How can we Bridge the Gap:
Health Literacy among Older Adults Diagnosed with Diabetes

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A Thesis

in

The Department

of

Education

Presented in Partial Fulfillment of the Requirements

For the Degree of Master of Arts (Educational Studies) at

Concordia University

Montreal, Quebec, Canada

April 2021

CONCORDIA UNIVERSITY

School of Graduate Studies

This is to certify that the thesis prepared.

By: Ann Marie Cote

Entitled: How can we Bridge the Gap: Health Literacy among Older Adults Diagnosed with Diabetes

and submitted in partial fulfillment of the requirements for the degree of **Master of Arts (Educational Studies)**

complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

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Abstract

How can we Bridge the Gap: Health Literacy among Older Adults Diagnosed with Diabetes

Ann Marie Cote

A review of the literature confirms that health literacy impacts society tremendously. This research project responds to the question: How can the gap between health literacy efforts and educating older diabetic adults be bridged? The aging of the population, as well as a greater absolute increase in the prevalence of diabetes among elderly people is expected to become an epidemic. While online health information has lessened the gap, as it is free and often simplified, the emphasis is on self-management and self-care, leaving some individuals still without easy access to health care guidance. Currently there is a global push from governing agencies to improve health literacy. Overall, patients with low health literacy need to understand the implications of diabetes and how they can better cope with it. This exploratory qualitative research study explores the literature, searching for gaps in what is known, and conducts narrative interviews to understand how to bridge the gap between health literacy efforts and older diabetic adults. It concludes that improving health literacy within this population requires more transmission of health information, promoting health education that will improve individuals' confidence and ability to self-manage their care.

Acknowledgements

Thank you to the Department of Education, my professors and fellow students for their support, encouragement, guidance and wisdom.

Thank you to Professor Arpi Hamalian for being the first person to encourage me to do this research study. The engaging conversations in your class and your office provided me with clarity on the importance of health literacy.

Thank you to Professor Ailie Cleghorn for your guidance. You deepened my reflections and provided an environment where I could explore my perspective of health literacy.

Thank you to my incredible daughters, Cora and Renata, who both commenced their graduate degrees after me and finished their graduate degrees before me. You gave me encouragement and set an example that I had to achieve. You motivate me every day to be the best that I can be. I love you both so much.

Dedications

I dedicate this thesis to my colleagues who work in the field of health care. I have written this thesis in the middle of a challenging pandemic that has brought focus to the importance of knowing what it is, knowing what to do, and knowing how to do it, to the surface. I witnessed my fellow health care workers wait daily for updated briefings and government guidelines because we realized that clarifying health information for ourselves and our patients was of utmost importance. Ironically, while writing this thesis about health literacy I witnessed healthcare workers' commitment to communicating and ensuring proper health care, and constant attempts to save lives during this pandemic. I observed so many levels of government working together to navigate Covid 19, keeping it under control and the population safe. I observed that when everyone works together, we can be very effective in dealing with challenges. I witnessed health care workers keeping the virus contained by promoting health literacy and self-management. Thank you, health care workers, you are the key components to society staying healthy.

To my Dad and Mom: you died many years ago after suffering with chronic disease affecting your quality of life. You both died too young, but you influenced me to promote good health management.

Table of Contents

Table of Figures

Introduction

"Health literacy is a stronger predictor of an individual's health than income, employment status, education level, and racial or ethnic group." World Health Organization, 2013

This research project examines the issue of health literacy among older adults. Older adults currently make up the fastest growing group in North America. Demographic estimates from Statistics Canada (2014) reveal that the baby boom generation is accelerating the aging population at a growth rate of 3.7%, more than triple the growth rate of the whole population of Canada. They also show that seniors are living longer. This has resulted in an increased need for supporting the health and well-being of this population. With medical advances, it has been observed that the increase in life expectancy correlates with a greater number of cases of chronic disease, a potential major global concern. Our health systems need to be equipped to deal with and inform society about chronic illness. One of the most prevalent chronic diseases that is raising concern is diabetes. The aging of the population combined with a greater absolute increase in the prevalence of diabetes among elderly people is expected to become an epidemic. According to the World Health Organization (2019) people sixty-five years and older will make up most of the diabetic population.

Diabetes is a primary disease that can cause many health problems. This has resulted in an increased need for informed educators with accessibly written information to support older adults diagnosed with this chronic disease. With over twenty-five years of experience working in health care, I have witnessed firsthand the pivotal role of health literacy in positively impacting health outcomes and decreasing hospital stays. Health documentation that is not accessibly written, uses medical jargon, does not provide information, or provides but does not interpret it, can serve as setbacks to individuals diagnosed with diabetes. In an ethnically diverse society, this information must also be available in languages other than English and French. Furthermore, in both the medical and general population, understanding how to control the prevalence of diabetes is lacking, thus the education and promotion of health literacy is essential.

Junghyun (2016) explains that diabetes is one of the foremost public health issues worldwide that can lead to many complications. Similarly, Tabish (2007) points out that diabetes is the fourth leading cause of death in most developed countries. Many complications and secondary diseases, such as heart disease, vascular disease (strokes), diabetic neuropathy, amputations, and kidney failure, can result in increasing disability, causing poor quality of life due to illness. For example, diabetes is the leading cause of chronic kidney disease necessitating regular medical interventions. Consequently, the demand for renal replacement therapy (dialysis) among the aging population, in order to survive and live longer, has dramatically increased, and continues to increase,. Apart from quality of life issues, this is a costly medical intervention putting significant strain on insulin research funds. Yet, preventive measures, such as diet and active lifestyle, have proven to be highly effective at managing diabetes.

The specifics of how to best manage diabetic seniors and implement effective interventions for functional outcomes are still being figured out. More than explaining conditions, there is a dire need for additional efforts to increase the understanding of the prevalence of diabetes. It is for this reason that health literacy, a comprehension of medical texts describing disease management, is so central to health outcomes. It has been noted that this diabetic population is particularly susceptible to low health literacy due to having less knowledge and awareness about their illness, less readiness to take care of their health and poor self-management skills (Al Sayah & Williams, 2012). Greater training for, focus on, and promotion of health literacy is thus essential. This is particularly the case with the looming boomer spike.

Background

I witnessed the effects of diabetes within my own family. Family history of diabetes on my father's side is very prevalent; however, the increased risk was and is still ignored by my close relatives. In my father's case, he lacked understanding of the importance of chronic disease management. He was surprised when his diabetes got out of control because he was only a "little bit" diabetic for several years. He believed that if his blood sugar levels did not go too high, he would still be okay. He did not understand that long term effects of high blood sugar, regardless of "how high," could still lead to major health complications. This led to a lot of suffering, and amputation of a leg in his last year of life. I witnessed him become more compliant to health recommendations once he understood what he needed to do, but it was already too late, and he died of complications from diabetes after much suffering at 72 years old.

I work at the McGill University Health Centre, in Montreal, Quebec, Canada, as the Therapeutic Recreation Specialist. One of my job responsibilities was to organize a pre-dialysis education day on a regular basis, and to manage up-to-date resources from the Canadian Diabetes & Kidney Foundations for patients. The information days were crucial for informing patients and families about their condition and what they could do about it. I believe knowledge and information make for a very empowered and healthier individual. However, I witnessed patients demonstrating very poor comprehension of what their health situation was. The present approach to health education and health communication does not appear to be effective in teaching very important health information. It is either written in too complicated medical and technically specific terms, or lacking an effective approach to changing health behaviors in order to produce better health outcomes. This research project emerged from my desire to understand what I have witnessed in both my personal and professional life. It was also borne out of a desire to make a difference and lead to a productive change in health education promoting health literacy. In this thesis, I will be presenting facts, my findings, and what I have personally experienced.

Problem Statement

While online health information has lessened the knowledge gap as it is free and often simplified, individuals without easy access to computers are unable to extract the information. Moreover, the emphasis is on self-management and self-care and people with limited comprehension of how to provide self-care, remain unable to properly manage their own health. Health information campaigns and health communication tools have been created to address this problem; however, they are still not proving to be effective in helping to improve health literacy for many individuals. Many seniors who do have easy computer access, for example, might minimally understand how to use them. As the number of older people with diabetes increases, addressing the lack of health literacy will be increasingly essential. As a health practitioner, I continually witness the gap between health education approaches and effectiveness in ensuring individuals affected by diabetes comprehend necessary information. As a further complication, the health promotion and education efforts that do exist are not comprehensible or attainable by many individuals in need, due to low levels of reading literacy. Low levels of literacy may stem from poor early schooling, or some individuals may only be literate in languages other than French or English.

Purpose of the Research Study

The primary objective of this study was to investigate health literacy and older adults. In order to understand the gap between health literacy and understanding of older diabetic adults, I conducted an exploratory qualitative research study. I used four strategies for this study:

1. I conducted a thorough review of literature on health literacy, searching for gaps in what is known.
2. I conducted narrative interviews with three older adults diagnosed with diabetes.
3. I collected anecdotal data which involved casual conversations with several individuals.
4. I analyzed the findings and interviews to better understand the gap and make recommendations for improving health education for older adults with diabetes.

Research Questions

The main research question is: How can the gap between health literacy and the health of diabetic older adults be bridged? Given the pivotal role of health literacy for health outcomes, my study focused on how we can make our health education and health promotion efforts more accessible and comprehensible.

Through my research, I explored the gap between health literacy efforts and the education of diabetic older adults. My hope was to begin to understand why this population has limited health literacy and why it faces so many challenges when trying to make sense of health information. By using the narrative interview approach, I was able to focus on individuals' own stories about their health and illness. I encouraged storytelling to aid divulging personal information in an informal setting. I selected four individuals to conduct narrative interviews; however, one participant fell very ill and was unable to continue the conversation. In order to help guide my work I focused on asking the following questions:

- What was your experience being diagnosed with a chronic illness?
- Did you suspect you had diabetes?
- Were you told what to do in order to take care of yourself?
- Did you have access to health information? Where? How?
- What is your understanding of health literacy?
- What do you feel can be done to help improve health literacy?

Literature Review

What is health literacy?

Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments (Nutbeam, 1998, p. 357). This definition is central to improving the effectiveness of health literacy efforts. Health literacy thus defined is very close to Brian Street's (1984) notion of ideological literacy: the ability to read, understand, evaluate, and communicate knowledge that is always embedded within a particular cultural, professional and political context. Street argues that literacy is an important factor that influences the lives of people and any success they may have. More recently, Nutbeam (2008) discusses that there continues to be a lack of attention to a broader view of health literacy. Therefore, it is important to distinguish between health literacy and literacy in general. Sorenson et al. (2012) argue that it is important to understand that health literacy places emphasis not only on reading and writing but on the ability to comprehend written health information, communicate with professionals and understand health instructions. Hence, health literacy refers to the capacity to make sound health decisions in the context of everyday life, whether at home, work or in the healthcare system. More recent definitions are focusing on skills needed to provide self-care and navigate the health care system. Therefore, as the prevalence of chronic disease increases worldwide among our aging population, health literacy will be crucial in managing chronic disease and supporting the overall health and wellbeing of this population.

Advances in Health Literacy

The adoption of information technology has improved the capacity to provide much needed health education. More and more popular are online health information websites, electronic health records, telehealth, and other new health applications that hold promise that consumers can access much needed information. However, health interventions targeted at older adults are not addressing key barriers to knowledge access. Many within the older population have issues with accessing, understanding and internalizing this type of health information. The Canadian Council for Learning recognizes that with the rapid older population increase, and the surge in online health digital literacy promotion, greater efforts need to be made to link the two (Murray et al., 2008).

The increasing digitization of information and communication has undoubtedly impacted the ways in which people communicate and access and interpret health information (Welch et al., 2010). With the emergence of new digital technologies, individuals will face even more complex health decisions. Increasingly, the individual cannot be empowered to manage his or her health if s/he does not have access to digital tools. Secondly, many do not know how to use these digital tools by themselves. Thirdly, some individuals might not have the will power or strength to take initiative to access online information. Connoly and Crosby (2014) demonstrated in a study examining e-health literacy that having access to technology is not necessarily associated with usage. A gap in information retrieval and usage was demonstrated among their participants verses a gap in access to technology. Another study, by Levy et al. (2015), concluded that low health literacy is associated with significantly less use of the Internet for health information. This clearly demonstrates that a digital divide can affect an individual’s ability to secure health information, services and support.

Over the past decade, the field of health literacy has advanced from providing limited tools for simplifying language in order to increase the ability to solve problems, to providing knowledge in order to change attitudes, and to evaluate information. A high or low health literacy will directly impact health outcomes ranging from the individual to the societal level. A health-literate person can improve their individual decision-making and health awareness to make healthier lifestyle choices. They are more informed of the social, economic, cultural and environmental determinants of health, such as: tobacco use, food choices, social support, safe physical environment, and are better prepared to engage in individual and collective actions that change those determinants (Nutbeam, 2006).

The field of health literacy has recently experienced very rapid growth in terms of the number of peer-reviewed journal articles, such as, *Journal of Health Communication*, and *Medical Internet Research*. “As a field of research, an approach to improved health care, and an important area of policy work, health literacy has experienced significant growth and considerable evolution” (Pleasant et al., 2015, p. 1176). Numerous research efforts have demonstrated that patients with low health literacy experience: poor adherence to medical regimes, low understanding of the complex nature of their own health, a lack of knowledge about medical care and conditions, poorer comprehension of medical information, low understanding and use of preventive services, poorer overall health status, and earlier death. As a result of these findings, addressing the health and education divide to deal with the health literacy gap is a primary focus of many government agencies (Rootman & El-Bihbety, 2008). It is considered an urgent matter to help assist in improving the health of older adults, a population that makes up the fastest growing age group in Canada. Many seniors will most likely develop and need to manage chronic disease; thus, health literacy will be vital in coping with a large population needing health information and education (Smith, 2012).

Health Literacy and Health Education

Health, education and health literacy are viewed as key determinants in the ability to make sound decisions in the context of everyday life—at home, in the community, at the workplace, within the health care system, within the marketplace, and in the political arena. While addressing the issue of health literacy and education, Kickbusch (2001), states that "education and literacy rank as key determinants of health, along with income and income distribution, employment, working conditions and the social environment, although the inter-relationships and weighting of these various determinants demand further research" (p. 290). From this perspective, health literacy and health education are critical empowerment strategies to increase people's control over their health, their ability to seek out information, and their ability to take responsibility.

Peerson and Saunders (2009) discuss how the term "health literacy" was first used in the 1970s in discussions about health education as an issue affecting the health system. They elaborate that definitions of health literacy have evolved so that the concept commonly refers to people's capacity to obtain, process and understand basic (written or oral) health information needed to make appropriate decisions regarding their health. Interestingly, they also maintain that placing greater emphasis on health literacy outside of health care settings has the potential to prevent certain health complications and thereby reduce demand on the health care system. This implies that health education should also be the responsibility of other communities, such as educational institutions, and possibly a role for higher education. Likewise, Belcastro and Hansen (2017) explain:

> Health Literacy is the benchmark of a person's ability to read and comprehend

> basic health (medical) terms and information. Nevertheless, it is the process of health education that fosters a person's knowledge, skills, and motivation to acquire, comprehend, and base health decisions on scientifically verified health knowledge. (p. 971)

From the same perspective, Nutbeam (2000) states that health literacy is a concept in health promotion and that health education is aimed at improving health literacy. Therefore, improving health literacy will require more alliances between the health and education sectors.

According to Vamos and Hayos (2010), "Health education is an emerging and evolving field in Canada, which highlights the need for designing, implementing and evaluating health-related programs by skilled practitioners and professionals" (p. 310). They suggest that this would result in developing professional and competent health-related practitioners, thereby enhancing capacity building in the health education and promotion workforce. Furthermore, Vamos and Hayos argue that, from local to government to international perspectives, the implementation of health education within higher education is a path worth exploring to further advance the field of public health practice within Canada and elsewhere. They conclude that higher education is critical to promoting skilled health educators. Canada's Expert Panel on Health Literacy agrees that cooperation and collaboration from a wide range of systems and organizations in education and health will be required to be successful in tackling the problem of health literacy, especially with the current statistics demonstrating an increase in chronic disease and older adults (Rootman & Gorden, 2008).

Health literacy and Aging population

A review of the literature demonstrates that Canada's population is aging, and that this will have a great demographic effect on our society. Statistics Canada (2020) highlights that, in relation to the whole, the elderly portion of the population continues to outgrow the younger. This is due to fertility rates being below the generation replacement threshold since the early 1970s, and the continuous increase in life expectancy. The advancing age of the large generations of baby boomers, born between 1946 and 1965, is accelerating this aging demographic. More than one in two seniors (55.6%) were from the baby boom generations on July 1, 2020. While baby boomers formerly made up a large component of the workforce and are retired or are beginning to retire with expectations of continuing a good quality of life, there is concern about how to support these older adults. Statistics Canada concludes that current trends expecting seniors to live longer at home or in the community are common; however, globalization has pushed communities to be more mobile and busier compared to two to three decades ago. Keefe et al. (2007) discuss that lower fertility rates created a trend in smaller families and, as a result, less support for elderly relatives from family members. This factor raises concerns about the risk for elderly people who are being encouraged to live longer in the community. If more elderly members of society are projected to be at risk for diagnosis with chronic disease, health literacy will be essential for coping and managing chronic disease so that seniors can remain as independent as possible.

Health literacy and Chronic Disease Management

In a report about chronic disease related to aging issued by the Canadian House of Commons, it was reported that North American life expectancy has reached an average of 80.9 years, a substantial improvement over fifty years ago. In addition, the incidence of chronic disease among seniors is very high and the major cause of death. It was reported that 74% to 90% of seniors suffer from at least one chronic condition, costing the Canadian economy $190 billion annually. Among the most prevalent chronic diseases are heart disease and stroke, cancer, respiratory disease, arthritis, chronic pain, mental health issues such as depression and dementia, and diabetes (Smith, 2012). Health literacy plays a crucial role in chronic disease management, particularly with diabetes. Tabish, (2007) argues that diabetes is becoming the biggest epidemic of the 21st century; however, prevention of diabetes is proven and possible when proper resources are made available to the individual and issues preventing self-care are addressed. Similarly, Al Sayah and Williams (2012) recognize that the burden of managing diabetes rests on the individual affected with the disease. This requires a high degree of self-care and an ability to navigate the health care system, but low health literacy prevents self-management. They discuss that providing detailed diabetes self-management education and counseling is needed to improve an individual's ability for self-care. However, this poses a big challenge due to the prevalence and globalization of diabetes, which is one of the biggest health challenges today.

In simple terms, globalization refers to processes that increase world-wide exchanges of national and cultural resources. Education has a central role in globalization, for it has the potential to influence change and act as a compassionate force in shaping a global community. Health literacy is an issue that our aging population around the world is facing, one that can be affected by globalization (Goyal et al., 2020). There is evidence that indicates the prevalence of diabetes on a global level is on the rise. The increasing diversity of immigrants and refugees arriving in Canada from other countries, will require linguistic and educational solutions to improve health literacy in this country, which can have the potential to positively affect the aging populations globally.

It is important to examine practices that effectively address and manage chronic disease in order to encourage healthy living for aging Canadians. Interventions are needed that range from incentives for physical activity to addressing socioeconomic or cultural barriers for the elderly to have adequate and equitable access to care, including health literacy programs. The importance of greater focus placed on prevention strategies, coupled with improved diagnosis and management is needed as Canada moves into the coming years of an aging demographic (Smith, 2012).

Manafo and Wong (2012) conducted a systematic literature review of publications about programs that focus on health literacy for the older adult population. They mention that The Canadian Council for Learning, a leader in promoting health literacy in Canada, identifies a framework for understanding the basis of health literacy (p. 948). This basis is divided into five categories which include: health promotion, health protection, disease prevention, health care, and navigation through available knowledge. This framework identifies the variety of health activities and behaviors that impact individuals' health-related decisions; factors which lead to positive health outcomes. For example, self-motivated learning about the importance of disease prevention is an example of health literacy. Belcastro and Ramsaroop-Hansesn (2017) also emphasize the importance of motivation in developing skills for positive health behaviors and outcomes. The authors note that there is a limited number of health literacy programs that target the older adult population, most likely due to health literacy being a relatively new concept. Furthermore, they mention the central need to identify the role of health literacy skills for overall health and well-being. They conclude that health literacy programs continue to gain attention, notably in health literacy literature, as well as in the health promotion literature as it relates to aging and good health. Moreover, supporting health literacy in the aging population has important implications for public health professionals and educators.

Health educators must keep adapting on many levels to respect the diversity of our aging population. Many adults have come to expect that educators/instructors will understand and take into consideration their individual needs and desires, such as, social participation, and/or promoting self-esteem, and may leave programs when these are ignored (Edwards et al., 2012). Accepting diversity and understanding the correct approach to educate older adults with chronic disease will allow educators to motivate adult learners to stay on top of updated information. This approach will be necessary in the future creation of health education/health promotion programs to improve health literacy programs among the aging population with high incidence of developing chronic disease.

Health literacy and Health Promotion

Health promotion is a process that aims to engage and empower individuals to choose healthy behaviors. This approach seeks to empower individuals to take control of their own health and enable people to take actions that foster self-management. Kumar and Preetha (2012) argue that health promotion is being recognized as a viable and effective tool to help prevent diabetes and other chronic diseases. The interventions at both community and individual levels include lifestyle modifications for weight control and increasing physical activity. Modifications can be directed toward priority health conditions and take into account the complex health determinants such as behaviors, cultural beliefs and practices to promote well-being. Similarly, Nutbeam (2008) explains that promoting confidence and empowering behavior change helps to improve health literacy; therefore, health literacy is an outcome of health promotion. He suggests that health education focus on health promotion outcomes, such as, improved knowledge, understanding of health determinants, changed attitudes, motivations in relation to health behavior and improving self-efficacy.

“Self-efficacy refers to an individual’s belief in his or her capacity to execute behaviors necessary to produce specific performance attainments” (Lee & Oh, 2020, p. 407). Regarding this definition in relation to health promotion, Lee and Oh (2020) state that individuals with high self-efficacy are more likely to benefit from health education programs and have improved compliance with self-care activities. They studied self-efficacy in relation to health-related quality of life in older adults and their findings suggested that self-efficacy may be a crucial consideration when managing chronic disease and health promotion.

Discussing the promotion of self-efficacy as a self-management intervention in self-care, Saroni et al. (2018) concluded that self-efficacy theory should be incorporated into diabetes education. Diabetes management requires major changes in behavior and this study utilized Albert Bandura’s self-efficacy theory. In his research on human learning, Bandura (2010) found that self-efficacy plays a vital role in learning. Self-effectiveness has often been defined as the belief in the ability to perform and succeed in a job. Self-efficacy gives a learner the confidence to tackle and undertake a particular learning situation successfully. A learner's self-efficacy will determine whether they feel adequate to take on a particular job or not; that is, self-efficacy influences learners’ attitude towards learning.

Bandura (2010) argued that the expectations of self-efficacy are deduced from performance accomplishments, physiological states, verbal persuasions, and vicarious experiences. Adult learners with a strong sense of self efficacy normally see challenging tasks as problems to be mastered, are more interested in their learning activities, become committed to their learning, view setbacks and disappointments as part of the learning process, and recover from them faster. Learners with low self-efficacy tend to stay away from challenging tasks, lose interest in learning when faced with disappointments, believe that they are incapable of tackling difficult tasks, and focus more on the failure and negative results. Therefore, health promotion strategies to increase self-efficacy and promote healthy behaviors could yield good results regarding positive behavior change.

Current Health Literacy Strategies

Given the potential of health literacy to help individuals lead healthier lifestyles, it is worthwhile to examine current strategies to improve health literacy. Numerous tools to screen for and measure health literacy have been developed in the past few decades. The collected data from these tools have been analysed to associate that low health literacy can indicate poor health status and poor health system performance. The field has focused on using such results to influence policy and practice in public health contexts (Pleasant et al, 2015). Similarly, Nutbeam (2008) concludes that a number of studies have demonstrated the impact of low health literacy and high cost to the health system. This has attracted the much needed attention of policy makers and health service providers to increase the awareness of the relationship between health and literacy and support programs that improve health literacy.

Approaches to improving low health literacy is to make information more accessible. Historically, health information was provided by healthcare providers but today's modern health care system is using new health information technologies to enhance delivery of health care. According to Connolly & Crosby (2014), seeking health information is one of the leading uses for the Internet. eHealth literacy (health information from electronic sources), has been associated with positive health outcomes for those who are capable of accessing eHealth and self management of their health and health behavior. Telemedicine and Internet based interventions can reach a broader population. Kickbush (2001) emphasizes that new information technologies are providing learning opportunities that are more visual and interactive. It can be used individually or in groups and allows talking to others with the same problem. The Internet can help address health literacy and health challenges by offering new ways of learning.

Numerous health professionals use the Internet to promote self management skills and active information and use. Edwards et al. (2012) demonstrated in their study that health care professionals had success in developing health literacy skills and practices by teaching their participants how to use a computer to seek health information. Health literacy interventions aimed at patient involvement were successful at promoting self management skills. The study also concluded other effective strategies to improve health literacy was for health professionals to build trust with their patients by communicating at their level and allow indviduals to express needs and concerns.

Intentions to develop more strategies to improve health literacy are becoming more apparent in the literature. However, Pleasant et al. (2015) argue that the bulk of research on health literacy is guided toward the negative effects of a lack of health literacy. They suggest that a more practical approach of measuring changes in health and well-being produced by an intervention based on the best practices of health literacy is needed. In addition, information access is evolving very rapidly and more research is needed to best understand what methods for information access would best fit our older adults.

Summary and Navigating the Gap

To conclude, this literature review illustrates that health education is needed to improve health literacy to affect health outcomes. Efforts directed at how to foster the skills needed for informed health decisions or to motivate positive health behaviors continue to be studied. Even with globalization pushing our digital age, making more material about health available on the Internet, health education promoting health literacy is still not meeting the needs of all people.

Bogden and Bilken (2007) discuss that there is a split between academic research and action research. They argue that collaborative and action research have the potential to bridge the divide between research and practice in adult literacy. The field needs to focus on the strength of health literacy as a solution and promote best practices for behavioral change. With an aging global population, information needs to be made more readily accessible. Despite the abundance of information on the Internet, it is not always understandable or accessible to those who need it. As a result, those who have chronic illnesses often lack the information or motivation needed to improve their lives. There is a gap in the literature concerning how to be effective in promoting improved personal health and health outcomes by improving health literacy. This is the gap I am seeking to address.

Methodology

Narrative Interviewing to gain perspective.

In order to address this gap, I chose narrative interviewing because it is often described as a post structural approach to research practice. Atkinson and Silverman (1997) claim that the interview has discursively established itself as a neutral method of data collection, producing trustworthy and accurate, unbiased and fair results within the context of a relationship between interviewer and interviewee. It provides a personalized account of a situation which can be valuable in either supporting or contesting research findings. Similarly, Sandelowski (1991) argues that narratives are life stories that put sense and order to events and give meaning to individual experiences that permit researchers to gain insight into how people understand and enact their lives. Anderson and Kirkpatrick (2016) argue that narrative interviews are not set out to be generalizable and therefore may only involve a small set of interviews. On examining the literature, the narrative interview approach seemed best suited to my purpose of examining how to bridge the gap.

The qualitative approach helped to better understand the experiences of older adults diagnosed with diabetes. My methods supported “interacting with people in their social contexts and talking with them about their perceptions” (Glesne, 2011, p. 8). I interviewed three individuals and gained perspectives through narrative qualitative research because it provided an opportunity to listen to individuals’ stories, validating their experience and informing our efforts to lessen the gap.

Research setting

The interviews were conducted in a variety of settings. The location was agreed upon by the participants and I suggested interviews by phone, online, or face-to-face. The research was conducted the summer of 2020, during a pandemic, so compliance with the government restrictions on gatherings was necessary. Interviews were done either over the phone or face- to-face (keeping a 2-meter distance with face masks on) in an area free of distractions.

Type of Study

I used interviews to collect narratives about participants' experiences of being diagnosed with diabetes. The narrative inquiry approach, using a pre-constructed questionnaire, permitted me, the interviewer, to let the interviewee explain and possibly make sense of their own health literacy issues in a semi-structured interview. I was able to compare each patients' experiences in order to better understand the issue of low health literacy within this population.

Selection of Participants

Using word of mouth, I asked my circle of friends and family to spread the word about my research, and that I was looking for candidates. Surprisingly, within a week I already had four participants interested. I had also intended to use social media to recruit, but it was not necessary. The four participants were over 65 years of age and diagnosed with diabetes. Despite differences in backgrounds and life experiences, the common theme was that they had all been diagnosed with diabetes that required regular medical attention and treatment. They were also cognitively intact with good ability to converse and still lived independently within the community. Interestingly, into the late fall of 2020, I continued to receive suggestions about possible participants, or individuals continued to contact me saying they were interested in participating. This provided me with an opportunity to collect some anecdotal evidence; I explained to these individuals that they were welcome to give me any information they felt would be valuable to my research, but not as formal participants in the study, due to the fact that ethics review had already approved that I accept the four who agreed to participate. Late in the summer, one of the participants to be interviewed fell very ill and was hospitalized. While waiting to interview this individual I continued to collect anecdotal evidence. By late fall, I decided not to interview this individual as s/he was still struggling with health issues. I did, however, include their opinions from a conversation, which are included in the anecdotal evidence summary.

Validity

The credibility of patient/interviewee information in discussing the problems with health literacy and chronic disease was assured by using multiple interview sessions. Glesne (2011) asserts that usually "it is important to plan a series of interviews with the same person over time so that rapport can be established, and time can be sufficient for learning from respondents" (p.107). The first conversation with each participant was over the phone and consisted of getting more familiar with the research project. It also allowed for building a rapport and planning to meet again to conduct the interview. This helped develop trust and allowed the exchange of information to evolve. I also organized a follow-up phone call to share some interview transcripts and analytical thoughts with the participants to ensure correct representation of their stories and ideas. The interviews were structured in a way to keep the door open for follow-up questions or interviews later via telephone or email. By allowing this open door, I was able to revisit the transcripts, double check the clarity of the answers, observe the themes that were developing and expand on themes and experiences that I may have not accounted for when designing my study. I did have to contact my participants on a few occasions to clarify certain statements that were made.

I am extremely invested in this research study and recognized that I might be biased concerning the issues of well-being and quality of life among older adults. In order to mitigate this, I continualy addressed my subjectivity; both before and after my interviews, I wrote down any observations to address any pre-conceived opinions. To help with threats to the credibility of the research, I arranged a follow up call with the participants to go over their answers and statements. This allowed them to reflect on the information they provided to me. It also allowed me to review the research participants' answers and ideas so that representation of their input was accurate. I found this process very helpful; it allowed me to identify gaps in data collected. As mentioned above, the participants were from different backgrounds, which added to the credibility of common themes.

Data Collection Techniques

I received ethics approval on June 11, 2020 and proceeded immediately to recruit participants. I developed an interview schedule to be done before the end of September, and a set of questions for a semi-structured conversation style interview (see Appendix A). This is a commonly used method in qualitative research that not only provides a framework but also gives the interviewer the flexibility to probe certain issues with more open-ended and follow-up questions. So, although the interviews were relatively structured in that there were a designated series of main questions that every interviewee was asked to respond to, the questions were not necessarily asked in the same order and individuals were also encouraged to talk about, and elaborate on, other connected areas if they felt so inclined. Interviews were scheduled 2-3 weeks apart, depending on availabilities of the participant. I also kept a notebook in my purse to ensure jotting down thoughts or ideas when needed so that I would not forget, and to keep ideas organized. The privacy and confidentiality of the participants was protected using pseudonyms relating to their own names. The pseudonyms selected do not necessarily reflect the gender or gender identity of the participants; they are simply a means to ensure complete confidentiality.

Prior to the interviews, I assured my respondents that all personal information would remain confidential. Participants had the right to withdraw from my study at any point if they did not wish to continue. However, they all agreed to remain involved. The process of reading the information and consent form (see Appendix B) with the participants helped to clarify the research question, the type of information needed, and the focus of the interview. However, storytelling was encouraged in answering research questions in order to get the narratives of each participant.

I informed all participants that data collected from interview sessions would be incorporated into my master's thesis to be presented within Concordia's Educational Studies program. I suggested to participants that interviews would last 60-90 minutes. However, every interview naturally exceeded the 90 minutes. All three participants continued talking after I stopped recording and officially announced that the interview was over. Interestingly, they began to talk even more freely. I was prepared and took notes while they were continuing to explain their experiences.

I focused on listening carefully, attentively, and analytically to the descriptions and explanations being described because they were of utmost importance. Participants sharing their impressions and conveying their thoughts, experiences and identity were important factors to facilitate the participants interviews, and to learn relevant life history that would help to understand why low health literacy exists. The interview questions themselves, were primarily open-ended (Glesne, 2011, p. 134). The goal of open-ended questioning is to obtain answers which are not probed but given freely. While my interviews consisted of the same basic questions, there were various follow-up questions that were used in direct response to the answers that were given. These participant-specific questions were not planned, happening through natural conversation. Interviews were recorded on my phone (to which only I had access), and notes and key points were transcribed within a few weeks following the conversational interview. Each participant received the transcription of their interview to make sure that I represented their answers correctly.

I reviewed the recorded data immediately after the interview session. Since data collection involved interviews, once transcribed, the data was analyzed using narrative analysis. Focus was on both form and content; the content of what was said and how it was told in the storytelling. I placed importance on taking note of the events included in each story as well as the feelings and reactions that were expressed during the storytelling. Lastly, I paid attention to any commonalities of themes within the narratives across and within participants.

Limitations

The strength of this study lies in the use of narrative methods in order to obtain in-depth data on the subject at hand. To this extent, the study is limited by not being able to include many respondents who could, for example, provide generalized results. Limitations associated with narrative research include possible inaccuracies due to anecdotal information given by interviewees. An interviewee might not remember the details of their experience or they might leave out pertinent information. The primary focus of this research was to gain an overall picture of participants' experiences and how they feel they could be better informed; therefore, details about the process they went through are not as relevant to this study as their overall impression of health literacy in the face of a diabetes diagnosis.

Presentation of Data

I applied early narrative analysis, as suggested by Glesne (2011), analyzing simultaneously while collecting data. This allowed me to reflect upon and shape the study as it proceeded. Once the data was collected, I continued the analysis, which, I will present in three parts. The first part provides some narrative descriptions and quotes of each participant's experience. Secondly, a discussion of anecdotal evidence helps to provide clarity. This is followed, thirdly, by the thematic analysis (Glesne, 2011, p. 187). This process aims at analyzing people's life experience and aims to uncover essential themes and patterns in the narrative interviews.

All narrative interview participants had experience navigating the health care system. They have all been diagnosed with diabetes for a minimum of ten years and have other chronic conditions. They are frequent visitors to outpatient clinics for appointments with family physician and specialists. They all wanted to be heard and to have a voice in improving health literacy. I observed that they were very committed to helping to make a difference in bridging the knowledge gap identified above. In order to focus on each interview participant as a full and complex individual, I will provide a brief description of each and include some interview quotes that I think deserve attention. I also want the reader to gain more insight from reading the direct quotes, from verbatim transcriptions, for accurate depictions of the interview. The authenticity and perspective of their own words is important when answering each question and allows readers to focus on the primary substance of the participants' quotes.

How about George's story?

George is the oldest participant at 76 years old, happily married with children and grandchildren. Highest level of education completed is high school. George was diagnosed with diabetes over a decade ago and he is insulin dependent. He also has heart disease requiring daily medication. The interview lasted two hours and George was very engaged in the process, keeping me informed of any other insights he had outside of the interview. He contacted me several times afterwards to further clarify his answers.

1. What was your experience being diagnosed with a chronic illness?

George: I was very disappointed. I uh, not really understanding why, but then as time progressed after seeing several doctors, that this would explain well what I was feeling, and I went on medication, of course.

George: And, I didn't, I don't think I really understood the seriousness of it, at first, the first going. But as time progressed, I realized how important it was to have it under control.

George: Yeah. Well, there was nothing, no diabetes in the family – but that's not to say they didn't have it.

George: They perhaps just weren't checked… They could have very well had it. And then, the blood tests and what not were not as sophisticated, shall we say, as they are now.

2. Did you suspect you had diabetes?

George: No. Not at all. No symptoms. None that I knew of.

AMC: Now once they told you, you had diabetes, what was your first reaction?

George: I didn't want to be bothered (laughing) but in retrospect, it was the wrong, the wrong decision, but anyways, that was the way it was to start.

George: Well, I think the blood tests are wrong, there's got to be something wrong, they can't find that I have diabetes, I feel pretty good". And I said, it's probably related to, like I used to drink quite a bit - it's probably related to that, it's probably that the blood tests were around the time of when I was over-indulging, and that's had a effect on it, but I'm digressing here-digressing?
AMC: No no no, go ahead- this is a narrative; you can say whatever you want at any time.

George: But I found, through my personal research, that whenever I was drinking, my blood tests in the evening were pretty good (AMC: Pause. Laughing). They were pretty low, under control- I'm not kidding!

George: And I saw, 100%, without fail, my reading was lower when I, when I …and I tested every night, whether I was into the sauce or not. And there was definitely a correlation between the alcohol, and reduction in the glucose mostly only, only 8. And I told my doctor about this, and he said, "Well, I don't know that might be so but it's not a good idea to be drinking", he said. Which is right (laughing).

(AMC): How many years into being a diabetic, did you start to take better care of yourself?

George: Ahh…I think it's only been in the last couple of years maybe?- if that! I used to be pretty obese, and I still am, but when Zachariah (my grandson) appeared, I was at 259.6pounds and my doctor had warned me about this, and I had fallen a couple of times, and they had a hell of time getting me back up. So, Zach said, "You're going on a diet and that's it", so…I'm on the diet and I've lost a little over 18 pounds (AMC: I find you look amazing, you're looking good, thank you, Zachary). And my readings are really under control now.

3. Were you told what to do in order to take care of yourself?

George: Yes. My doctor told me every time I went to see him."

AMC: "*So, he did tell you every time?*

George: Oh yes, yeah. The big issue was the weight and exercising. (AMC: Okay). You know, you get lazier as you get older, or just not able to do all the stuff, exercising and what not, and you start 'blossoming'(holding tummy), if you're not careful of your diet, and then you're too big and fat to do your exercises! For example, and another thing that happened to me, I think it was two years ago or so, I broke my foot. And before that, I was walking about a kilometer every day. Because of my congestive heart failure, but I was able to walk every single day, until I broke my foot. And I never got back to it. That was the end of my walking.

AMC: So if the doctor was regularly telling you what to do then you were a non-compliant patient at that time (GS: Yeah, yeah). He admitted to non-compliance!

George: Well, uh…your lifestyle. It's very difficult to change. Very difficult. I was into drinking- I know that that was bad, plus the congestive heart failure (AM: Okay), although I did my research, that it was helping my diabetes (laughing), I knew I shouldn't be doing it. But…it's hard to change. I love to eat. I love potatoes- meat and potatoes (AM: Yeah), but potatoes are deadly, with the starch, French fries for example. But it's difficult to change your lifestyle; you're used to living a certain way, and you end up continuing your lifestyles. Even though there's a little person on one side saying, "Don't do it", there's a little devil standing on the other side, saying, "Have another big serving, yeah, go for it" (laughing), while the good guy on this side is going, "Don't do it George, don't do it".

4. Did you have access to health information? Where? How?

George: Well, my doctor is very good at it (AMC: Okay), and I might go online if I have any- like I researched why I was feeling the way I was, with the shakes and the sweating and I would be sitting here as I am now! (AMC: Yeah). Couldn't tell ya. And I wouldn't be able to move! And I *would have to get the service- I probably had taken too much insulin. (AMC: Yeah). There was that after when I had researched on the Internet (AMC: And then you went on to find something- so you were) - the next time, I took with three tablespoons of maple syrup. The next time I would have those symptoms (AMC: Yeah, it's so hard to control, it's so hard to know when, how, when to take sugar, when not).*

George*: But I don't trust online stuff either, (AMC: No), because there's always a lot of stuff.*

5. What is your understanding of health literacy?

George: Well, I think it's…having the knowledge of what's possible about a disease out there and an understanding of how serious the disease is (AMC: Mmhmm). Like I never put diabetes into a serious category, which I really should have.

6. What do you feel can be done to help improve health literacy?

George: I think maybe patience and remember people do stretch the truth a little bit. You don't want to be ill, you don't want to have the chronic disease like we've been talking about so you probably do not tell the doctor all the facts; "I don't believe you when you say this George, and I don't necessarily buy what you're telling me " (AMC: Aha, oh…): "But I can prescribe to you, but I have to base my decision on what you are telling me, and I'm not going to set up a lie detector on my desk to strap on you to see if you're telling the truth or not" (AMC: Ohhh…) because sometimes you don't want to admit that you are telling the truth or not but Dr needs to tell it the way it is, explain what can happen, tell it the way it is, what the possibilities are.

According to George, he did not understand the seriousness of being diagnosed with diabetes. As time progressed, he developed secondary conditions related to diabetes and then he began to recognize how important it was to have it under control. He was very insightful and brought quite a few themes to the surface. First, he did not suspect he had diabetes upon diagnosis, and he did not want to be bothered with the idea. This expression of denial was directly related to his lifestyle. He admitted to being non-compliant because he did not want to change his lifestyle and expressed that he enjoyed drinking alcohol and did not want to change that habit. He discussed how changing his mindset was integral to becoming more compliant to health recommendations, as well as having his family motivate him to want to comply. George was the only participant that said he felt his family doctor kept him well-informed; however, he also remarked that he was not always able to get in touch with his doctor and was told to go to the emergency room if any issues arose. George's final recommendation to help bridge the knowledge gap is to explain the importance of weight and diet in controlling diabetes, to "tell it the way it is, what the possibilities are," to help increase awareness of how to control diabetes.

How about Ruth's Story?

Ruth is 73 years old, married with children and grandchildren. Her highest level of education is grade 9. Ruth is very concerned for her health. She was diagnosed with diabetes ten years ago and has other chronic conditions. She is also a cancer survivor and has had several surgeries. The interview lasted 95 minutes, but she contacted me several times afterwards with more thoughts and insights. She was adamant that her words be heard and asked me to quote her in my thesis.

1. What was your experience being diagnosed with a chronic illness?

Ruth: I found out because the doctor often asked me, "Are you diabetic?" and I kept on saying, "No…not as far as I know". "Is there anyone in your family that is diabetic?"
I said, "Yes, my half-brother." "Anybody else?" "Not that I know of", and he said, "Okay." And I said, "I have never been tested for it." And every time I went to him, it was the same thing. Finally, he said, "Okay, I'm going to give you a blood test" and I went for the blood test and he found that I was borderline, but he didn't do anything about it at the time because he felt, well if I just watch my diet, watch my sugar, then I should be fine, which I did- until I consumed a lot of sugar.
And a few days after I consumed all that Halloween stuff, I had a blood test done, and yes, I was right up there, as far as things go.

2. Did you suspect you had diabetes?

Ruth: No, I had no idea.

3. Were you told what to do in order to take care of yourself?

Ruth: No information. A good friend of mine did, but never a health professional. The only information I was given was to cut down on the sweets.

4. Did you have access to health information?

Ruth:: I was very disappointed that a lot of things weren't said to me - so at that point, yes I came home, and I opened up my computer and looked up what's good for me and what's not good for me.

AMC: So again, to clarify: if you would have been given suggested websites to look at on the Internet to get more information would you have looked at these websites? (RB: Yes I would have looked, definitely). And you would have been comfortable using the Internet to access that health information? (Ruth: Yes).
Ruth: I would have been very comfortable using the Internet, but I also know people who are diabetic and I talked to them as well, because I wanted to know what they were going through. Because I was having things that were happening to me that I didn't know if were related to being diabetic.

5. What is your understanding of health literacy?

Ruth: Well, I couldn't really tell you...as well as health literacy goes, as for the words they use, I don't understand half the words that they use (AMC: Yeah) But you know, if they would come down and keep it simple.

6. What do you feel can be done to help improve health literacy?

Ruth*: I suggest in the first place that medical persons should not rush through their interview with you, especially for something like diabetes. (AMC: Okay).*

Ruth: Now, when I talked at one point, about my vision not being that good, I was told to have my eyes checked (AMC: Okay…) When I talked about my dry throat, I was told that it could be anything. (AMC: Okay). Now this is a medical professional, professor- they should know that dry throat is caused by diabetes. They should know that my eyes are because of diabetes. They should know that my nails could be caused by diabetes (AMC: Yes). I didn't know any of this or that so here I am wondering, "Well what's going on?" Well with me, I think it's an "I need to know" and if you're not going to tell me, I am going to go on the computer and find out. Because I think, when anything that happens to a person and the results are not good, the medical person should be saying, "What can I do to help you"- your exact words-

AMC: Anything else

Ruth: More compassionate, give more information-)
And ask what you need. "What can I do to help you, what do you need"- That's the first words that should come out," What can I do to help you?" after telling the patient that this is what's happening and just leaving it at that.

According to Ruth, she was not given much health information from her doctor, or from other health professionals. She did ask her pharmacist, who explained her medication to her. She appears very self-motivated to get information about diabetes from friends and the Internet. She appeared to be the least informed of the three participants. She was also the participant with the least amount of formal education. When diagnosed with diabetes, she explained that she did not know what “chronic” meant when her physician told her that diabetes was a chronic condition, and searched for the meaning on the Internet. She expressed feeling mis-informed and confused about what she needed to do when first diagnosed. She often feels rushed when seeing her doctor and it makes her too nervous to ask questions. My concern after speaking with Ruth is her continuous use of the Internet for health information. When I asked her if the pharmacist had given her resources for the Internet, she replied no. It was apparent after Ruth’s interview that proper use of the world wide web might be an issue for individuals like her. When prompted to recommend a good website she was not able to reply. Her recommendation to help bridge the knowledge gap is that health professionals should ask their patients what they can do to help, and what the individual needs in order to better understand health recommendations.

What about Dean’s story?

Dean is 65 years old, never married, and has no children. His has a Bachelor of Arts in theology. His mother is still alive, and he has one brother and nieces and nephews. He still works as a chef/baker from his home and volunteers as pastor for his local church. He was diagnosed with diabetes seventeen years ago. He has had a very hard time controlling his diabetes and has had an amputation of his toes on one of his feet. He is insulin dependent. He is very worried about his health.

1. What was your experience being diagnosed with a chronic illness?

Dean: Somewhat surprised, because there had never been any family history of it- that had probably been my first reaction.

Dean: (pause, reflecting) 2000...and 4- sixteen years ago. (AMC: So you’ve had it a while). I’ve had asthma for over 50 years (AMC: Yeah, but the diabetes-) 2004, October... I had been eating all sorts of bad things, too. I was on a sugar high, probably didn’t help it. I had eaten a whole sugar pie that day (AMC: Oh geez!) before I went to the hospital- and a bag of twizzlers.

2. Did you suspect you had diabetes?

Dean: I didn't feel I had any symptoms (AMC: Okay)- I had always drank a lot of water, so I just looked at that, I know water's good for you, so, I mean I don't drink a gallon a day but….

AMC: So even though you knew you were eating a lot of sweets, you didn't think you would be- Dean: I was working 100 hours a week; I didn't think I would be - I figured I was probably burning it off.

3. Were you told what to do in order to take care of yourself?

Dean: And none of them said a whole lot about- Well I think I was kind of handed a sort of sheet of paper- I don't even remember specifically. I don't remember the specific things. But then was it January? - if this was October of 2004, and I think it was January of 2005, I did go down to the hospital for sort of a 2-day, this 2-day workshop where you met with- I think he as the head- I don't know if the doctor- if he was the 'head head doctor' then, but he was one of the internalists, he was in internal medicine specialist, who had all the charm of a tarantula I would say. (AMC: Laughing). Well he's German and he's arrogant; he assumes you don't know one thing and he knows it all. And he does know it pretty well, but I just get irritated, but his bedside manner sucks, I didn't think it was overly useful. You couldn't get in to see him (the specialists), so so I thought, "If sick enough, would go to the emergency'. And I just never got back to seeing him until the foot kicked up in 2015.

4. Did you have access to health information? Where? How?

AMC: if your sugar went too low? If it went too high? What to do? Dean: They explained what they were because unless you were a moron, like if your sugar is low, you better eat something or if your sugar is too high, you had better- stop eating the sweet stuff).

5. What is your understanding of health literacy?

Dean: Well, I would say it was literature about health. I mean, it's rather self-evident (AMC: Exactly). If so, documentation about lifestyle, you know, if it was like I don't know, sometimes- the doctors are not always good at explaining what exactly is wrong with you, what are the - I'll call it, ripple effects, I mean, anybody that knows anyone diabetic, knows it's going to affect your kidneys, your eyes and your heart, and your lower, and your extremities.

6. What do you feel can be done to help improve health literacy?

Dean: Do they teach health in school anymore? (AMC: I don't know- I'm not sure) When I was a kid, they taught health, but I don't know if they still do (AMC: That's a very good question-) I mean, when I was a kid, we had health – we might have only had it once a week like music. I mean, we had health, we had science, we had history - I mean, we scratched the surfaces of a lot of things. I mean, you had art, you had music, you had French. You had history and geography, you had health, then you had reading, and you had a sort of language arts. But teaching health in school would help.

Dean: Make it into something like a level in a romper room, but I mean, not everyone is- I mean, not everyone is a rocket scientist and gets everything.

Dean: If your health professional does not inspire you, then you're not going to feel like you're going to want to listen to whatever the hell they say. I mean, don't start to talk to me like I'm a %$@$ idiot.

According to Dean, his experience being diagnosed with diabetes had ripple effects. Like George, he did not suspect he had diabetes and was surprised because he had no known family history. He presented non-complaint for many years after diagnoses and expressed, as an excuse, that he likes the social aspect of eating with family and friends. Besides liking his social lifestyle, he mentioned not having much confidence in health professionals or proper access to health care. He blamed his amputation on lack of proper care, not his non-compliance, although he admitted to a bad diet several times. Interestingly, he was the only one that received a formal two-day education about how to care for diabetes and had the most amount of formal education; yet, he demonstrated resistance to complying with health recommendations. In order to help bridge the gap in health literacy efforts, he recommends that family physicians should refer patients to specialists as soon as they are diagnosed with a chronic disease and that health care professionals should focus on building a rapport and trust with their patients.

Narrative Interview Themes

Although not specifically mentioned, several themes emerged from exploratory analysis of the narrative interviews. By comparing and contrasting the three participants' narratives, the following four main themes emerged:

1. The relationship with a health care professional is needed to cope with complicated and sometimes conflicting information.

2. Participants' experienced having to adapt their lifestyle to remain compliant to health recommendations.
3. Participants' motivation to follow health education advice.
4. Health literacy makes a difference in patients' ability to understand and use information.

Relationship with health care professionals:

The relationship with a health care professional is needed to cope with complicated and sometimes conflicting information. All participants felt they would have benefitted from direct, in-person health care information and more access to health care professionals. They expressed that understanding the complications of diabetes would have helped them to be more compliant with health care recommendations. They all said that, upon diagnoses, they did not feel any symptoms and that was a big factor in not understanding the seriousness of being diagnosed with diabetes. George was the only participant who seemed content with his family physician. However, he also stated he would have needed more information about how to control his condition with exercise and diet. Both Dean and George indicated that there is an incorrect perception about diabetes medication that you can eat whatever you want, and the medication will do the job. They indicated that health care professionals should be more specific in explaining the role of medication to prevent this misunderstanding. Ruth specified that more effective interventions should be designed and implemented among patients with inadequate understanding of diabetes in order to improve outcomes and establish better communications between patients and health care providers. She remarked several times that she was dumbfounded by, and had problems coping with the diagnosis. It made her anxious and she sought out information from unreliable sources. Thus, it was clear in the discussions that a relationship with a health care professional was lacking. Neither Ruth nor Dean had a health care professional to help them deal with the demands of being diagnosed with a chronic disease. They had scattered appointments in their health care institutions. All participants mentioned a lack of health education at these appointments. They would have appreciated more effort on behalf of the health care team to continue emphasizing the importance following their diet.

Experiences of having to adapt lifestyles:

Experiences of having to adapt their lifestyles were discussed by all three participants. George and Dean both stated that changing their lifestyle was too difficult and that they did not want to change when first diagnosed with a chronic disease. This directly contributed to their non-compliance. They both mentioned being surprised about having diabetes and that changing their lifestyle was not a priority at the time. Adapting lifestyle changes was also very difficult in relation to diet. All three participants expressed that eating was often combined with their social activity, which included family and social gatherings at restaurants. They expressed not wanting to be a burden on family and friends, or were afraid of being left out of social events if they mentioned their diet restrictions. They found it difficult to adapt their lifestyles to always follow their diet recommendations because seeing family and friends was important to them. They also felt regret about not making more effort to fully understand the implications of not adhering to their diet. George commented that if he had of been told that diet, exercise, and maintaining healthy body weight could reduce his dependance on insulin, he might possibly have made more effort to comply. He thought he would always need insulin and did not know a lifestyle change could make such an impact on his health condition. They all said that when their health conditions deteriorated, they were more careful. Ruth explained several times that if she felt unwell, she would follow her diet as recommended. Dean had a similar experience when faced with needing an amputation.

Gordon's neuropathy caused him to fall and that impacted his decision to lose weight. These experiences, as described by the participants, alludes to our next theme of motivation.

Needing motivation to follow health education advice:

When describing their issues with controlling their diabetes, participants' motivation to follow health education advice was discussed. The state of their health condition was an important driver in being motivated to change behavior and follow health recommendations. Both George and Ruth expressed that personal relationships with their spouses and grandchildren helped them adhere to health recommendations when their health was deteriorating. Dean mentioned his mother and being concerned for her health when he was so sick and hospitalized for an amputation. They all expressed a lack of understanding of the seriousness of diabetes and its secondary complications, and had a shared inability to retain and interpret complex health information. Ruth mentioned in the follow-up phone call after our interview, that she made more effort to get professional information when her health declined. Their immediate health condition was central to promoting motivation for all participants. All participants explained that they did not make sound decisions related to their health care due to not fully comprehending that their health condition could rapidly decline if not compliant. When they developed complications, they were motivated to get their diabetes under control. This directly demonstrates the need for health literacy to help individuals process much needed information and be involved in their health plan.

Health literacy does make a difference:

Health literacy makes a difference in patients' ability to understand and use information. It was clear during the interviews that health education was lacking and not fully understanding health recommendations was common. Dean is the only one who received a formal 2-day diabetes education workshop. However, it was years ago, and Dean mentioned that he did not remember the details of the workshop as he participated upon onset of his diabetic diagnoses. He was struggling with asthma at that time and the diabetes diagnoses was not a priority for him while struggling with another chronic disease. He mentioned that more frequent health education sessions would have been more helpful for him because there is a lot of information to absorb when being diagnosed with a chronic disease and some individuals need time to cope with the idea. Although Dean has the most formal education of all participants, he still felt he lacked health literacy in making important decisions. He said, “Like anybody you are never as smart as you think you are, and you don’t always know what you need to know.” Health literacy was an important factor in the participants feeling motivated to self-manage their health needs. Their deteriorating health made them want to understand more. While discussing the consequences of poorly controlled diabetes, and limited health services, they all constructed their own informal information network depending on their disease progression. The use of the Internet was common for all three, however, they all felt they lacked trusted resources.

Summary of Narrative Themes:

Interviews demonstrated that participant’s knowledge about diabetes mellitus, attitudes towards self-management, and self-management skills, together with lifestyle choices, were central to achieving and maintaining glycemic control, both in the short and long term. Participants did not know exactly what health literacy was. They had an idea, but were not certain. Once they understood how health literacy skills can be distributed through one’s social network and, thus, can support individuals in managing their condition, and can assist in communicating with health professionals and making decisions about their health care (self-care support), they agreed that having health literacy from the beginning of their diagnoses would have made it much easier acknowledge and manage their health.

This study used in-depth qualitative interviews to form narratives, and demonstrated the similarities between each elderly adult diagnosed with diabetes. The same categories were discussed multiple times, and created clear themes. This is demonstrated by the data information discussed in Table 1, below.

Table 1. Narrative interviews themes and categories

Themes	**Categories**
The relationship with a health care professional is needed.	Needing specific information Knowledge of health condition and complications Physician not supporting health education Lack of access to health care Trust and approachability
Participants’ experiences of having to adapt their lifestyle to remain compliant to health recommendation.	Gave diabetes diagnoses a low priority Social life did not encourage healthy diet Refusal to change diet Support of social network At the moment no negative consequences Too old to change
Participants’ motivation to follow health education advice.	State of health condition Personal relationships helped motivate to follow recommendations Managing diabetes with diet and exercise Awareness of limitations Gaining control Self-efficacy

Health literacy makes a difference in patients' ability to understand and use information.	Poor acceptance Inability to cope Make informed health decisions Self-care behaviors Better understanding Fears and misconceptions Lack of health education

Anecdotal Evidence

When first embarking on this exploratory study, I was focused on a small number of interviews to help address my research questions. I was grateful for the attention my study received when seeking participants. After selecting the participants, I continued to hear from people interested in participating, but my ethics clearance allowed for only three to four interviews. Several individuals wanted to share their insights and felt the need to give me feedback to help with this study. As a result, I decided to listen to what they had to say. Casual conversations provided additional information and helped to support information gained from narrative interviews. These conversations lasted between five minutes and twenty minutes, depending on the setting. I was impressed with these individuals' desire and willingness to contribute their insights. What I liked most about the anecdotes was that they were freely offered in a variety of settings, ranging from my workplace to a phone conversation. They greatly complemented the information gained from my narrative interviews and helped generate a better understanding of how to bridge the knowledge gap.

To keep these casual conversations focused on my research, I explained what health literacy was and then explained what information I was seeking. This generated a generous number of responses from people. This impromptu sharing differed from the narrative interviews because it was not systemically gathered; however, very relevant information emerged.

The most common anecdotal evidence that participants expressed was that an information overload confused their self-management efforts. They mentioned that the Internet misguided them or scared them with too much information. They recommended that a pamphlet of resources be available in all clinics in order to provide guidance to reliable sources of information. The second most suggested solution was that medical staff should not rush their appointments so that more attention can be paid to important details and information required to help control diabetes. When participants were rushed, they felt neglected and more like a burden than an important patient; some participants specifically used the word, “burden”. Some also confessed that at times they felt like that with their families as well.

Additional comments that helped illuminate the contextual nature of the research question can be paraphrased like this: “Allow yourself to seek alternative help; know your boundaries; seek stress management; deal with fear of hospitals; be willing to take care of yourself; confront your own issues before blaming health professionals; acquire some problem-solving skills; don’t try to impress the doctor by withholding information; have a good sense of humor.” These comments did not directly answer the research questions, but provided in-depth understanding of the issues facing diabetic patients.

The importance and relevance of patient abilities and characteristics, as well as health professional factors and broader contextual factors were mentioned. I noticed that a majority of the casual conversations were related to the patient approach or skills management, similar to what I heard in the narrative interviews. I divided the anecdotal comments into two new themes, patient approach, and skills management, as in Table 2, below.

Table 2. Anecdotal Evidence Themes

Patient approach	Management Skills
Speak same language as person whom information is needed.	Explain risks of not being compliant to health recommendations.
Explain to individuals to be conscious of adapting lifestyle for better health. Do not give up	Individuals must be willing to take responsibility and be assertive in seeking medical information.
Teach how to work with health information. Be wary that too much information on the Internet can be misguiding	Health care professionals should give specific resources that are trusted by health care institution.
Seek someone to help get information to patient if needed	Use family network or support and learning from other patients.
Teach about what food is unhealthy, handouts or written document with specific trusted resources is needed. Diet should be discussed in detail.	Engage in motivating individual to seek information and eat healthy.
Discuss stress management. Being diagnosed with chronic disease is stressful.	Encourage social support, social networking, support groups.
Promote self-confidence by teaching health education. Tell individual they can do it! Do not be negative.	Discuss problem solving skills. For example, if sugar is too high/too low. This avoids un-necessary panic.
Discuss medications in depth, do not prescribe a medication without explaining what it is for	Use clear simple language and diagrams.

Summary

In summarizing the data collected from both narrative interviews and anecdotal comments, anecdotal evidence contributed two new themes to the data collected from the narrative interviews. Collectively, the main themes in relation to diabetic older adults are:

1. The relationship with a health care professional is needed to cope with complicated and sometimes conflicting information.
2. Participants' experience of having to adapt their lifestyles to remain compliant to health recommendations.
3. Participants' motivation to follow health education advice is important.
4. Health literacy makes a difference to patients' ability to understand and use information.
5. Patient approach is an important factor in health education.
6. Management skills need to be emphasized in health education.

Relevant to older adults, this study identified abilities and themes that are required for their utilization of health information. Furthermore, factors were explored at the health care and community level to demonstrate how these influence health literacy. The findings demonstrated that older adults' health literacy is dependent on the relationship between individuals' capacities, the health system, and social network. This creates some concern that existing health literacy measures, by focusing more on making health information available online, omit individual literacy ability factors. This was clearly demonstrated in participants' narratives, which revealed that even if the individual possessed the necessary abilities to seek, understand and utilize health information, other influences such as frame of mind or outlook on life and, one's emotional state can hinder the process of seeking health information in order to become more health literate.

Data analysis provided some insight into which factors influence individuals to be more health literate. The recurrent themes illustrated that there is a crucial link between motivation and behavior change, and interventions to promote healthy lifestyles with respect to diabetes. Also, it emerged that there was a necessary relationship between knowing where to seek health related information and how to apply it for effective self-care and self-management. Family, peers, caregivers, and other social supports were often needed to help navigate the health system. Older adults with limited ability to retain information pointed to the need for someone to help them know when to seek information, where to get it, and how to get it.. Knowing this can assist health care educators to better tailor guidance to individual needs and to identify areas for the development of new interventions.

The narratives and voices in this study clearly demonstrate that promoting or maintaining good health requires basic understanding of health information. The results of this study identified that key abilities to seek, understand, and utilize information are critical for managing one's own health. Elements relating to health promotion and health education are apparent in the themes observed in the data collected. The literature review demonstrates that health literacy has been successful in helping to bridge perceived differences between health education and health promotion. The concept of health literacy's focus on skill's development and empowerment influences the purpose of health education (Nutbeam, 2019). Therefore, health literacy skills translate into positive decisions and actions promoting empowerment of the individual to make beneficial health related decisions.

To conclude this summary of data collected, I want to mention my personal observations while conducting this study. I observed that dignity and autonomy is threatened when people (and their caregivers) are not given adequate information or the opportunity to fully understand their diagnosis and, thus, to make informed choices about their care. Amputations, falls, emergency room visits, make individuals vulnerable and this can translate into a loss of dignity. Older people and their caregivers need to be given adequate information to enable them to make informed choices about care. Furthermore, attitudes of health care staff greatly affect both the quality of treatment of older people and the regard given to maintaining their dignity and autonomy. Therefore, focusing on improving health education to enable health literacy is of utmost importance to older adults.

Discussion and Conclusions

Addressing my research questions

How can the gap between health literacy and the health of diabetic older adults be bridged?

This qualitative study provides insight into the experiences of the participants interviewed, illuminating the gap between health literacy and the health of older diabetic adults. The narratives illuminate the personal, lived experiences of older adults diagnosed with diabetes. The themes that emerged from the interviews, as well as anecdotal corroboration, support some of the findings in the literature review. Both the interviews and anecdotal data point to what is needed to bridge the gap:

- increase motivation to improve health behavior;
- increase literacy skills to improve health literacy;
- increase the capacity to process and retain information by providing more health education;
- teach the skills needed to apply health-related information.

Given the assumed pivotal role of health literacy for good health outcomes, the focus of my study was on how we can we make health education and health promotion efforts more accessible and comprehensible to diabetic patients. As explored in the literature review and supported by this study, the gap that needs to be addressed is confirmed: improvement of health education requires development of health promotion, which requires development of health literacy. Health education needs to promote a person's knowledge and skills, and stimulate motivation to acquire health literacy. Patient centered care that addresses individual needs is highly relevant to providing crucial health education services.

Implications

It is important for health educators to be aware of the level of health literacy of the patients or clients they are working with. This study identified important data that demonstrated themes that are closely linked to a range of factors at healthcare and community levels. Being aware of these individual factors is important to addressing health literacy issues.

Limited health literacy presents a substantial barrier to communication and the acquisition of knowledge. This can lead to older adults committing to an intensive pattern of care without adequate information. Health education providers should consider health literacy when discussing diabetes at onset of diagnosis. Individuals who have restricted social networks, poor health literacy, or little or no access to people in their social network who can help, may be the most disadvantaged in terms of developing the health literacy skills needed to manage their own care. Therefore, health literacy measures need to include asking individuals if they have a supportive social network, and if those people can help them to locate accurate information and navigate the medical system.

Limitations

This study has some limitations. Only a small number of participants were part of the exploratory study so the abilities, themes, and broader factors may not be representative of all older adults diagnosed with diabetes. However, several commonalities of factors and abilities among the participants provide evidence that some health literacy issues for older adults diagnosed with diabetes have been identified. The sample may have included participants with a good baseline of literacy skills because they had chosen to take part in the study. None of our participants appeared to be socially isolated, and most had access to shared information within their social network. Nonetheless, when talking about support issues, their importance was highlighted and it is crucial for health care workers to consider this in their approach to elderly diabetic individuals.

Recommendations

- Focus more on health literacy and promotion to motivate and influence positive health behavior .
- Health educators must be more informative to improve health literacy.
- Improve self-efficacy to influence self-management in health care needs.

Health behavior and motivation to be health literate were key elements in this study. Participants in the study demonstrated they could be self-directed, had various life experiences conducive to learning, and developed an interest in following health recommendations when complications due to diabetes severely affected their health. Improving their health literacy was important when health issues relevant to their personal lives impacted them. The three narrative interviews pointed to a lack of health information. George stated, "Tell it, the way it is, what the possibilities are," when asked what he needed to motivate him to follow health recommendations. Regarding health educators, Ruth expressed the need to "be more compassionate, give more information." This demonstrates that health educators need to be more informative to improve health literacy so that, hopefully, this will motivate and influence individuals to execute behaviors required for self-care.

Regarding behaviors conducive to health management, research has indicated that improving self-efficacy levels in patients can result in increased confidence in making health behavior changes, which is fundamental to self-management. Improving learning sources to obtain health information and promote desired results for self-managing health is needed. Influencing factors on the ability to develop and use health literacy skills depend on health promoting behavior which can be improved by promoting self-efficacy.

A learner's self-efficacy will determine whether they feel adequate or not to take on a particular task. It is encompassed in the self-system that includes cognitive skills, attitudes, and abilities. Self-efficacy influences learners’ knowledge and attitude towards learning. When adults decide to participate in learning, they face challenges; self-efficacy is necessary for the achievement of learning goals, challenges, and tasks. This was discussed in the narratives; participants did not change their lifestyle. In fact, both George and Dean lacked self-efficacy and could not face the challenge of self-management. They barely acknowledged they were diabetic, and this resulted in major health complications.

A research study involving older adults with diabetes in a peer led self-management program demonstrated that enhancing self-efficacy strategies were successful in self-management. Also, when patients were successful in behavioral changes through self-management it enhanced self-efficacy (Chen et al., 2021). Researchers concluded that peer leaders can reduce the workload of health care workers. This can help address the current shortage of health care workers and allow older adults to learn self-management skills in the community. Therefore, improving self-efficacy is important in improving health literacy.

Future Challenges

With the current aging population and lifestyle changes, the prevalence of diabetes continues to increase. The literature review demonstrated that diabetes among older adults is a major public health problem. This exploratory study confirmed a lack of services in the health care system, and an inability to provide health education when needed. It is apparent that the health care system has not evolved to accommodate those with limited health literacy, and health care providers play an important role in health education. The development of interventions to enhance self-efficacy and promote self-management skills is necessary to help improve health literacy among older adults diagnosed with diabetes. Therefore, programs to develop health literacy and support accessing information to expand knowledge and skills to manage diabetes are essential.

The health care system is overburdened. Focusing on social networking interventions to enhance health literacy in patients with chronic conditions and to enable them to draw on the skills of others to help them manage and make decisions about their health could help. Bringing people together to develop health literacy and support self-efficacy within a community may be a useful way of distributing the responsibility and expectations that the current health system and policies impose on patients as individuals in managing their health. Promoting greater independence and empowerment will also help people gain confidence (Nutbeam 2006).

Participants in this study had little support in accessing information, expanding their knowledge and skills to manage their condition, and communicating with health professionals. They needed the help of others to be able to self-manage their diabetes. After completing this exploratory study, I suggest further study to explore evidence of any improvement in health conditions through the support of others.

Reading actual written materials was identified as the preference for learning. The Internet was mentioned as used when seeking health information, but participants said it could be overwhelming or confusing to navigate. Most participants preferred reliable sources directly given by health care professionals. This presents a challenge because of the increasing trend to promote online health services. eHealth is a recent healthcare practice that supports online services. Health records accessible online have been implemented in most provinces in Canada. However, older adults who prefer direct person to person care will feel neglected with the implementation of online only services. A recent study discussing eHealth literacy concluded that older adults experience technological discomfort and low technological adoption if they are not part of the interaction design process (Ahmad & Mozelius, 2019). Health educators will need to adapt to the technological expansion but will also need to consider the reduced ability of older adults to attain eHealth literacy.

Projected demographic changes will significantly challenge the health care system. Long term care of the older population is increasingly challenged, with healthcare worker shortages and the growing need for long term care services. As discussed in the introduction, as people age, they suffer more from chronic illness. This increases the burden on health systems and on households. Health educators will also need to be aware of the physical and emotional burden of providing care to an aging loved one and offer more caregiver support.

Lastly, this study demonstrated that lacking opportunities to discuss face to face with health care providers impacts motivation to follow health education advice. Those involved in health and social care systems need to consider new methods to motivate and produce self-efficacy.

Becoming health literate in the context of managing a long-term condition is an ongoing process that may include input from formal health education, communication with health professionals, and social support networks. Individuals benefit from the distribution of health literacy within their social network whatever their level of health literacy. Friends, family, colleagues, and even acquaintances mediate the development and practice of health literacy by sharing knowledge, facilitating learning, contributing their own skills, and supporting decision making. Health literacy research must move beyond describing the problem to designing potential solutions. The instruments currently used are beginning steps that have allowed for the estimation of overall prevalence of limited literacy among various patient populations, increasing the awareness of the problem and advancing further study. Now it is time to develop tailored intervention strategies and refine screening methods for clinical use. Guidelines are also needed that detail quality standards for patient materials and staff training. Such measures will allow health care workers to more effectively address the epidemic of low health literacy and to improve the quality of health.

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Appendix A

Narrative interviews will be conducted online or in person using the following questions to help guide my work:

1. What was your experience being diagnosed with a chronic illness?

2. Did you suspect you had diabetes?

3. Were you told what to do in order to take care of yourself?

4. Did you have access to health information? Where, how?

5. What is your understanding of health literacy?

6. What do you feel can be done to help improve health literacy?

Appendix B

INFORMATION AND CONSENT FORM

Study Title: Health literacy in older adults with diabetes through narrative interviews.
Researcher: Ann Marie Cote
Researcher's Contact Information: annmariec@sympatico.ca
cell:5148937307
Faculty Supervisor: Ailie Cleghorn
Faculty Supervisor's Contact Information:514-848-2424x2041
Source of funding for the study: NOT APPLICABLE

You are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

A. PURPOSE

The purpose of the research is to find out if older adults with diabetes access the available information they need to help themselves.

B. PROCEDURES

If you participate, you will be asked a series of questions to help better understand how to help understand what health literacy means and how information can help you in the treatment of diabetes in older adults. In total, participating in this study will take 60-90 minutes

C. RISKS AND BENEFITS

There are no actual risks in taking part in this study, however you may not enjoy talking about diabetes and the interview may feel tiresome. If so, you can ask the researcher to continue the discussion later. Potential benefits include: I hope it will be easier for you to think about what you need to know to help yourself.

D. CONFIDENTIALITY

We will gather the following information as part of this research: I will not allow anyone to access the information that we talk about; it is 100% confidential. I am the only one to know the content of our conversation. I will only use the information for the purposes of the research described in this form. I will not use your name or other identifying information in any written or oral report of my thesis. Instead, I will provide you with a code. That means that the information will be identified by a code on my personal device. I will have a list that links the code to your name. I will protect the information by destroying all the information that was not included in the thesis within one year of thesis approval. I will destroy the information five years after the end of the study.

F. CONDITIONS OF PARTICIPATION

You do not have to participate in this research. It is purely your decision. If you do participate, you can stop at any time. You can also ask that the information you provided not be used, and your choice will be respected. If you decide that you don't want me to use your information, you must tell me before June 17th, 2020. There are no negative consequences for not participating, stopping in the middle, or
asking us not to use your information.

G. PARTICIPANT'S DECLARATION

I have read and understood this form. I have had the chance to ask questions and any questions have been answered. I agree to participate in this research under the conditions described.

NAME (please print)
____
SIGNATURE
____
DATE
____

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor. If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.