Provider Readiness to Recommend Social Networking to Patients with Chronic Diseases

By

Judith Anne Dyck

Submitted to the Facultyof Extension

University of Alberta

in partial fulfillment of the requirements for the degree of

Masters of Arts in Communications and Technology

March 10, 2015

I. Acknowledgements

Thank you to my family for their support and commitment, my sister who listened and encouraged me, my MACT cohort who were there whenever I needed a hand, and to my supervisor, Dr. Fay Fletcher. My thanks as well to the chronic disease management educators who shared their knowledge and insights and were unafraid of exploring new material. I would not have been able to fulfill my dream of completing my Masters without all of you.

This is for James, Coel and Rhys. Love you guys.

Table of Contents

II. Abstract

Provider Readiness to Recommend Social Networking to Patients with Chronic Diseases

Chronic diseases are conditions for which there is no cure at present, such as diabetes, heart disease, arthritis and asthma. In 2008, it was estimated that one in three Canadian adults has a chronic disease (CIHI, 2008). Living a healthy life with a chronic disease can require complex and extensive self-management for the rest of the patient's life, as well as the support of health care professionals. Online health-related social networking and the use of online health communities (OHCs) can assist people with a chronic disease in the self-management of their condition (Magnezi, Bergman, & Grosberg, 2014). People look to health professionals for assistance and education in how to manage their condition (Wagner, 2000). Information on the use of online social networking by chronic disease management educators as part of the education curriculum would assist people in learning appropriate and effective use of social networking and incorporate it as part of their health regimen. Such use can lead to improved health outcomes and compliance with chronic disease management regimens (Magnezi et al., 2014). This research study examines the views of six chronic disease management educators working primarily with patients with diabetes. The research finds that educators are generally aware of the benefits of social media and social networking, but do not have sufficient information or corporate permission to recommend their use in chronic disease management. Nor do they have access to patient education materials in its safety and use, particularly around behaviour to safeguard privacy and identify misinformation.

III. Introduction

The purpose of this study is to assess the preparedness of chronic disease management educators to recommend the use of social networking and OHC to their patients as part of a chronic disease self-management regimen.

Chronic disease is a growing issue in health care and affects more and more people every year (CIHI, 2008). Its increased prevalence is a strain on health care resources and impacts quality of life for both people with a chronic disease and their families and support networks (Government of Canada, 2011). Living with a chronic disease can require complex and extensive self-management and active participation and engagement is critical (Bodenheimer, Lorig, Holman, & Grumbach, 2002, p. 151). Social networking provides access to emotional care, information and encouragement, and can assist patient compliance with a chronic disease management program. Support and education on the use of social networking by chronic disease management leaders could support appropriate and effective use and lead to improved health outcomes through better compliance with chronic disease management regimens.

In Alberta, people can access education on chronic disease self-management through community and online resources provided through Alberta Health Services (AHS) programming. AHS provides health services and programs across the province, including acute, ambulatory and community care, as well as public health. Others may receive education and support through their primary care network (Alberta Health Services, n.d.). As well, people with a chronic disease routinely go online to access monitoring tools, find information, discuss their condition with other people with the same condition and seek emotional and informational support (Fox & Purcell, 2010). There is evidence that health-related social networks have physical and emotional benefits for people with chronic diseases. The networks can enhance support services and education delivered face to face, and extend the provision of assistance beyond the doors of the health centre into the hands and home of the person with the chronic disease (Magnezi et al., 2014). There are risk factors associated with the use of health-related social networking, including loss of privacy, possible misinformation, and inappropriate marketing or behaviour (Moorhead et al., 2013; Househ, Borycki, & Kushniruk, 2014). These risks can be mitigated through behaviours such as the adoption of user names and self-censoring sensitive information (Weitzman, Cole, Kaci, & Mandl, 2010).

The care path for people diagnosed with a chronic disease often includes their participation in workshops that teach skills and build confidence in the participant’s ability to manage his or her care (Stanford School of Medicine, n.d.). The inclusion of information on the appropriate use and benefits of health-related social networks in the chronic disease management education curriculum could be an important pathway to more use overall, and more appropriate use, of health-related social networks. This would require chronic disease management educators to be aware of the benefits, the types of networks and sites available to people and appropriate behaviour. They would also require access to tools and resources that could be shared with participants.

A focus group was conducted with chronic disease educators who focus on chronic disease management for patients with diabetes to explore their experience and perspective on the use of social media by their patients and clients, as well as their preparedness and confidence in providing advice on appropriate use of social health networks. Potential patient education materials were shared with participants in order to determine if these materials would be beneficial in chronic disease management education.

The research identified a general awareness of social media among the chronic disease educators, but a lack of familiarity with specific health-related social networks. While there is a growing body of peer-reviewed literature to support its use in chronic disease management, the educators were not aware of it. They did not have the tools, curricula and resources which would enable them to deliver information on the benefits of health-related social networking, the types of networks and sites available, and appropriate behaviour. They also felt that their organization’s policies did not support them in working with patients on the use of social media and health-related social networking. The educators felt that their patients were ahead of them in the use of social media and health-related social networking, but that patients were at risk around information disclosure and inability to discern between appropriate information and misinformation. Educators indicated that they would like to have further education on the use of social media and health-related social networking. Further, they would find patient support materials and handouts helpful in their role in the support of patients with chronic disease.

IV. Purpose of the Research

The purpose of this research is to examine the readiness of chronic disease management educators to recommend participation in health-related social networks to their patients and clients. As part of the research, educator readiness to provide assistance to their patients and clients in the appropriate use of *social media and health-related social networks* was explored. Information was sought as to what would increase the inclusion of information on the benefits and use of social networking within the education process. The hypothesis was that while chronic disease management educators are aware of health-related social networks, they would benefit from additional information on the research which supports the use of such networks. As well, they would be more likely to recommend its use to their patients and clients if they had more information on best practices in its use within a chronic disease management regimen. The findings have the potential to lead to recommendations for chronic disease management educator training and educational materials.

The objectives of the research were two-fold. The first was to determine the level of awareness of the benefits of social media and health-related social networks within a cohort of chronic disease educators. The second was to examine what could facilitate its incorporation into self-management education, including information and materials. A subordinate inquiry related to the second objective was an exploration of what chronic disease educators perceive as key factors in successful chronic disease management.

The research project addressed three questions:

- What do educators working in chronic disease management know about the use of health-related social networks? Are they recommending their use to their patients and clients?
- What do educators describe as key factors in successful chronic disease management?
- What information or materials would educators find useful in educating their patients and clients in the optimal use of social media and health-related social networks in their self-management regimen?

V. Literature Review

A. Overview

The areas covered in this literature review include: the definition of terms used, including eHealth, social media and social networking; a review of different types of social media platforms; an examination of the impact chronic disease has on the regimen required to live a healthy life; an overview of the literature on self-management competencies; the benefits of health-related social networks, evidence of their usefulness in chronic disease management and examination of which populations use social media and social networking sites; a review of the particular requirements to manage diabetes that make it a good focal point for the use of social networks; an examination of communications theories which help explain the effectiveness of social networking and benefits of health-related social networks; and what the literature says about risks involved in the use of social media and health-related social networking.

B. Defining social media, social networking and eHealth

eHealth is the use of information and communication technologies in health care. It encompasses “treating patients, conducting research, educating health care providers, tracking diseases and monitoring public health (Bulletin of the World Health Organization, n.d.). van Gemert-Pinjen et al. (2011) provide Canada’s Health Informatics Association’s description of eHealth as a useful definition: Using technology “to connect providers, patients, and governments; to educate and inform health care professionals, managers, and consumers; to stimulate innovation in care delivery and health system management; and, to improve the health care system” (para. 33). Hordern et al. (2011) identified five areas in which the Internet is playing a part in consumer health and changing people’s expectations of the system and their own response to health concerns:

- Online support groups;
- Self-management and monitoring applications;
- Tools to assist in decision making;
- Personal health records; and
- Internet use (search functions and way finding, for example).

Social media are forms of communications online where people create communities in order to exchange information, ideas and advice, that is, create user generated content (Househ et al., 2014; Kaplan & Haenlein, 2010). Kaplan & Haenlein define social media as “a group of Internet-based applications…that allow the creation and exchange of User Generated Content.” Social networking is a subset of social media where people create a profile and connect that profile to others in order to create a personal network (Lenhart, 2011; Kaplan & Haenlein, 2010). While social media and social networking are often used interchangeably, social media “functions as a communications channel that delivers a message…social networking is two-way and direct communications that includes sharing of information between several parties” (Moorhead et al., 2013). Social media platforms include blogs, microblogs such as Twitter, social networking sites like Facebook and specific online health-related sites, video sharing sites like YouTube, games and wikis (Househ et al., 2014).

Social networking sites like Facebook transform the Internet from an ‘information vending machine’ where people retrieve information into a community building tool where people share what they know, receive information and feedback from others, and develop new ways of dealing with their issues and concerns (Fox & Purcell, 2010). Online health communities are a subset of social networking sites. These web-based programs bring together groups of patients, professionals or both. Interactions take place through blogs, chats, forums and wikis (van der Eijk et al., 2013). People with similar health concerns gather on the sites to share information and offer and receive support (Bane, Haymaker & Zinchuk, 2005; in Hordern et al., 2011).

Various terms are used to describe online health communities, including social networking sites, online health forums, online health communities and health-related social networks (Fox & Purcell, 2010; Moorhead et al., 2013). For the purposes of this research, the term health-related social networks has been adopted, as used by Magnezi et al. (2014), who define health-related social networks as the various places online where people can get information and interact with others dealing with the same or similar health condition.

C. Common Social Networking Platforms

Common social networking sites that target people with chronic diseases include pages on Facebook, Twitter, and health-related social networks organized on a website around a disease state or states such as Diabetic Connect, and TuDiabetes (Moorhead et al., 2013). Facebook is discussed extensively in this section, as the features of health-related social networks are similar to those used by Facebook, with exceptions as noted.

Facebook is arguably the best known and most commonly used platform. In 2013, 85% of adults in the United States had access to the Internet. Of those, 71% were on Facebook. The next most popular social media website was LinkedIn (22%), Pinterest (21%), Twitter (18%), and Instagram (17%) (Duggan & Smith, 2013). As of December 2014, Facebook had 1.23 billion monthly active users worldwide (PR Newswire, 2014). In Canada, 14 million people log in to Facebook every day and another five million log in at least monthly (Oliveira, 2014).

Facebook shares a range of features with other social networking sites. While it primarily offers a way to post status updates and receive information on the activities of one’s connections, it also offers:

- Private, secure email;
- Live instant messaging;
- The ability to establish, search for and join groups that share one’s professional or personal interests. Groups can be limited to members or open to anyone who wants to join. People can discuss and post links to articles, videos and other information on group sites. The information is stored on the site and can be searched using tags;

- The ability to organize contacts into lists of close friends, acquaintances and public members and selectively share information;
- The ability to easily create pages where information can be quickly and shared. People follow a page by “liking” it;
- Easy photo and video sharing;
- Games which provide another way to get to know someone; and
- Easy event planning (Miller, 2011).

Facebook facilitates personal interchanges and adds social information to a community (Ractham & Firpo, 2011). It can be a group’s virtual ‘water cooler’ and enhance interpersonal relationships and build trust. Schleyer et al. (2008) studied the use of social networking technologies for scientific communities. They found that successful collaboration requires more than exchanging facts about each other; social connections, personal and professional compatibility, and understanding another’s standing within the scientific community are also important. Knowledge management systems that do not “model and leverage social context are at a clear disadvantage” (Schleyer et al., 2008, para. 44).

Facebook also surfaces networks, allowing others to see who is a friend of their friend. This expands a user’s network to include additional networks and allows people to use their friends as intermediaries to other people and information (Schleyer et al., 2008). Facebook is predicated on making connections with people that you know. That means that a person’s profile on Facebook is generally identifiable in the ‘real world.’ Facebook’s principles state that they are “building Facebook to make the world more open and transparent which we believe will create greater understanding and connection” (Facebook, 2015). Facebook and offline personas are more alike and someone can often be recognized in real life from their Facebook activities.

Organizations can create pages on Facebook where people interested in the organization can ‘like’ the page and subsequently receive updates on new developments. For example, Diabetic Connect has a Facebook page where they post information. In this instance, the organization moderates people’s posts. If people begin to share personal health information on Facebook which is a public forum, Diabetic Connect encourages them to take the discussion over to its own health-related social network where there is greater privacy (Diabetic Connect, n.d.).

Health-related social networks are often hosted on stand-alone websites. They include blogs, articles, forums where people can comment and information on topics such as healthy living, dealing with emotional issues and how to handle different aspects of a disease. They are often membership-based and people can sign up using an anonymous name so that their online identity cannot be linked with their real life (Weitzman, Cole, Kaci, & Mandl, 2010). Moorhead et al. (2014) discuss the importance of ensuring that information shared on health-related social networks is accurate and reliable and that user confidentiality and privacy is maintained. A study of health-related social networks used by adolescents with diabetes identified five features characteristic of such communities. These included social learning and networking, information, guidance, engagement, and the sharing of personal health data. The authors found sufficient evidence of the effectiveness of the use of health-related social networks to be optimistic about their effectiveness as part of chronic disease management (Ho, O’Connor & Mulvaney, 2014).

D. The Burden of Chronic Disease

Chronic disease refers to a condition which requires management over a long period of time, generally for conditions where there is no cure at present. These conditions include diabetes, heart disease, arthritis and asthma, among other diseases. Increasing numbers of people are living with a chronic disease (Alberta Government, 2014). In 2008, the Canadian Institute for

Health Information estimated that one in three Canadians were affected by chronic disease (CIHI, 2008). By 2013, the Public Health Agency of Canada increased the estimate to sixty percent of Canadians over the age of 25 as having a chronic disease. In addition, another 20% were estimated to be at risk of developing a chronic disease. This growth can be attributed to lifestyle factors such as eating habits, exercise and tobacco use, along with advances in treatment that have transformed formerly life threatening conditions into conditions that can be treated (Government of Canada, 2008).

The toll of chronic disease includes financial, emotional and physical impacts on patients and their families, the health system and the economy. In 2004, it was estimated that 80% of primary care physician visits and two out of three dollars spent on health care were related to chronic disease (Morgan, Hindmarsh, & Zamora, 2007). In Alberta, it is estimated that 5% of the population accounts for 60% of the use of emergency departments, inpatient care, urgent care and primary care fee for service payments. Most of these users have multiple chronic diseases (Alberta Government, 2014). The Government of Canada estimated the cost of chronic disease in Canada to be $190 billion in 2010 (Government of Canada, 2011). Chronic disease also increases the use of emergency departments and length of hospital stays, and reduces quality of life (Government of Canada, 2013).

E. Self-Managed Care and Competencies

This section of the literature review examines the care and competencies required for successful management of a chronic disease. In subsequent sections, the literature will be reviewed for ways in which eHealth, social media and social networking can support chronic disease management.

Successful chronic disease management requires a number of different strategies and approaches, including the involvement of a team of providers including physicians, pharmacists, nurses, social workers, dietitians and others (Wagner, 2000). This health care team is a critical and respected source of information for patients and clients (Wagner, 2000). Providing education and support to help people become good caregivers for themselves is another critical part of better health outcomes for people with chronic diseases and an important task for the health care team (Bodenheimer et al., 2005).

The person’s own self-management and engagement in dealing with physical and emotional aspects of chronic disease over time is important (Magnezi et al., 2014; Bandura, 2004). As Evans (n.d.) has found, up to two-thirds of care is delivered in the home and community rather than in a health care setting. Therefore, success also requires a 365 day a year focus on self-management in addition to the ongoing feedback and support from health care providers responding to clinical information gathered and reported by patients (Adaji, Schattner, & Jones, 2008; Dedding, van Doorn, Winkler, & Reis, 2010). Ahern, Kreslake and Phalen (2006) point out that even in a high quality and well-resourced clinical practice, it is unlikely that there are sufficient resources to monitor and counsel at-risk patients at a sufficient level to ensure optimized health. That gap in care needs to be filled through by the individual’s self-care practices.

Self-management of a chronic disease is often a complex task for patients, their families and others. In order to be as healthy as possible and avoid recurrences and complications, people often have to adhere to complex regimens which include exercise, diet, self-testing, and monitoring symptoms, test results and moods (Rosland, 2009). It also can require adaptations of daily living routines and environment in order to continue on with regular day to day activities (Bodenheimer et al., 2005).

Self-management also requires patient activation. Patient activation is a term used to describe a person’s involvement in managing his or her own health condition. Activation is about being capable and willing to manage one’s health and health care. Higher levels of patient activation are associated with healthier behaviors and more favourable health outcomes. People who have higher levels of activation are also more optimistic and hopeful and believe they have better control of their lives. Activated people work to understand their condition and are confident that they can solve problems they encounter with self-management (Magnezi et al., 2014).

Becoming an engaged and activated self-manager of one’s chronic disease is a process that occurs over time. Healthy habits need to be practiced. Complex information on how to monitor conditions requires the acquisition of new skills and referral back to authoritative information to determine what a self-administered test indicates i.e. checking blood pressure levels or monitoring blood glucose levels (Gluekauf & Lustria, 2009). Other skills required are literacy and numeracy. Proficiency in handling numbers can be especially difficult for patients with diabetes, who need to be able to count, do basic mathematics, use fractions and decimals and understand graphs and tables (Kerr, 2010).

Another area of skill development is the ability to deal with the emotional aspects of chronic disease management, including anger, fear, depression, frustration or isolation. Isolation can occur both through decreases in mobility or feeling that no-one around understands what the person is dealing with (Lorig et al., 2013). People with chronic diseases need to build support systems. These social support systems help protect people from the effects of the stress they encounter. This buffering model posits that social capital and other networking benefits bring down someone's stress level. Another way that social support is thought to improve health outcomes is through the experience of positive interactions which lift people's mood and help them cope (Wright, 2009).

Family support is a critical part of people's networks. Rosland (2009) points out that families set the stage for patient self-management through a myriad of decisions and practices, including food choices and preparation, making time for activities, supporting through helping patients get to appointments and keeping them involved socially. They create the "practical, social and emotional context for self-care" (Rosland, 2009, p. 6). Families can also be a source of barriers to successful self-management through behaviors such as smoking, keeping high calorie foods in the house, or distracting a person from an exercise regimen, for example. Family dysfunction has been linked to poorer outcomes (Konen, Summerson, & Dignan, 1993). Nevertheless, people whose families are engaged in their chronic disease management regimens report lower stress levels and better health outcomes (Griffith, Field, & Lustman, 1990).

While family and close ties are important, the ability to access resources outside of one's usual network of support can be particularly important for the long term well-being of people with a chronic disease and the functioning of close relationships with spouses, other family members and friends. Chronic diseases are a burden for everyone close to the person with the condition (Albrecht & Goldsmith, 2003). People report not wanting to burden their close tie relationships with all their fears, concerns and daily health status. People involved in a close tie relationships with a person with a chronic disease can become overwhelmed by the obligations inherent in close relationships and feel resentful. As well, close tie relationships are complex with a range of different relational needs. Asking family members and close friends to always be the primary source of chronic disease support adds to the burden (Wright, 2009).

Reciprocity is another important aspect of close relationships. People with a chronic disease may begin to feel that they are the ones always needing something from the people with whom they have close relationships. They can experience distress if and when they are unable to reciprocate that support because their significant other does not need them in the same way (Wright, 2009)

F. Social Media and Health-Related Social Networks for Self-Management

As we have seen, chronic disease management involves complex monitoring regimens, the availability of supportive social networks and reliance on familial relationships, regular exercise and attention to diet and weight. While support from a team of health professionals is a critical aspect of chronic disease management, social media and health-related social networks can follow the patient home and become part of successful chronic disease management (Evans, n.d.). The World Health Organization calls for the integration of traditional care with care delivered with the use of information technology in order to reduce waste and replace high cost hospital-based care with lower cost and more effective primary care and prevention (van Gemert-pijnen et al., 2012). This section looks at why one aspect of the use of information technology, online social networking, is a valuable part of chronic disease management, including self-management.

Systematic reviews of the literature point to gaps in knowledge around the relative effectiveness of different types of social media, the extent to which it enhances the effectiveness of communications generally and patient assessments of the impact of its use (Moorhead et al., 2013; Househ et al., 2014). There is, however, considerable agreement on ways in which patients use social media and social networking. These include “education, information, networking, research, support, goal setting and tracking personal progress,” (p. 51) as well as storytelling, learning from each other and spreading what they have learned (Househ et al., 2014).

Health-related social networks can become part of a person’s emotional support network, lessening the burden on family and friends. Online health communities can be rich sources of stories and provide a way for people to easily share their own experiences. Millions of people go online every year to look for health information and to share their experiences and information (Fernandez-Luque, Karlsen & Bonander, 2011). Fox and Purcell (2010) reported that people with a chronic disease were significantly more likely to use social media, either blogging or participating in an online discussion, and described being online as the trump card for people managing a health condition: People share what they know and receive information from others, using the Internet as a communications tool and not solely as an information vending machine. An anecdote from a patient perspective illustrates their usefulness. Diabetic Connect is a social media site owned by Alliance Health that works to empower people living with diabetes. In an article on communications found on the site, a regular contributor wrote this: “Remember that nobody’s going it alone. When one person in the house is diagnosed with a chronic condition, everyone in the house lives with that diagnosis” (Diabetic Connect, n.d.). The Diabetes Hands Foundation operates a website for people with diabetes. Their philosophy underscores the social aspects of chronic disease management: “Diabetes can be a very isolating disease, so we provide platforms where people with diabetes and their loved ones can connect and have an open dialog about their experience with this chronic condition. Instead of looking at the disease, Diabetes Hands Foundation seeks to understand, connect and energize the millions of people living with this condition” (http://diabeteshandsfoundation.org/, n.d.).

Online participation is beneficial for a range of people, not just people who are very active in the management of their health. For example, people who are less active have been found online participation more useful than those more active. Magnezi et al. (2014) postulate that less active people may know less about managing their condition and therefore, more of the information available online is relevant and new. They also may be more willing to receive information about their condition and health status at the early stages of their chronic disease management journey. It may be that they begin to model healthier behavior of others on the site and improve their own health status as a result (Magnezi et al., 2014).

Interactive technologies such as social media and social networking can be an important part of support and guidance (Bandura, 2004). Social media can be particularly well suited to the provision of support and guidance. It is there when the individual needs it, not just during office hours. People can communicate with others about how they overcame obstacles to manage their chronic disease and electronically monitor and track progress towards their goals (Adaji et al., 2008). The peer to peer interactions may also be more effective than health provider to patient interactions with regard to the adoption and maintenance of healthy strategies; people see others that are facing the same issues that they are and can model successful behavior (Helgeson & Gottlieb, 2000; in Wright, 2009).

Interaction on social media involves expressing oneself, often by writing a message, or by posting a picture or video that a person creates or shares someone else’s work. The act of writing down one’s thoughts and by extension, telling one’s story through various media, allow individuals to distance themselves from their emotions and has a therapeutic effect by (Wright, 2009). Wright (2009) reported on a study by Floyd et al. (2007) that found that supportive messaging is related to lower cholesterol and cortisol levels. Elevated levels of both cholesterol and cortisol are both are linked with heart disease and stroke (p. 250). Tamir and Mitchell (2012) report that self-disclosure engages the parts of the brain that are associated with reward and this feeling of pleasure helps explain why people participate in social media.

Greene, Choudrhy, Kilabuk and Shrank (2010) noted that discussions online between people were open and encouraging, recognized and accepted the other's limitations and encouraged people to set self-defined incremental goals (p. 289). They found that people shared clinical information, asked for feedback and advice on disease management strategies and to give and receive emotional support. Most often, information provided was accurate. Where it was not, it was generally associated with the promotion of a product or service.

On a social media site the user can ask a question and receive a targeted answer as people weigh in and share their experiences. As they do so, they share knowledge as well as provide information. Cook and Brown (1999) call this type of knowledge *knowing*; knowing is what people have learned from their engagement with the world (p. 61). "Knowing is to interact with and honor the world using knowledge as a tool" (p. 64).

Social media can connect people with others who understand what they are experiencing and provide the social support that is critical to health without the complexities inherent in close tie relationships. It also gives the person with the condition more options as to what they share and where they share it (Wright, 2009).

A key part of knowledge sharing and creation processes is a willingness to be open to interaction: by participating in an online community, users signal their desire to interact. While this kind of sharing can be found in face to face support groups, those groups are limited by the number of people who can physically attend and the need to all be in the same space at the same time. Social media is freed from the restrictions of time and space. People also have more distance from each other than they would in a face to face situation, which can lessen people's concerns about interactions with people they have only just made contact with. (Wright, 2009).

Over time, people build an online identity that tends to be idealized; people project their best selves. Social information processing theory posits that people do this to attract others. Those in turn receiving the message get an idealized sense of the people they are interacting with and respond with their better selves. The asynchronous nature of the communication online allows people to edit what they say. This back and forth communication provides a feedback loop that intensifies the positive reinforcement going on between people. This can make online group participation more effective than face to face group work (Wright, 2009, p. 253). The development of online competence and ability to express oneself and use technology is also thought to enhance confidence and is associated with success in changing behavior and the perception of effectiveness (Mitchell et al., 2014). However, in one study, this tendency to present an idealized image was felt to be a problem from the perspective of eliciting honest responses (Househ et al., 2014).

When people go online and choose to belong to a community, they participate in creating, synthesizing and disseminating information (Ractham & Firpo, 2011). People build a profile or identity that tends to be stable and recognizable to others. This stability enhances the strength of relationships mediated by social media (Weitzman et al., 2010). Eland-de Kok, van Os-Medendorp, Vergouwe-Meijer, Bruijnzeel-Koomen, & Ros (2011) found that chronically ill patients showed some slightly better results when they were offered e-health interventions instead of or in addition to other primary care (p. 1).

Organizational knowledge is formed out of people's interactions with each other in what Nonaka (1994) describes as "the continuous dialogue between tacit and explicit knowledge" (p.

14). People connect their profile with others to create a personal network (boyd & Ellison, 2007; Lenhart et al., 2011). These networks or online health communities can act as knowledge management (KM) communities. As Ardichvili, Page and Wentling (2003) explain, KM communities exist in their members' minds and are held together by personal connections and shared interests. Stories and social context help people understand social norms and build trust within organizations (Thomas, Kellogg & Erikson, 2001). The key is finding the right technologically-mediated communication channels to enhance opportunities to build relationships optimized for knowledge exchange and creation.

Chou, Hunt, Beckjord, Moser, & Hesse (2009) found that more people used social networking (23%) than blogging (7%) or online support groups (5%). Age was the most significant predictor of use, with young adults using social media more than middle aged or older adults. As a result of their online interactions, people report that they feel better able to manage their condition, have better health outcomes and are less lonely (White & Dorman, 2001; in Hordern et. al, 2011, p. 7). Online support groups dealing with medical issues are used to help people understand their condition and develop behaviors that will help them in self-management activities. They also are used to help people deal with the emotional burden of chronic disease (Magnezi et al., 2014).

While technology is increasingly performing calculations and delivering information in new ways that can be easier to understand, numeracy and health literacy barriers still exist. Low levels of health literacy are associated with poorer health outcomes. Social networking can create opportunities for people to share information and learn in ways that are gauged to their ability to understand and apply the information. These opportunities include the development of communities of people that have a common interest and use language that each other can understand; the ability to get feedback immediately after learning a new skill or using a new device; the ability to reach out to organizations that would otherwise be inaccessible to most people; practical and emotional support; and being able to include people who are hard to reach because of physical, time or distance barriers (Kerr, 2010).

G. Who Uses Social Media and Why

The literature shows that gender, age, socio-economic status and education are all important factors in whether people use social media and what activities they undertake on eHealth. Research generally finds that women are more engaged with health-related social networking (Fox & Purcell, 2010). However, this is not always the case. Ethnicity and socio-economic factors, as well as a patient's level of engagement in the management of their health, are also factors. In a study of users of an Israeli site, Magnezi et.al (2014) found that men used the site more and postulate that men might be less willing to disclose or discuss personal health issues, and therefore they were more inclined to use the website to seek information and improve their health. Other research indicates that being an extrovert or openness to trying something new can be important (Moorhead et al., 2013).

Income and education can also be powerful predictors of the use of eHealth in general and the activities people undertake online. Kontos, Blake, Chou, & Prestin, (2014) looked at data from the National Cancer Institute's 2012 Health Information National Trends Survey (HINTS) and defined different uses in three domains: Health care – looking for a provider or communicating with health professionals; Health information seeking – looking for information for themselves or using a website to track personal health information; and User generated content and sharing – visiting a social networking site, using email to write or blog or participate in an online support group.

Kontos et al., (2014) found that people used the Internet most often for seeking information, and less so for interacting with others. “In terms of engagement with user-generated content, only a small proportion of the population (3.26%-4.63%, 76-110/2358 of online US adults) took advantage of interactive Web features, such as participating in an online support group or health-related blog. Use of social networking sites (SNS) for health is a bit higher, with 16.80% (345/2358) of online Americans saying they have visited sites such as Facebook or LinkedIn to read or share about medical topics” (Kontos, et al., 2014, para. 17).

People under the age of 50 were more likely to use the Internet to search for information. Both lower income and lower education correlated positively with the use of Facebook and similar sites to share and gather information. Again, age was a factor in the use of online communities. People aged 18 to 34 were 3 times more likely than those aged 65 and older, and people 35 to 49 were twice as likely to have participated. Women participated twice as often as men. While both income and education were factors in use of eHealth generally, education was slightly more predictive. People with lower levels of education were more likely to use social media and sites like Facebook. People with lower levels of education were also less likely to track personal health information online, however, women were 1.5 times more likely than men to do so. Kontos et al. (20140 conclude that a one size fits all approach to the development of eHealth interventions will not be as effective as targeted approaches.

H. A Focus on Diabetes

Social media interventions may be particularly beneficial to the chronic care sub-population of people with Type Two diabetes, as management of this condition requires multiple changes in diet and exercise, ongoing medication adjustments and the need to monitor blood glucose levels on a daily and sometimes hourly basis (McMahon et al., 2005). In Canada, diabetes is among the most common chronic diseases. The Public Health Agency of Canada estimates that close to 2.4 million Canadians had been diagnosed with diabetes. Among adults, the rate is one in 11 people living with the disease (Government of Canada, 2011). Diabetes is also one of the most complex chronic diseases for people to manage and requires extensive self-monitoring. Diabetes patients often have to take medication and maintain a healthy lifestyle. They have to check their blood glucose levels, blood pressure, cholesterol levels, weight, food intake and physical activity, as well as take medication, in an ongoing balancing act in order to optimize their health (Gluekauf & Lustria, 2009). This complexity requires the knowledge and skills of a range of health care providers including physicians, nurses, pharmacists and dietitians. Primary health care providers have increasingly turned to team based care in order to better support people with diabetes, as well as other chronic diseases (Bodenheimer et al., 2005; Walker, 2000).

Effective diabetes self-management includes the development of behavior-based skills and habits (glucose monitoring, exercise, blood pressure monitoring, etc.) and the maintenance of treatment regimens (Gluekauf & Lustria, 2009). Often people are counseled to lose weight along with other behavioral changes like quitting smoking and moderating alcohol use. “In order to successfully manage their disease, diabetes patients must not only take medications and maintain a healthy lifestyle but also monitor a number of variables (i.e., blood glucose values, blood pressure, cholesterol levels, weight, food intake and physical activity) in order to reduce risk factors” (Gluekauf & Lustria, 2009, p. 159).

Adaji, Schattner & Jones (2008) reviewed 29 articles on the use of IT systems to support diabetes care and concluded that information technology can lead to improved care. Other studies have shown that the use of text message reminders and feedback helps people reduce blood sugar levels (Fischer et al., 2012; Yoon, & Kim, 2008).

I. Theory

Different theories help to explain the utility of health-related social networks and social media. The following theories and their applicability to the area of research have been examined: social cognitive, narrative, network and social comparison theories.

Social Cognitive Theory. Social cognitive theory posits that people gain knowledge, skills and new behaviors by observing others and attempting to duplicate what is observed. There are three components that form the context in which learning takes place and guide the design of health interventions that promote psychosocial change. The first is the identification of the mechanisms that produce change. These become the guiding principles. The second is the identification of the activities, programs and strategies that operationalize the principles. The third component is a social diffusion model in which the actions are modified in order to ensure that they are relevant to the culture of the target audience (Bandura, 2004).

Ho et al. (2014) describe social cognitive theory as “one of the most influential and effective frameworks used to guide intervention design in diabetes…This theory explains the acquisition and maintenance of health behaviors through the interaction of cognitive, behavioral, and environmental factors…One reason SCT has been widely translated into health behavior programs is the specification of mechanisms of change, such as modeling and guided mastery (para. 3).”

Bandura (2004) states that a person’s belief that they are able to control what occurs in their life is central to personal change. This belief is the pathway through which change occurs.

> “…self-efficacy beliefs operate together with goals, outcome expectations and perceived environmental impediments and facilitators in the regulation of human motivation, behavior and well-being…This core belief affects each of the basic processes of personal change – whether people even consider changing their health habits, whether they mobilize the motivation and perseverance needed to succeed should they do so, their ability to recover from setbacks and relapses, and how well they maintain the habit changes they have achieved.” (p. 143)

Human health is a social matter. People learn from observing what others are doing and the more people are exposed to healthy behaviours, the higher the adoption rates (Bandura, 2004). People who are provided with support and guidance during early stages of the adoption of healthy practices such as those that support effective chronic disease management do better in the longer term. Social support and guidance will be more effective, furthermore, if it increases people’s beliefs that their actions will be effective. Bandura (2004) also states that social cognitive theory is also based on the concept of human effectiveness or agency as collective agency. We do not operate as individuals. People work together to improve their lives and accomplish social and personal change.

Narrative theory. Narrative theory may also provide insights as to why people benefit from online social networking and OHC. Narrative theory posits that we create reality through our stories (Bruner, 1991). The stories that patients tell about their disease state and their use of eHealth technologies may indicate their readiness to use and benefit from social networking. Haidet, Kroll and Sharf (2006) found that patients who described themselves as active participants in their care sought out information on the Internet and brought the information into the interactions with their providers. The narrative themes they identified in patient stories included how central a role people felt their illness played in their lives, their perceptions of being able to change for the better, their willingness to participate in their care by taking largely self-management actions, and their role with their health care team. Further, their research indicated that by understanding a patient's narrative, health professionals can suggest tailored strategies that encourage more effective self-management.

Network theory. Social media allows people to build new social networks. Kadushin (2012) states that social networks have value because people can access resources through them and build a sense of trust in the veracity of the information found through social networks. Social media provides opportunity for reciprocity within online social networks. People can share information with those from whom they have received information and support and are able to experience a sense of shared community (p. 164). An online community can supplement and add to other networks and offer support that cannot be provided by face to face networks. Weak tie relationships made online are there in abundance; these weak ties have not grown weary of a person's demands and concerns and can offer a new perspective. Weak tie relationships also provide people with an opportunity to be helpful to others, which may mitigate feelings of helplessness and inadequacy (Wright, 2009). As well, the simultaneous use of digital and physical interactions endemic in a chronic disease management regimen that incorporates health-related social networking can contribute to the virtual becoming indistinguishable from the physical world and help build stronger ties (Benkler, 2006).

Social comparison theory. Social comparison theory says that finding others in similar circumstances can make people feel that they are not alone and their situation is normal given what they are dealing with (Helgeson & Gottlieb, 2000; in Wright, 2009). This reduces stress for people facing health issues. Using social media to connect with others in the same situation allows people to feel less isolated, even if they do not know anyone with their condition in their face to face interactions with people.

J. Risk factors in the use of social networking

The literature discusses the risk factors or concerns about patient use of social networking and health-related social networks. These include privacy concerns and the potential for misinformation (Moorhead et al, 2013; Househ et al., 2014). Both are important issues. Health-related social networks cater to populations who are vulnerable and who may not understand the privacy risks of sharing personal health information. The risk is real: Users are sharing large amounts of information on, for example, diabetes-related sites, which may retain user profiles and information indefinitely (Weitzman et al., 2010l; Li, 2013). People may create fake accounts in order to gather data; content may be disclosed to third parties; and aggregated health information can be sold to companies which may use it to market to individuals (Li, 2013). As well, technology has advanced such that data can be mined for secondary purposes, which increases the risk of misuse and privacy breaches (Li, 2013). Li cautions while certain pieces of information by themselves may not reveal much, when linked together a lot could be revealed. Inappropriate disclosure and data aggregation can affect people’s relationships, reputation, employment and insurance choices. Further, patients may not realize when information presented as scientific is in fact only opinion and make choices which are not in their best interests and are even harmful (Weitzman et al., 2010).

People make choices about what they reveal. They will say one thing about their desire for privacy and act in a different manner. The difference between what people say about their desire for privacy and their actions is known as the privacy paradox. A relatively minor number of teenagers actively manage their privacy settings, despite being concerned about keeping their health status private and separate from their other online activities (van der Velden & El Eman, 2013). The need for privacy is the antithesis of the human desire to associate with others and share information and both privacy and interaction are critical to the human experience. The ability to maintain a balance between the two is essential, although what that balance looks like is dependent on a person's tolerance for disclosure. Burgoon et al. (1989) describe privacy as multidimensional, including physical privacy, social privacy, psychological privacy and informational privacy. Physical privacy is defined as "the freedom from surveillance and unwanted intrusions upon one's space" that reduce stress and stimulation (Burgoon et al, 1989, p. 132). Social or interactional privacy allows people to control their interactions with others and allows them to be close to some and more distant from other people and relationships. The difference between physical privacy and social privacy can be understood in a crowd situation where people have limited physical privacy, but their relative anonymity allows them to control their social or interactional privacy. Psychological privacy protects people from others who would control their thoughts, feelings and values and provides them with the ability to decide what and with whom they share personal thoughts and feelings. Informational privacy is the ability to control who can gather, share and disclose an individual's information and the circumstances under which they can do so. Privacy violations regularly occur in daily life and people develop mechanisms for dealing with them, including their withdrawal from a situation or expressing their discomfort. Ways in which people may feel their privacy is violated include situations where they are criticized, called names or when others reveal inappropriate detail (Burgoon et al., 1989).

Li (2013) says the “only tried and true solution to social network privacy issues is either to limit the data shared or to protect the data shared” (p. 707) and advocates for a social network framework with three principles: privacy by education of people using social networks, privacy by design of a site’s architecture; and privacy by policy by regulators and governments. Users need to be involved in the protection of their own privacy and that means education in online privacy issues and how to select privacy settings. The second principle, privacy by design, means that sites make protection of people’s information part of the architecture of the site without requiring that a person choose stringent privacy settings. In other words, the default should be protection from unauthorized access, use, disclosure or sharing so that an unsophisticated user would be protected. The third principle calls for greater regulation and legislation in order to hold organizations and companies accountable (Li, 2013).

The quality of information on social networking sites can be highly variable in terms of accuracy. Sites also vary in terms of the level and thoroughness of oversight by health professionals and whether the sites were ‘policed’ for accuracy (Shrank et al., 2011; Weitzman et al. (2010). Kar (2013) advises medical practitioners to participate in social media in ways that suit their patients while maintaining professionalism. A review of 18 online health communities identified aspects that have been positively associated with improvements in self-management. More assistance and guidance was thought to be needed in order to enhance the use of these health-related social networks for effective diabetes self-management (Ho et al., 2014).

Another risk factor is inappropriate behavior on social networking sites. If online interaction can be hyper-positive, it can also be hyper-negative as bullying cases in the media have amply demonstrated (“Cyberbullying,” 2012). On Diabetic Connect, information that does not meet the code of conduct is removed. This breaks negative feedback loops before they can intensify. The site also employs patient advocates and others who monitor and step into conversations to help ensure that people are being supported. Other organizations scrutinize their Facebook pages and have the ability to remove posts which are inappropriate for the goals of the site (Diabetic Connect, n.d.).

VI. Methodology

A. Research Design

The research was exploratory in nature and used a focus group comprised of six chronic disease educators located in Edmonton. This approach was undertaken to gain insight into the perceptions of chronic disease management educators into the use of social media, including social networking and client participation in health-related social networks. The focus group participants were sourced through a process that utilized the snowball technique. The focus group script included structured questions and semi-structured probes.

B. Sample Population

The participation requirement included clinical training and involvement in chronic disease management education that included direct patient involvement. The focus group participants included one registered dietitian and five registered nurses. All were employed by a major health care organization and were involved in chronic disease management, including group education and individual clinician-client work. In addition, an interview was held prior to the focus group with a registered dietitian as a pre-test of the focus group script.

C. Research Execution

Ethics approval was received from the University of Alberta. The snowball sample began with a contact with a chronic disease management consultant in the organization. That individual provided a referral to a program manager for chronic disease management with responsibility for primary care and chronic disease management in the local area. The program manager provided names of seven individuals employed as chronic disease management educators. The individuals were followed up with separately. Of those, six were invited to participate in the focus group. The seventh was invited to participate in the pre-test of the focus group script.

An initial email from the research investigator was sent to the seven individuals in early February. The email informed the prospective participants of the purpose of the research project: to examine the readiness of health professionals to recommend and support the use of social media by their patients and clients with chronic diseases, in particular for managing diabetes. It included the consent form for their information, along with a commitment to have copies of the consent form for them to sign at the focus group should they agree to participate. Potential participant were asked to reply by email or telephone. Follow-up was done by email to confirm the logistics of the focus group.

Participants were ensured that their name and organization would remain confidential and that results would be reported on the basis of their role in chronic disease management, not names or specific position descriptions. The nature of a focus group is such that participants are interviewed and engage in a face-to-face discussion, so it was not possible for participants to be anonymous.

The focus group guide was organized in four sections: 1) factors contributing to successful self-management of type 11 diabetes; 2) perceptions and awareness of the use of social media as a strategy in chronic disease management; 3) perceptions of risk around the use of health-related social networking; and 4) patient education on the appropriate use of health-related social networking to mitigate risk. See Appendix A for the focus group guide. In total, eleven questions were used to elicit the insights of the participants. Responses were coded and analyzed for themes, including consensus around key points as well as the range of insights and opinions.

D. Data Collection

The focus group was held in a conference room with boardroom style seating arranged to facilitate discussion. A semi-structured guide was used by the research investigator. It was organized around four broad themes:

- The participants' views on factors involved in successful chronic disease management;
- Awareness levels and perceptions of the effectiveness of social media and social networking as part of a chronic disease management self-management regimen, including exposure to literature and research on its use;
- Perceptions of risk and barriers to teaching the use of social media and social networking as part of chronic disease management self-management education; and
- Recommendations on what would encourage the incorporation of social media and social networking skills into chronic disease management self-management education.

The focus group guide is included in Appendix A. A handout providing definitions for social media and social networking was provided to participants at the introduction to the section on perceptions and awareness in order to provide a common starting point for the discussion (Appendix B). As part of the examination of patient education as a means to mitigate risk, participants were provided with two handouts: one focused on tips for patients on social media use (Appendix C), and the second provided online safety tips for patients (Appendix D).

The focus group was an hour in length and took place on February 24, 2015.

E. Data Analysis and Final Report

An audio recording was made of the focus group discussion and transcribed by the research investigator. The data was analyzed to prepare the final report, based on case analysis methodology: The data was organized, patterns identified, ideas developed and conclusions drawn (Merrigan, Huston, & Johnston, 2012).

F. Reliability and Validity Considerations

A focus group is loosely organized around topics and questions so that a range of information is gathered. Focus groups provide information, facilitate brainstorming, identify common themes and can help provide insights which are not those of the researcher (Merrigan, Huston, & Johnston, 2012). Results are indicative and qualitative.

The guide was designed to solicit discussion and piloted in a trial interview. The population of the focus group was representative of the larger population of chronic disease educators who have a clinical background as a dietitian or registered nurse. This contributes to the validity of the research.

G. Limitations

Limitations of this study include the size of the focus group sample and having only one focus group. This means that the results can only be inferred to apply to the larger population of chronic disease management educators, rather than allowing for a direct extrapolation. As well, focus groups may deter people from the disclosure of their views if they feel that their views run counter to the prevailing views (Merrigan, Huston, & Johnston, 2012).

VII. Findings

The focus group process was developed to address the objectives of the research: explore the level of awareness amongst educators working in chronic disease management of the use and benefits of health-related social networking for chronic disease management; and what would facilitate the incorporation of information on social media and health-related social networks in order to educate patients in its optimal use within a self-management regimen. A subordinate field of inquiry related to the second objective was an exploration of what chronic disease educators perceive as key factors in successful chronic disease management. This provided information that became the basis for a comparison of the literature on the benefits of social media and social networking in support of what educators themselves perceive to be important factors in successful chronic disease management.

The findings provide valuable insight into the awareness and use of social media and health-related social networking, as well as direction on what can be done to enhance its use in chronic disease management.

A. Awareness of Social Media and Health-Related Social Networking

Overall, participants did not appear to be confident of their knowledge of social media and online social networking. When provided with a handout that defined social media and social networking, participants were not familiar with the differences between the terms. The participants were also not as conversant with the effectiveness of social media and social networking as part of a chronic disease self-management regimen as they indicated they would like to be. Participants were aware that their clients and patients were using social media and social networking, as well as using mobile applications to track and monitor various aspects of their chronic disease management regimen. However, none of the participants recalled reading about the use of online health communities in peer-reviewed literature.

Awareness of health-related social networks. Participants were unfamiliar with health-related social networks specific to diabetes or specific Facebook pages or Twitter communities.

Their experiences with Facebook were personal, although one person had heard about Facebook groups made within the chronic disease community from a client. Another was familiar with the Canadian Diabetes Association's Facebook page, as well as the organization's weight loss program. Another indicated that her patients would tell her about blogs they were following.

> "I've…heard about people following blogs. And on those, I remind them that as long as they know the information is correct, they really need to have a look at the credentials of the person blogging and if anything seems, like if it seems unusual, like 'This person said if I take cinnamon my diabetes will go away.' That's where the challenge is."

It did not appear that any of the participants were themselves using social media or participating in health-related social networking sites.

They were aware that some areas of the organization were using electronic communications and social media. One area using social media platforms was a weight management program, which uses it primarily for journaling and logging activity. People were recording their information and uploading it on platforms, which they would then use to go over their results with their provider.

> "…social media platforms are used in the bariatric clinic for people that are doing a lot of food journaling. We promote using some of the electronic [applications] and the dietitians and everyone can go through things while they're there. They can bring it up online or they can look through their phones and look it up."

While the bariatric clinic is encouraging the use of activity trackers, for example, they find that people are using the community functions built into many of the mobile applications to create personal support networks.

> "…it was brought to my attention the other day by a man that the one I am on (for personal use) actually has a community based feature where you can monitor your results amongst your friends. So they [networking features] are not specifically promoted [by the organization] but I've certainly had people talk about it when we're together in the weight management classes, [saying things like], "Well, my friend and I are trying to outdo each other," and I didn't realize how that was being done until this man said, 'You add them to your friends and it comes up on your phone, and then you can see, oh so and so is how many steps ahead of you.'"

In one hospital, it was noted that at-risk pregnant women would email their blood sugar levels to a nurse and food consumption to their dietitian. This allowed women who were out of town or otherwise unable to attend in-person appointments to access the care they required. In other cases, people would bring their electronic records to appointments: “Sometimes people bring their stuff in to download at a visit.”

Participants indicated that the organization’s weight loss program and its website promotes the use of tracking applications. Participants also indicated that the discussion about social media tended to focus on the use of monitoring applications.

> “We have our own site [weight loss], but [the applications] it is not our product and we don’t pick one over the other.”
>
> “There are pockets of use, but it’s more from the perspective of a tool to track, as opposed to an interactive thing.”
>
> “In the discussions, we point out these [the use of applications] as options and then they’ll say ‘Oh this app is awesome and I can get it to send me messages.’ I think it helps promote their self-management, but I don’t think it necessarily promotes the [establishment of] community, not just yet.”

Awareness of Benefits. Most participants described the use of social networking and social media as being positive overall. The benefit most frequently mentioned was the ability for patients to address their desire to network with people in similar situations.

> “That’s probably the biggest demand from people, social networking, that getting together. When I did classes, that is their question, they don’t really, they are not asking for social networking with their health care provider. They want to find a social network [with their peers].”
>
> “They want to find people that they can connect with that understand them and that are at the same level as them…and I have been asked I don’t know how many times for details on ‘where can I find a support group?’ That’s what they want.”

They also noted the benefits of using social media and social networking for rural populations and people who are members of sub-culture and may feel even more alone when they have been diagnosed with a chronic disease.

> "In some of the rural areas, the biggest concern is being able to get together and discuss issues and I know in this one area somebody got…people together to do that from different towns. So having the social media would close that gap and I don't know if people are doing that, but I can see that would be helpful."

> "I had a client where social networking and social media actually helped a lot because there were social media on board for people who had type one diabetes and had tattoos and that sort of thing. For that person – it normalized things for him because he was feeling very distraught about things that had happened and he realized that maybe he could continue doing some of the things that he liked to do."

The benefits noted included the ability to connect at times which made sense for the individual, including the asynchronous nature of social networking from a peer to peer perspective:

> "…from a social media perspective, it certainly allows people to access multitudes of way to get information on their own time, at their leisure, at a pace that is comfortable for them."

Participants also discussed the potential for the use of the Internet and the information being collected electronically by their patients to provide better care and improve provider-patient communication.

> "…from the client and provider's perspective…when people are logging their information and they can provide it electronically [to their provider], I think that really helps people so that they don't have to make an appointment they can't fit in, so they can send their information and someone can get back to them and they can discuss it." (2e)

There was some awareness that the type of social network a person was using was a factor in its benefits, including the ability to participate anonymously.

> "…if you're using a network where you didn't have to use a picture of yourself, it gives them some anonymity and helps them to express maybe more because they're feeling that 'people don't know who I am,' that kind of thing."

One participant indicated that as people go to more sites and read more online, they would begin to develop a knowledge base that helped them to discern which information was beneficial from that which is not.

> “[Social networking] does let people with like issues get together and talk about things, which from a health care perspective has a good (side) and a downside…you don’t know all the information that gets out there about what they should be doing and if it’s really a good network for them.”

> “If they have different places to go to read information, they may themselves be able to start flushing out the wrong information from the right information because they’ll hear things.”

One participant spoke for the group to indicate that chronic disease educators are not teaching the use of social media or the benefits of belonging to health-related social networks because of the restrictions on its use within the organization and the lack of protocols and information.

Awareness of populations using social media. The participants had insights into which of their client groups were using social media. They felt that both men and women under 40 were more likely to use social media and social networking than any other demographic. The next most salient factor was a person’s professional or employment status, as well as commitment to fitness.

> “…it depends on maybe what your work life is like. A lot of our business people, professionals, they are quite savvy, and then if you are a pretty serious kind of athlete or very committed to your activity regime, you’re probably pretty aware of the number of tracking apps for that and that would be even between males and females.”

Teens and young adults were perceived to be the most savvy.

> “I sat in on a class of type one diabetics, who are a much younger population, and they were all ‘Oh yeah, did you see this app and did you see that app?’ They were very much into using those tools.”

Participants pointed out that older people and seniors were often online to a significant degree, depending on their curiosity and enjoyment of new experiences. Some found that once people retired, they had the time to go online and search out information and monitoring applications.

> "I do still see people up to age 60, maybe I should say that men, you get a lot of men that have been all these websites and checked all these apps and they're like, they're 55, and they're 60. My aunt is like 60 and she is crazy into Facebook. It depends on the person."

Awareness of risk and risk mitigation. Participants expressed concerns about the accuracy of information available online and what people might believe to be accurate when it was not scientifically valid information. Two of the participants identified the risks involved if people relied on their social networks and social media for information and stopped consulting with their health care providers. There was also a concern expressed that the 'natural' approaches they are reading about in social media may be harmful.

> "…they could shift to that [social media] as their primary source as opposed to their health care team, and that would not be a good thing."

> "They're led astray. You get some people who wonder whether or not to take medication, and where they are looking for more natural ways…they stop taking their metformin and then a few years later, they'll enter into our health care system again and their blood sugars will be really high and they are at total risk of complications…they've made some choices on the basis of their social network and they're getting support from that group…[taking them] down a path that puts them at risk and they experience complications."

> "What's a little problematic is that they are unlikely to be aware of truth versus fiction…where you are going to get the real story versus sites where you are going to get a manufacturer's version of the truth or something that is promoted by a pharmaceutical company or something like that is going have a very obvious bias and may not be in their self-interest - testimonials, those kinds of things. So the filters aren't there to assist them to get the real story…"

The other major concern was around the plethora of information on the Internet, much of it felt to be contradictory. One participant felt that people could get confused and stressed when the information they are reading may contradict other information they have read or is not relevant to their particular health status or condition.

> "… we have had people who have called in and said 'I've read [all] this…and now I don't know what is right and what is wrong. Because one site says have more protein and another site say whole grains and the other site may say, No, cut them out [altogether].' And it might get overwhelming: with the web unfortunately, a lot of it is opinion based… they're upset and they're confused…If they don't have a good health care provider in

> place in those situations, that can be really daunting. That's a huge drawback, because it's a big world."

> "I also wonder if we talk about this, some people will read health suggestions online, but they're usually for people who don't have a chronic disease."

One participant recommended that people always be told to check back with their health care team. Another thought that people should be encouraged to go online and look at information for themselves, particularly information that confirms what their health care team has told them. In that way, the information becomes something the patient has informed his or herself about and is therefore more likely to adopt.

Provider and Organizational Alignment with Patient Use. The participants felt out of step with their patients and were concerned that while their patients were using social media, email and social networking, organizational policies were not aligned with that use.

> "… there are a lot of unknowns [with the use of social media] and when that happens, we are told not to use it."

> "I feel like the public is there, but we are not there. For me, outside of my role as a nurse, I'm there, I get it. I can network and I can meet friends. Amongst ourselves, when I come into work as a nurse, my hands are so tied."

> "… as the organization that we are, we are prohibited from using email [to communicate with patients and clients], so it doesn't really matter what department you are in, it is not a sanctioned mode of communication [with patients]."

> "Amongst the professionals, we can email and there are certain criteria around what can be shared, but we can't patient to professional and vice versa."

This was seen as a barrier to better care and communication:

> "That just makes it such a barrier between patient and professional because then they have all these great programs and apps to communicate and network and we're saying, 'Sorry, I can't use that.'"

> "…it's like we are still using old ways of communicating with people. We're not using social media to its full extent."

> "…because it would eliminate the need for people actually getting in for what we would consider to be relatively innocuous appointments."

Inclusion of Social Media in Current Curriculum. Participants indicated that they do not teach the use of social media, nor do they discuss it in-depth with their patients. One said that she asks people how they get information on diabetes management and indicated that people were not readily forthcoming about their online activities.

> "…when I prompt them and say 'Well, how about the Internet?' And then they'll say "Well, I've looked and I've been on this or that." And they'll say they've been on Diabetes.ca, but other than that, they don't say much. So I don't know if I need to ask them about social media more, but I just ask where they get their information from and they say friends and family, and that's not usually that positive."

B. Factors in Successful Chronic Disease Management

The participants described a series of factors that contribute to people's success in the management of their chronic condition, including Type II diabetes. The primary factor centered on whether a person had accepted the diagnosis and the reality that their condition is chronic and requires lifelong management.

> "Have they accepted it and are they ready to make those changes? So whether they are sitting there and saying, "Okay, I can easily start eating more healthily and increase my activity level," or whether that is something that is going to take them a bit longer."

Early success was another factor. Some people were more motivated by improvements in how they feel and positive feedback.

> "…some motivated by health, seeing that their blood sugars are within target range, some by feeling better because for some, when they're diagnosed, they're feeling really crummy."

Acceptance and readiness were also linked with whether the person had experience with a family member who had diabetes. This was perceived to be both positive and negative. From a positive perspective, having a family member with diabetes gave the person first-hand experience, a source of information, and an awareness of the potential negative consequences of the disease if not well managed.

> “If they have been intimately involved with a family member who has diabetes, in my experience, they seem to be in a better place for managing their own. They’ve had some intimate experience already.”

> “I think it also brings in that fear factor: ‘I saw that happen to my relative so I don’t want it happening to me.’”

> “…I don’t hear that much positive [about family experiences]; it’s more the negative experiences that they share. They don’t want what happened to their relative to happen to them.”

> ”I had a client just recently who had had diabetes for quite some time and her parent just got recently diagnosed and went to classes and was saying that ‘this is what they’re saying now.’ So she phones me and says, ‘I better get to classes because that’s quite a bit different from what I learned many years ago.’”

However, having a family member with the chronic condition also had negative connotations. For example, some people followed the advice of a family member who was not managing his or her condition well, rather than the advice of the health care team. Having a family member with the chronic condition was also linked to a person’s belief that they could not manage the disease well and acceptance of a negative family narrative.

> “…they will listen to a family member who is not managing well and they will do it their way rather than listening to and seeking more expert advice and doing it that way.”

> “I had a client who never had a hemoglobin A1C under 10. Because her family had never had a hemoglobin A1C under 10, she felt she could never get below that. So it was quite a big aha moment when she actually did and she was quite excited about it, but it took a while.”

Being able to discuss their condition with others in a group was seen as an important way to ease feelings of isolation and an indication that the person accepted his or her condition.

> “I think it’s a sign that if you have accepted it [your disease state] you will talk about it. It kind of goes hand in hand.”

> “I think they don’t feel so alone or abnormal or weird…it helps normalize the abnormal for them…when they are in a group… they hear other people talking, you start to hear people open up that might not have otherwise …you can almost see it in their face – they may have not spoken yet, but as a group will go on, they feel that little bit more comfortable because it’s a safer place to be.” (1i)

> [They think)] “I’m not the only one who this is happening to.”

C. Use of Information Materials and Support for Further Education

Participants were provided with handouts that provide information for people going online, one focused on tips for patients on social media use (Appendix C), and the second provided online safety tips for patients (Appendix D). The participants all felt that both patient tip sheets were needed and would be useful. No-one could recall seeing similar materials.

> “We have had recommended websites, but we don’t have anything like this.”
>
> “It’s good work that you are doing.”
>
> “This might be good for back table material and resources. It may be that we can’t speak to it [because of organizational policies], but it’s there for them [patients] to take.”

They felt that having the information would empower their patients to go online with confidence and encourage responsible online behaviour.

> “It’s a piece of paper that they can take and they can control. They can read it. It’s not just a health care provider saying it.”
>
> “It’s not telling them what they have to do. It’s encouraging responsible behaviour.”
>
> “This is needed. There is more and more in the schools about how to be safe online, so why not have this for adults who are learning [about chronic disease management] and didn’t grow up with the Internet.”
>
> “It may help people who are hesitant to go onto the Internet to feel more confident. They would have a checklist and they are an intelligent consumer. They then can think, ‘I have some tools at my disposal that help me make decisions.’ I can see that being of a benefit to those people if the resource is there.”
>
> “These are wonderful things.”

Participants welcomed the opportunity to learn more about social media and social networking. They felt that chronic disease educators would appreciate more education in the area so they could better assist their patients as they go online. They appeared to feel empowered themselves by the information, in part by seeing that “there are ways of doing things that can mitigate risk.”

> “I would really love the education on social media. I think everybody on all the teams would.”

> “It is good work because there isn’t enough out there and that’s where you need someone who does that research to get it out to other people so it becomes more common knowledge.”

> “It isn’t that they don’t want to do it [teach people about the use of social media.] It’s whether they can confidently do it.”

There was an appreciation that people were going to be going online, whether or not chronic disease educators advocated the use of social networking and social media. It included a brief discussion about MyHealthAlberta, a government site, and the potential for their organization to develop its own health-related social network. They indicated, however, that while the organizational and governmental sites could have exemplary privacy standards and protection for people, people would still be using other sites and would benefit from advice on what to do and what not to do.

> “There is MyHealthAlberta, but that’s only one stop to the rest of the Internet.”

> “Our organization is behind in the use of social media [but] that’s where we [as a society] are going.”

> “It’s unrealistic to think that people won’t go online because everything is always pointed towards going onto the Internet: ‘Oh, download it, find it. Put your name there and you’ll find it.’”

Generally, the participants reinforced the importance of tips already included in the information sheets, including finding out who is giving advice and who owns the site. They made several suggestions for additional information or emphasis where the information was already contained in the handouts. These included strengthening the need to check people’s credentials so that people have a better sense about who is giving the advice, recommending that people look to see if claims being made online are supported by peer-reviewed research, and reinforcing the information that people should be very cautious of so-called miracle cures.

> “…people can give themselves titles that sound very reputable or professional and they’re not. I know people who say ‘I’m a nutrition expert’ and they’re like ‘Great, they’re an expert,’ but they aren’t.”
>
> “Just because they’re in the media a lot doesn’t make them an expert.”
>
> “Some people put a bunch of nice letters behind their name and it looks legitimate and you say, ‘Wow, they must have a lot of education.’ And maybe they have six months’ worth or a year, but they’ve taken four 3-month courses and they have designations behind their name, but none of them are legitimate. But they come across looking like experts.”
>
> “When they look for an online site, it’s important that the site reference the science behind their claims. There are bad papers out there, but sometimes it would weed out opinion from science. When they see something, they should ask, ‘Where is the science?’”
>
> “I find when people have a chronic disease, they’re looking for something, the magic bullet – sometimes people post that they have this great idea and people latch onto it [thinking] ‘That’s what’s going to cure me or I’ll lose weight or whatever it is.’”

When probed about privacy, participants agreed with the recommendation that people should only post personal information under a user name or pseudonym that could not be connected to them personally. They also agreed with the need for people to examine privacy policies and determine how the information they post is going to be used.

> “[If people post a lot of personal information online] organizations look at profiles. It could make a difference between whether you get an interview [for a job] or not. It’s discriminatory, but that’s what can happen. That’s why it comes back to being vulnerable. Post nothing that can be linked back to the real person.”
>
> “Look at things like are you paying to use the site… [if] you providing information to the site that’s free, then they’re using your information for money to run the site ... It’s incredible. You think it’s all free, but in the end, we are the commodity now.”
>
> “This is the thing. People need to understand [about privacy.] That maybe they should be anonymous and not connected to their real person.”
>
> “It’s such a sketchy world.”

VIII. Discussion

The research set out to explore awareness levels among educators working in chronic disease management about the use of health-related social networks and whether they recommend their use to their patients and clients. It also explored the potential use of patient education materials on the optimal use of social networking and health-related social networks in self-management regimens. The findings were informative and confirm the usefulness of further education and protocols to support chronic disease management educators. This would enable them to help ensure that their patients maximize the benefits and minimize the risks associated with the use of social media and health-related social networks.

A. The Knowledge and Policy Gap

The research identified a general awareness of social media among the chronic disease educators, but a lack of familiarity with specific health-related social networks. There also were gaps in understanding how online communities are built and sustained and their potential benefits for people with a chronic disease. While there is a growing body of peer-reviewed literature to support its use in chronic disease management, people on the front lines were not aware of it. Further, they did not have the tools, curricula and resources which would enable them to deliver information on the benefits, the types of networks and sites available, and appropriate behaviour.

The findings support the hypothesis that while chronic disease management educators are aware of health-related social networks, they would benefit from additional information on the research which supports the use of such networks. As well, the focus group findings indicate that educators would be more likely to recommend the use of social media to their patients and clients if they had more information on its use within a chronic disease management regimen. The educators were very open to learning more about the use of social media and safe practices that they could then use in their work. They wanted the information and they wanted to be able to use the handouts used in the focus group. Clearly, there is a gap that needs to be filled.

That gap is not only in the area of patient education materials and training for the educators. Policies and protocols within the organization were found to play a role in inhibiting the educators in discussing social media and social networking with their patients. Participants expressed uncertainty about what the rules were in some instances, but were clear that they did not feel they had permission to use email or other methods to communicate with clients and did not believe they could talk about specific social networking sites or practices. Without clarity and support, there was a hesitancy and lack of confidence on the part of the educators. Even in circumstances where they had some personal knowledge, they expressed reluctance to discuss social networking use in depth with patients.

When participants described the factors contributing to successful self-management, they talked about people’s acceptance of the reality of their condition, their ability to observe others in similar situations, and opportunities to talk about their condition and issues with others. These are all areas where health-related social networking has demonstrated its usefulness (Adaji, Schattner & Jones, 2008; Fischer et al., 2012; Yoon & Kim, 2008). Social media and health-related social networking would help the educators assist their patients in the achievement of better health outcomes.

The educators also identified instances where social media and health-related social networking could benefit their patients. These included the development of connections with other patients in their chronic disease management classes and hard to reach populations, such as people in rural and remote areas. They felt that they would be able to deliver better care as an organization if they had permission and training to use tools such as online sites, email and Skype.

The knowledge and policy gap may extend further than the organization within which the educators worked. Information for health professionals on teaching the use of social media and health-related social networking does not appear to be readily available. For example, diabetes educators in Canada are certified through the Canadian Diabetes Education Certification Board (CDCEB). The Board sets out competencies, including understanding the pathology of diabetes, nutrition for diabetics, use of medication, self-care management, psychosocial lifestyle factors, and education theory (CDCEB Competencies, n.d.). There is no specific reference in the competencies around social networking or social media. In another example, the Institute for Healthcare Improvement, a leader in evidence-based quality improvements in health care, advises that email, telemedicine, and Internet communication between physicians or nurses and patients can be used to manage patients with chronic conditions. Despite this advice, a search of its website did not turn up any material that would indicate what would constitute leading practices in their use, nor information on use by patients (http://www.ihi.org/knowledge/Pages/Changes/ChangestoImproveChronicCare.aspx).

B. Risks and Benefits

Knowledge and policy gaps on the part of both providers and patients have the potential to contribute to the risk to patients going online and minimize the benefits. The issue has an urgency about it and is not a problem that should be put off for the future. Patients are online now. They are ahead of providers in terms of their use of web-based applications and social networks. The educators they look to for assistance in the establishment of healthy self-management regimens do not have the tools and knowledge to support appropriate and potentially beneficial online behaviours. The problem is growing as more and more people are online. The participants identified those under 40 as heavy users, but also noted that their older patients were often online, too, particularly people who had used information technology in their work lives.

The risks are very real. The educators themselves related instances where people changed their self-management regimens in ways that negatively impacted their health, based on information found on the Internet. They also identified that people are at risk of negatively impacting their lives by sharing too much personal health information online that could potentially identify them in real life. The third risk identified in the literature, bullying, was not raised by the educators. It may be that they are unaware that this could occur on social networking sites. Again, this is a gap in their knowledge and impedes their ability to let people know how to protect themselves (“Cyberbullying,” 2012). As one participant said, it’s a big world out there and we are only a small part of it.

The benefits are also real. The participants identified ways in which people were networking through their monitoring applications such as activity trackers and being motivated by the peer to peer interaction. However, without education on appropriate behaviour, educators do not have the tools or knowledge they need to teach people about the potential upside of participation in health-related social networks and how it could assist them in a healthy self-management routine.

The information and research exists. Research has looked at factors such as privacy, security, monitoring by health professionals, potential for misinformation, censoring of inappropriate behavior and a code of conduct (Househ et al., 2014; Li, 2013). Other features and benefits of health-related social networking have been identified as social learning and networking, information, guidance, engagement, and personal health data sharing (Ho et al., 2014). The research also correlates to the competencies the chronic disease educators perceive as important in the successful management of a chronic disease, including an ongoing relationship with health care providers, feedback and support, learning self-mangement techniques, engagement and activation, networking and connection with family. See Table 1. This information should be systematically shared by health care organizations, professional bodies, certification boards and others in a position to do so so that front-line educators can better assist their patients.

C. Theories in Support of the Findings

The four theories examined in the literature review informed and shaped the analysis of the findings. These include social cognitive, narrative, network and social comparison theories.

Social cognitive theory provides insight into why the educators were appreciative of the opportunity to discuss social media use with the research investigator and how they described conversations they have with patients. Bandura (2004) tells us that human health is a social matter and that people learn from observing what others are doing. The more they observe healthy behaviour, the more they adopt healthy behaviour. The context in which learning takes place includes the identification of the mechanisms that produce change; the identification of activities which operationalize the mechanisms for change; and the social diffusion of the actions into the culture of the organization (Bandura, 2004, p. 162). The research findings indicate that the mechanisms of change include the introduction of social media information into the chronic disease management sphere, which was supported by the participants. Provider education, the development and dissemination of patient education materials and organizational policy updates would help operationalize the provision of social media support for patients. The third element would be through patient and provider feedback and a culture that embraced the benefits of the

Internet, from email to Skype to social media and health-related social networking. This would help empower patients and providers.

The power of narrative theory can be seen in the stories that the educators told. The experiences patients undergo within their families were described by the educators as having the most effect on a person’s success in the management of their chronic disease. This echoes the findings of Haidet, Kroll and Sharf (2006) who found that the narrative themes described by patients correlated to their willingness to participate in their care. Health-related social networks help people develop and share their stories and as they become more competent, they become more confident and successful in managing their condition (Mitchell et al., 2014; Wright, 2009).

The participants described networks their patients were developing online and the patients’ excitement in the comparison and competition found when they networked their monitoring applications with their friends. This supports the tenet of network theory that says that an online community can supplement other networks and offer support that cannot be readily done offline. In order to mimic the networked applications, the patients would have to engage in face to face or online meetings, something that would be almost impossible as part of a daily routine. As well, the simultaneous use of digital and physical interactions i.e. the use of monitoring applications by patients on their own and in the clinical setting such as at the bariatric clinic, supports Benkler’s (2006) observation that such behaviour builds stronger ties within a network.

The fourth, social comparison theory, postulates that finding that other people who are in similar circumstances can make people feel they are not alone. This came out clearly when participants described how some of their patients had used social networking to find others in their particular sub-culture e.g. diabetics with numerous tattoos, and how it helped to normalize their condition for them. Another example of the application of social comparison theory could be found in the focus group itself. As the participants began to talk about the use of social media and how they felt they were not able to support their patients in its use, they began to realize that they were not the only ones feeling that way and that, collectively, they wanted to address the issues.

D. Support for Providers and Patients

The research findings indicate that chronic disease management educators would like to support their patients in their use of social media and health-related social networks. They want to have more opportunities to learn more about the benefits and risks associated with social media use, and have patient education materials and handouts to use in their practices. All this would help them to normalize going online for their patients.

Their experience with patients being online made them particularly interested in issues around misinformation and the dangers of patients not sharing information they have learned online with their health care providers. They also felt that patients needed more education on appropriate behaviour in order to safeguard their privacy while being active participants in online communities. They wanted to reinforce that miracle cures being promoted online need to be treated with skepticism and require further investigation: If something looks too good to be true, it usually is too good to be true.

E. Recommendations

The findings from this research support the incorporation of actions that could assist chronic disease management educators and their patients to better understand social media and health-related social networks and support appropriate and beneficial online behaviour. The research identifies a lack of information and support materials on appropriate use of the Internet. It also provides insight into how the lack of corporate policies and protocols for front line staff inhibits the willingness and ability of the educators to respond to current issues and practices in the field of chronic disease management.

Recommendations for Chronic Disease Educators and Health Organizations

1. Organizations should review their policies and procedures and ensure that they support the appropriate use of information technology and social media in chronic disease management. Where they do not exist, protocols should be developed that support the use of social media, social networking and Internet-based functions such as email and Skype.
2. The policies and protocols should be supported by education and training for providers involved in chronic disease management, particularly people working directly with patients and clients who increasingly are online.
3. Patient education materials should be developed based on the literature. The patient tip sheets developed for this project provide a starting point. This information can be used as the basis for presentations, newsletter articles, online patient tips and modules in chronic disease management education programs.
4. Health care organizations should build information into their websites that supports the development of privacy awareness by users. Privacy policies should be clear and reference what will be done with people's information as well as what will not be done.
5. While not directly within the scope of the research findings, health care organizations should examine their Facebook policies and ensure that they are not encouraging people to post personal information in the highly public world of Facebook.

Recommendations for Further Research

This research contributes to our understanding of chronic disease management educators' awareness and support of social media and health-related social networking. It also provides insight into the role of organizational policies and protocols in encouraging or discouraging the use of electronic communication, social media and social networking between patients and providers. The small sample size does not allow for the findings to be generalized beyond these individuals' experiences. However, the findings do indicate the need for more research on the role of health-related social networks in chronic disease management. Based on this research, a more in-depth study of provider attitudes and awareness, organizational attitudes and awareness, and patient attitudes and awareness is recommended. Further work should also be done to demonstrate the alignment between research that demonstrates the benefits of online activity with desired competencies and attributes of successful chronic disease management. As well, educational materials should be developed and piloted to determine if the intended audience – patients with a chronic disease – find the materials relevant and useful. Future short and long-term goals could include research to determine if the introduction of relevant curricula improved patient self-management practices and health outcomes, and increase the confidence of providers in their ability to work with patients on the use of social media and health-related social networking.

IX. References

Adaji, A., Schattner, P., Jones, K. (2008). The use of information technology to enhance diabetes management in primary care: A literature review. *Informatics in Primary Care, Vol 16, no. 3, November 2008*, pp. 229-237.

Ahern, D., Kreslake, J., & Phalen, J. (2006). What is eHealth (6): perspectives on the evolution of ehealth research. *Journal of Medical Internet Research 8*(1). Retrieved September 18, 2012, from http://www.ncbi.nlm.nih.gov/pubmed/16585029

Alberta Government. (2014). *Alberta's Primary Health Care Strategy*. Edmonton, AB: Government of Alberta.

Alberta Health Services. (n.d.). Chronic Disease Management Resource Centre. Retrieved February 19, 2015, from http://www.albertahealthservices.ca/7700.asp

Albrecht, T., & Goldsmith, D. (2003) Social support, social networks and health. In J. Parker & E. Thorson (Eds.), *Health communication in the new media landscape* (p. 247). New York, NY: Springer Publishing Company.

Ardichvili, A., Page, V., & Wentling, T. (2003). Motivation and barriers to participation in virtual knowledge-sharing communities of practice. *Journal of Knowledge Management, 7* (1), 64 – 77.

Bandura, A. (2004). Health promotion by social cognitive means. *Health education & Behavior, Vol. 31 (2):*142-164.

Benkler, Y. (2006). Chapter 10 Social Ties: Networking Together. In *The Wealth of Networks: How social production transforms markets and freedom*. Yale University Press New Haven and London. Retrieved from http://www.benkler.org/Benkler_Wealth_Of_Networks_Chapter_10.pdf

Bodenheimer, D., Lorig, K., Holman H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. In J. Parker & E. Thorson (Eds.), *Health communication in the new media landscape* (p. 151). New York, NY: Springer Publishing Company.

Bodenheimer, D., MacGregor, K., & Sharifi, C. (2005, June). Helping Patients Manage Their Chronic Conditions. California Health Care Foundation. Retrieved from http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/H/PDF%20HelpingPatientsManageTheirChronicConditions.pdf

boyd, d. m., & Ellison, N. B. (2007). Social network sites: Definition, history, and scholarship. *Journal of Computer-Mediated Communication*, *13*(1), article 11. http://jcmc.indiana.edu/vol13/issue1/boyd.ellison.html

Bruner, J (1991). The narrative construction of reality. *Critical Inquiry*, 18, 1-21

Burgoon, J., Parrott, R., Poire, B., Kelley, D., Walther, J., & Perry, D. (1989). Maintaining and Restoring Privacy through Communication in Different Types of Relationships. *Journal of Social and Personal Relationships*, *6*(2), 131–158. doi:10.1177/0265407589006002001

Cyberbullying-linked suicides rising, study says. (2012, October 20). CBC News. Retrieved from http://www.cbc.ca/news/technology/cyberbullying-linked-suicides-rising-study-says-1.1213435

CIHI Directions. (2008). Retrieved May 13, 2012 from http://www.cihi.ca/CIHI-ext-portal/pdf/Internet/NLETTER_01NOV08_PDF_EN

Chou, W., Hunt, Y., Beckjord, E., Moser, R., & Hesse, B. (2009) Social media use in the United States: implications for health communication. *Journal of medical Internet research 11*. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2802563/

Canadian Diabetes Educator Certification Board. (n.d.) Exam handbook and documentation: Appendix A - competencies. Retrieved March 3, 2015 from http://www.cdecb.ca/files/cdecb/Exam%20-%202015/APPENDIX%20A%20-%20Compentencies.pdf

Cook, S., & Brown, J. (1999). Bridging epistemologies: The generative dance between organizational knowledge and organizational knowing. *Organization Science, 10*(4), 381-400.

Dedding, C., van Doorn, R., Winkler, L., & Reis, R. (2011). How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients. *Social Science & Medicine, 72(1)*, 49-53. doi: 10.1016/j.socscimed.2010.10.017

Diabetic Connect. (n.d.) Retrieved from http://www.diabeticconnect.com

Duggan, M., & Smith, A. (2013). Social media update 2013. Pew Research Center, January 2014. Retrieved from http://www.pewInternet.org/files/2013/12/PIP_Social-Networking-2013.pdf

Evans, D. (n.d.). 30 minutes a day to a healthier you. Retrieved October 15, 2014 from http://www.speakers.ca/2014/09/30-minutes-a-day-to-a-healthier-you/

Eland-de Kok, P., van Os-Medendorp, H., Vergouwe-Meijer, A., Bruijnzeel-Koomen, C., & Ros, W. (2011). A systematic review of the effects of e-health on chronically ill patients. *Journal of Clinical Nursing, 2011 Nov; 20(21/22)*: 2997-3010

Facebook. (2015). Facebook principles. Retrieved February 20, 2015 from https://www.facebook.com/principles.php

Fernandez-Luque, L., Karlsen, R., & Bonander, J. (2011). Review of extracting information from the social web for health personalization. *Journal of Medical Internet Research 2011 Jan-Mar; 13(1):* e15. Published online 2011 January 28. doi: 10.2196/jmir.1432 PMCID: PMC3221336

Fischer, H., Moore, S., Ginosar, D., Davidson, A., Rice-Peterson, C., Mackenzie, T., Estacio, R., & Steel, A. (2012). Care by cell phone: Text messaging for chronic disease management. *American Journal for Managing Care, February 1; 18(2):e42-7*. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/22435883

Fox, S., & Purcell, K. (2010). Chronic disease and the Internet. Pew Research Center's Internet & American Life Project. Retrieved October 9, 2012, from http://www.pewInternet.org/Reports/2010/Chronic-Disease.aspx

Gluekauf. R. & Lustria, M. (2009). E-health self-care interventions for persons with chronic illness: Review and future directions. In J. Parker & E. Thorson (Eds.), *Health communication in the new media landscape* (pp. 159-242). New York, NY: Springer Publishing Company.

Government of Canada, Public Health Agency of Canada. (2008, November 14). Preventing Chronic Disease Strategic Plan 2013-2016 - Chronic Diseases - Public Health Agency Canada. Retrieved March 16, 2014, from http://www.phac-aspc.gc.ca/cd-mc/diabetes-diabete/strategy_plan-plan_strategique-eng.php

Government of Canada, Public Health Agency of Canada. (2011, September 19). United Nations NCD Summit 2011. Retrieved February 17, 2015, from http://www.phac-aspc.gc.ca/media/nr-rp/2011/2011_0919-bg-di-eng.php

Government of Canada, Public Health Agency of Canada. (2011). Diabetes in Canada: Facts and figures from a public health perspective. Retrieved February 19, 2015 from http://www.phac-aspc.gc.ca/cd-mc/publications/diabetes-diabete/facts-figures-faits-chiffres-2011/pdf/facts-figures-faits-chiffres-eng.pdf

Government of Canada, Public Health Agency of Canada. (2013, November 27). Chronic Diseases and Injuries in Canada - An environmental scan of policies in support of chronic disease self-management in Canada - Public Health Agency of Canada. Retrieved March 16, 2014, from http://www.phac-aspc.gc.ca/publicat/cdic-mcbc/34-1/ar-08-eng.php

Greene, J., Choudrhy, N., Kilabuk, E., & Shrank, W. (2010). Online social networking by patients with diabetes: A qualitative evaluation of communication with facebook. *Journal of General Internal Medicine 26(3)*, 287-292. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/20945113

Griffith, L. S., Field, B. J., & Lustman, P. J. (1990). Life stress and social support in diabetes: association with glycemic control. *International Journal of Psychiatry in Medicine, 20*(4), 365–372.

Haidet, P., Kroll, T., & Sharf, B. (2006). The complexity of patient participation: Lessons learned from patients' illness narratives. In G. Makoul, L. Wissow & A. Visser (Eds.), *International Conference on Communications in health care* - Chicago 2005 - ICCH 2005

Hordern, A., Georgious, A., Whetton, S., & Prgomet, M. (2011). Consumer e-health: An overview of research evidence and implications for future policy. *Health Information Management Journal Vol 40 No 2 2011*, pp. 6-14. Accessed March22, 2011 from http://www.ncbi.nlm.nih.gov/pubmed/21712556

Ho, Y., O'Connor, B., & Mulvaney, S. (2014). Features of online health communities for adolescents with type 1 diabetes. *Western Journal of Nursing Research October 2014 vol. 36 no. 9 1183-1198.* Retrieved from http://wjn.sagepub.com.login.ezproxy.library.ualberta.ca/content/36/9/1183.full

Househ, M., Borycki, E., & Kushniruk, A. (2014). Empowering patients through social media: The benefits and challenges. *Health Informatics Journal 2014, Vol. 20(1) 50–58*

Kadushin, C. (2012). Understanding social networks: Theories, concepts and findings. New York, NY: Oxford University Press.

Kaplan, A., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of social media. Business Horizons, 2010, 53, 59-68. Retrieved February 22, 2015 from http://openmediart.com/log/pics/sdarticle.pdf

Kar, P. (2013). Social media in diabetes: bane or boon? *Practical Diabetes, Volume 30, Issue 1*

Kerr, D. (2010). Poor Numeracy: The Elephant in the Diabetes Technology Room. *Journal of Diabetes Science and Technology*, *4*(6), 1284–1287.

Konen, J. C., Summerson, J. H., & Dignan, M. B. (1993). Family function, stress, and locus of control. Relationships to glycemia in adults with diabetes mellitus. *Archives of Family Medicine*, *2*(4), 393–402.

Kontos, E., Blake, K., Chou, W., & Prestin, A. (2014). Predictors of eHealth usage: Insights on the digital divide from the health information national trends survey 2012. *Journal of Medical Internet Research* 2014; 16(7):e172. Retrieved from http://www.jmir.org/2014/7/e172/

Lenhart, A., Madden, M., Smith, A., Purcell, K., Zickuhr, K., & Rainie, L. (2011, November 9). Teens, kindness and cruelty on social network sites | Pew Research Center's Internet &

American Life Project. *Report: Teens, kindness and cruelty on social network sites*. Retrieved April 4, 2012, from http://pewInternet.org/Reports/2011/Teens-and-social-media.aspx

Li, J. (2013). Privacy policies for social networking sites. *Journal of the American Medical Informatics Association, 20(4)*: 707-707. Retrieved February 23, 2015 from http://www.ncbi.nlm.nih.gov/pubmed/23599228

Lorig, K., Holman, H., Sobel, D., Laurent, D., Gonzilez, V., & Minor, M. (4th ed.) (2013). Living a healthy life with chronic conditions; Canadian edition/content by McGowan, P., LaBossiere Huebner, T. Edited by LaBossiere Huebner, T. Boulder, CO: Bull Publishing Company.

Magnezi, R., Bergman, Y. S., & Grosberg, D. (2014). Online Activity and Participation in Treatment Affects the Perceived Efficacy of Social Health Networks Among Patients With Chronic Illness. *Journal of Medical Internet Research*, *16*(1), e12. doi:10.2196/jmir.2630

McMahon, G., Gomes, H., Hohne, S., Hu, T., Levin, B., & Conlin, P. (2005). Web-based care management in patients with poorly controlled diabetes. *Diabetes Care 28:* 1624-1629.

Merrigan, G., Huston, C., Johnston, R. (2012). *Communication research methods*. Canada: Oxford University Press.

Miller, M. (2011). *Facebook for Grown-Ups, Second Edition*. Que. Retrieved from http://proquest.safaribooksonline.com.login.ezproxy.library.ualberta.ca/book/web-applications-and-services/social-media/9780132877718/firstchapter

Mitchell, S., Mako, M., Sadikova, E., Barnes, L., Stone, A., Rosal, M., & Wiecha, J. (2014). The comparative experiences of women in control: Diabetes self-management education in a virtual world. Journal of Diabetes Science and Technology 1-8. 2014 September 10.

Retrieved October 10 from http://www.unboundmedicine.com/medline/citation/25212580/The_Comparative_Experiences_of_Women_in_Control:_Diabetes_Self_Management_Education_in_a_Virtual_World_

Morgan, M., Zamora, N., & Hindmarsh, M. (2007). An inconvenient truth: A sustainable health care system requires chronic disease prevention and management transformation. *Healthcare Papers. 2007,7(4):*6-23. Longwoods Publishing. Toronto.

Moorhead, S., Hazlett, D, Harrison, L, Carroll, J. Irwin, A, & Hoving, C. (2013). A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for communication. Journal of Medical Internet Research. 2013 April; 15(4):385.

Nonaka, I. (1994). A Dynamic Theory of Organizational Knowledge Creation. *Organization Science, 5* (1), 14-37.

Oliveira, M. (2014, February 19). 10 million Canadians use Facebook on mobile daily. *The Canadian Press*. Retrieved from http://www.theglobeandmail.com/technology/10-million-canadians-use-facebook-on-mobile-daily/article16976434/

Ractham, P., & Firpo, D. (2011). Using Social Networking Technology to Enhance Learning in Higher Education: A Case Study Using Facebook. In *System Sciences (HICSS), 2011 44th Hawaii International Conference on* (pp. 1–10). doi:10.1109/HICSS.2011.479

Rosland, A. (2009). Sharing the care: The role of family in chronic illness. California Healthcare Foundation. Retrieved September 30, 2014 from http://www.chcf.org/publications/2009/08/sharing-the-care-the-role-of-family-in-chronic-illness.

PR Newswire. (2014). Facebook reports fourth quarter and full year 2013 results. Retrieved from http://www.prnewswire.com/news-releases/facebook-reports-fourth-quarter-and-full-year-2013-results-242637731.html

Schleyer, T., Spallek, H., Butler, B., Subramanian, S., Weiss, D., Poythress, M., & Mueller, G. (2008). Facebook for Scientists: Requirements and Services for Optimizing How Scientific Collaborations Are Established. *Journal of Medical Internet Research*, *10(3)*(e24). Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2553246/

Shrank, W., Choudhry, N., Swanton, K., Jain, S., Greene, J., Harlam, B., & Patel, K. (2011). Variations in structure and content of online social networks for patients with diabetes. JAMA Internal Medicine. Retrieved October 10, 2014 from http://archinte.jamanetwork.com/article.aspx?articleid=1105928

Stanford School of Medicine. (n.d.). Chronic Disease Self-management program. Retrieved February 19, 2015, from http://patienteducation.stanford.edu/programs/cdsmp.html

Tamir, D., & Mitchell, J. (2012). Disclosing information about the self is intrinsically rewarding. *Proceedings of the National Academy of Sciences of the United States of America*, *109*(21), 8038-8043.

Thomas, J., Kellogg, W., & Erickson, T. (2001). The knowledge management puzzle: Human and social factors in knowledge management. *IBM Systems Journal*, *40*(4), 863 - 884.

van der Eijk, M., Faber, M., Aarts, J., Kremer, J., Munneke, M., & Bloem, B. Using online health communities to deliver patient-centered care to people with chronic conditions. *Journal of Medical Internet Research, 15(6), Article e115. doi:10.2196/jmir.2476*

van Gemert-Pinjen, J., Nijland, N., van Limburg, M., Ossebaard, H., Kelders, S., Eysenbach, G., & Seydel, E. (2011). A holistic framework to improve the uptake and impact of eHealth technologies. *Journal of Medical Internet Research, Oct-Dec2011, 13* (4). Retrieved from http://www.jmir.org/2011/4/e111/

Van der Velden, M., & El Eman, K. (2013). “Not all my friends need to know”: a qualitative study of teenage patients, privacy, and social media. *Journal of the American Medical Informatics Association 2013; Vol. 20:* 16-24. Retrieved February 17, 2014, from http://jamia.bmj.com/content/20/1/16.full

Wagner, E. (2000). The role of patient care teams in chronic disease management. *British Journal of Medicine 2000, Vol. 320*: 569-72. Retrieved February 13, 2015 from http://rcpsc.medical.org/publicpolicy/documents/2007/10_outUS.pdf

Weitzman, E., Cole, E., Kaci, L., & Mandl, K. (2010, November). Social but safe? Quality and safety of diabetes-related online social networks. *Journal of the American Medical Informatics Association 2011; 18*: 292-297. Retrieved October 9, 2012, from http://jamia.bmjjournals.com/content/18/3/292.full.pdf+html

Wright, K. (2009). Increasing computer-mediated social support. In Parker, J. & Thorson, E. (Eds.), *Health communications in the new media landscape* (pp. 243-265). New York: Springer Publishing Company.

Yoon, K., & Kim, H. (2008). A short message service by cellular phone in type 2 diabetic patients for 12 months. *Diabetes Research and Clinical Practice*, *volume 79*, *issue 2*. Retrieved from http://www.sciencedirect.com.login.ezproxy.library.ualberta.ca/science/article/pii/S016882270700469X

X. Table One

Table 1: Participant-identified competencies in relation to the literature

Participant-identified competencies/ Alignment with literature review	**Related research that identifies social media and health-related social networking benefits**
Acceptance and connection with others for emotional support and networking (Lorig et al., 2013)	People see others that are facing the same issues that they are and can model successful behavior (Bandura, 2004; Wright, 2009, p. 256). Supportive messaging is related to lower cholesterol and cortisol levels (Floyd et al., 2007, in Wright, 2009).
Ongoing relationship with health care team (Wagner, 2000)	Information technology can lead to improved care Adaji, Schattner & Jones (2008) (pp. 233-236). Use of text message reminders and feedback helps people reduce blood sugar levels (Fischer et al., 2012; Yoon, & Kim, 2007).
Daily feedback and support (Adaji, Schattner, & Jones, 2008, p. 234; Dedding, van Doorn, Winkler, & Reis, 2010, p. 50)	People can communicate with others about how they overcame obstacles to manage their chronic disease and electronically monitor and track progress towards their goals (Adaji et al., 2008).
Acquisition of skills and habits and adherence to daily routines (Gluekauf & Lustria, 2009; Kerr, 2010; Rosland, 2009)	Online competence and ability to express oneself is associated with success in changing behavior and the perception of effectiveness (Mitchell et al., 2014). Chronically ill patients showed better results when e-health interventions provided instead of or in addition to other primary care (Eland-de Kok et al., 2011). Writing down one’s thoughts allows individuals to distance themselves from their emotions and has a therapeutic effect (Wright, 2009).
Patient engagement/activation (Bodenheimer et al., 2005; Magnezi et al., 2014; Wagner, 2000)	People less engaged can benefit more from online participation as they acquire information and model healthy behaviour of others (Magnezi et al., 2014).
Family support (Rosland, 2009)	Patients and their families can participate on social networking sites (Diabetes.ca).

XI. Appendix A: Semi-Structured Focus Group Guide

Social Networking and Chronic Disease Management

Introduction

(Introduce myself.)

Thank you for your time today. This focus group should not take more than one hour. By participating, you are helping me to better understand how you as chronic disease management experts perceive the use of social media by patients, including social networking and participating in online health communities.

- There are no right or wrong answers; I am interested in your perceptions and opinions on the subject matter.
- I will be recording the conversation so I can transcribe the conversation we have today.
- This report will be shared with my project supervisor at the University of Alberta. Your confidentiality will be protected as your name, title or organization will not be revealed.
- If you speak about this focus group afterwards, please don't identify anyone else who is attending or attribute their comments to them.

Do you have any questions before we start?

Chronic Disease Management

1) Based on your experiences, what factors contribute to patients' successful management of type II diabetes?

Probe: Ability to observe others and model behavior (Social cognitive theory)
Ability to talk about their condition and be positive (Narrative theory)
Building connections with others in similar situations (Network and social comparison theory)

General Awareness of Social Media in Chronic Disease Management

I want to talk now about social media.

I have a handout that basically defines social media and social networking. (Quickly read through it to them.) How many of you use Facebook? Some of you? Facebook is a good example of a social network – user generated content.

2) Generally, what are your perceptions of the effectiveness of social media and social networking as part of a chronic disease self-management regimen?
3) Are you aware of health-related social networks like Diabetic Connect or TuDiabetes?
    a) Probe – What about Facebook pages? Twitter? Others?
    b) What about Facebook?
4) Do you discuss their use with your clients and patients, or with educators you work with?
5) Have you seen anything about the use of online health communities in peer-reviewed literature?
6) Do you think that chronic disease educators are teaching the use of social media and benefits of belonging to online health communities as part of self-management skills? Are you seeing patients or clients who are using social networks or Internet tools to help them manage their diabetes? Who are they generally (women, men, younger, older, socioeconomic factors?)

Perception of Risk

7) What risks do you see in the use of social media and social networking as part of CDM self-management education?

Mitigation of Risk

8) What recommendations would you make that would encourage the good incorporation of social media and social networking skills into CDM self-management education?
9) My review of the literature indicates that social networking and belonging to online health communities can provide people with emotional support and information; encourage them to monitor their blood sugar levels and maintain a diet and exercise regimen. However there is evidence that suggests that more guidance or structure would be helpful to ensure that what happens online is focused on promoting positive beliefs and behaviors. That help could include providing more guidance to people around how to use online health communities for effective diabetes self-management.

   I have developed two tip sheets for use by people going online. The first is more general advice and the second focuses on online safety.

   I'd like to hand them out to you for your quick review. I'll give you a few minutes to look them over and then I'd like to get your views.

   Do you have any comments or questions about any of the tips?
10) Would you find these or something like this useful as part of chronic disease management education?
    a) Probe – Why or why not? Anything else?
11) Are there any other comments you want to add on the use of social media that we didn't discuss or you would like to add?

Thank you for your time. I very much appreciate it.

XII. Appendix B: Social Media and Social Networking Handout

Social media and social networking are often used interchangeably, but they aren't the same thing.

Social media are a collection of Internet-based applications that allow people to create and exchange information, ideas, stories, etc. Social media acts as a communications channel that delivers a message.

Social networking is a subset of social media where people create a profile and connect that profile to others in order to create a personal network. Social networking is two-way and includes sharing information between several parties.

Social media platforms include blogs, microblogs such as Twitter, social networking sites like Facebook and specific online health-related sites, video sharing sites like YouTube, games and wikis.

References

Househ, M., Borycki, E., & Kushniruk, A. (2014). Empowering patients through social media: The benefits and challenges. *Health Informatics Journal 2014, Vol. 20(1) 50–58*

Kaplan, A., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of social media. Business Horizons, 2010, 53, 59-68. Retrieved February 22, 2015 from http://openmediart.com/log/pics/sdarticle.pdf

Lenhart, A., Madden, M., Smith, A., Purcell, K., Zickuhr, K., & Rainie, L. (2011, November 9). Teens, kindness and cruelty on social network sites | Pew Research Center's Internet & American Life Project. *Report: Teens, kindness and cruelty on social network sites*.

Moorhead, S., Hazlett, D, Harrison, L, Carroll, J. Irwin, A, & Hoving, C. (2013). A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for communication. Journal of Medical Internet Research. 2013 April; 15(4):385.

XIII. Appendix C: Handout - Ten Tips for Patients Going Online

1. Inform yourself about what is available by going online and checking out sites. Talk to other people about what they've found online.
2. Try different applications to determine what is useful to you. Download a monitoring app. Log your workouts. Follow a blog. Join an online health community.
3. Find a site that is checked by health professionals and community participants. Look for a commitment to removing or identifying misleading, inaccurate and abusive posts.
4. Find a site that allows you to post with a user name. It is almost always better not to use your own name if you are going to share personal experiences about your health.
5. Find out who is giving advice. Know if it is a patient, a clinician or someone interested in selling or promoting something. Factor that into what you do with the information. If you can't find out or have concerns, proceed with caution. Like everything in life, you have to assess the risks and benefits.
6. Find out who owns the site. It provides a lot of insight into what is featured on the site.
7. Check with your health team before making changes to your treatment plan. A reputable site will recommend that you do this. Your health team considers all aspects of your health. What works for one person may not work for you.
8. Read the privacy policies on sites before you join a site. Are their policies clearly written? Can you figure out if your personal information will be shared with advertisers and how that might happen? Will you be contacted by other organizations? Who can access your information? You need to know and be comfortable.
9. Use Facebook pages as an information source. 'Liking' Facebook pages is a great way to get information delivered to your page on Facebook. However, personal health information shared on Facebook can be linked to other aspects of your life and may be readily accessible far into the future.

10. And finally, participate. That's how you will get the most benefit. Interaction can help you feel happier, improve your health outcomes and help answer your questions.

References

Fox, S., & Purcell, K. (n.d.). Chronic disease and the internet. Pew Research Center's Internet & American Life Project.

Van der Velden, M., & El Eman, K. (2013). "Not all my friends need to know": a qualitative study of teenage patients, privacy, and social media. *Journal of the American Medical Informatics Association 2013; Vol. 20:* 16-24.

Weitzman, E., Cole, E., Kaci, L., & Mandl, K. (2010, November). Social but safe? Quality and safety of diabetes-related online social networks. *Journal of the American Medical Informatics Association 2011; 18*: 292-297.

XIV. Appendix D: Handout - Online Safety Tips

1. Look for sites where the basic description of the disease and how to care for it is consistent with information provided by your doctor. Be very cautious of sites that advertise miracle "cures."
2. Find the privacy policy of any website where you register as a member, and make sure that you understand it. If you can’t, consider looking at another site. Remember, it isn’t right or wrong if someone wants to sell your information. Decide what you are comfortable with in terms of privacy. Will they send you emails? Will they send your information to a company that wants to sell you something? All that should be clear to you.
3. Try to use sites where you have the greatest amount of control over the sharing of your health data -- where you can decide whether the information you share will be available to anyone online, to members only or members who are "friends."
4. Look for websites that clearly label advertisements and disclose conflicts of interest.
5. Try to use sites that have moderators and are checked by external reviewers.
6. Always remember that going online is not a replacement for visiting your doctor or other health care provider.
7. If you see some information about a different treatment or a change in treatment, always check with your health care team before making any changes that you haven’t discussed with them first.

Reference

Weitzman, E., Cole, E., Kaci, L., & Mandl, K. (2010, November). Social but safe? Quality and safety of diabetes-related online social networks. *Journal of the American Medical Informatics Association 2011; 18*: 292-297.