negative, which can limit their usefulness for users (Hu, Pavlou, & Zhang, 2006; Schoenmueller, Netzer, & Stahl, 2019). Ensuring that the reviews shared in the proposed CHIS are balanced and accurately reflect a local resource's suitability in helping individuals who have chronic health conditions to manage their health will be essential to the proposed system's success. Future research should determine possible strategies to reduce extreme user reviews that are overly negative or overly positive, and focus on methods to help users more appropriately describe their experiences in a way that is useful for this population.

Maintaining this type of proposed CHIS will also be a challenge. Although crowdsourcing information will reduce some of the burden on administrators, this type of system will still require significant resources to limit inaccuracies, redundancies, and outdated information. Conferring with technical experts in information management on these types of issues prior to the development of this system could further inform the design and development of the proposed CHIS.

Despite the limitations and need for additional research, this dissertation makes an important contribution to the field by filling a critical gap in the literature related to the information needs and information behavior of individuals who have chronic health conditions. The findings from this research highlight an important unmet need among this population for information on health-related (clinical and nonclinical) local resources. Drawing on information behavior theory, this dissertation offers an actionable strategy for meeting this information need by enhancing information scent and optimizing information foraging for this population as they look for local resources that can help them to better manage their health.

References

1. Fleming, S., Scaffidi, C., Piorkowski, D., Burnett, M., Bellamy, R., Lawrence, J, & Kwan I. (2013). An information foraging theory perspective on tools for debugging, refactoring, and reuse tasks. *ACM Transactions on Software Engineering Methodology, 22*(2). Retrieved from: http://dx.doi.org/10.1145/2430545.2430551.
2. Hu, N., Pavlou, P.A., & Zhang, J. (2006). Can online reviews reveal a product's true quality?: Empirical findings and analytical modeling of online word-of-mouth communication. *EC '06: Proceedings of the 7th ACM Conference on Electronic Commerce*, 324-330.
3. Gattis, L. (2002). Planning and information foraging theories and their value to the novice technical communicator. *ACM Journal of Computer Documentation, 26*(4), 168-175.
4. Goodwin, J., Cohen, T., & Rindflesch, T.C. (2012). Discovery by scent: Discovery browsing system based on the information foraging theory. *2012 IEEE International Conference on Bioinformatics and Biomedicine Workshops*, 232-239.
5. Hahn, J. & Kauffman, R.J. (2002), "Information foraging in internet-based selling: A systems design value assessment framework," in Shaw, M.J. (Ed.),

E-Business Management: Integration of Web Technology with Business Models. Kluwer Academic Publishers: Norwell, Massachusetts, pp. 195-230.

6. Kretzmann, J.P. & McKnight, J.L. (1993). *Building Communities from the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets*. Chicago, IL: ACTA Publications.
7. Lawrance, J., Bellamy, R., and M. Burnett, M. (2007). Scents in programs: Does information foraging theory apply to program maintenance? *Proceedings of the 2007 IEEE Symposium of Visual Languages and Human-Centric Computing*, 15-22.
8. Lawrance, J., Burnett, M., Bellamy, R., Bogart, C., & Swart, C. (2010). Reactive information foraging for evolving goals. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 25-34.
9. Loskutova, N.Y., Tsai, A.G., Fisher, E.B., LaCruz, D.M., Cherrington, A.L., Harrington, T.M., Turner, T.J., & Pace, W.D. (2016). Patient navigators connecting patients to community resources to improve diabetes outcomes. *Journal of the American Board of Family Medicine, 29*(1), 78-89.
10. McCart, J.A., Padmanabhan, B., & Berndt, D.J. (2013). Goal attainment on long tail web sites: An information foraging approach. *Decision Support Systems, 55*(1), 235-246.
11. Nabi, T., Sweeney, K., Lichlyter, S., Piorkowski, D., Scaffidi, C., Burnett, M., & Fleming, S.D. (2016). Putting information foraging theory to work: Community-based design patterns for programming tools. *Proceedings of the*

2016 IEEE Symposium on Visual Languages and Human-Centric Computing, 129-133.

12. Pirolli, P. & Card, S.K. (1999). Information foraging. *Psychological Review, 106*(4), 643-675.
13. Pirolli, P. (2007). *Information Foraging Theory: Adaptive Interaction with Information*. New York, NY: Oxford University Press, Inc.
14. Preece, J., Nonnecke, B., & Andrews, D. (2004). The top five reasons for lurking: improving community experiences for everyone. *Computers in Human Behavior, 20*(2), 201-223.
15. Schoenmueller, V., Netzer, O., & Stahl, F. (2019). The extreme distribution of online reviews: Prevalence, drivers and implications. *Columbia Business School Research Paper*, No. 18-10.
16. Tung, E.L. & Peek, M.E. (2015). Linking community resources in diabetes care: A role for technology? *Current Diabetes Reports, 15*(7), 614.
17. van Houten, Y.A. (2009). Searching for videos: The structure of video interaction in the framework of information foraging theory. Enschede: University of Twente.
18. Yang, X., Li, G., Huang, S. (2017). Perceived online community support, member relations, and commitment: Differences between posters and lurkers. *Information & Management, 54*(2), 154-165.