



McMaster eBusiness Research Centre

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Implications for Chronically Ill Patients**

By

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FOR CHRONICALLY ILL PATIENTS**

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ABSTRACT

Direct medical care costs for chronic disease account for over 40% of Canadian healthcare expenditures, so the use of self-management to shift more healthcare responsibility to the chronically ill themselves is becoming a major consideration in controlling healthcare costs. Self-management interventions (SMIs) using online patient centred support can enable a collaborative approach that empowers patients to manage their own chronic illnesses, supported by their circle of care. This can include support in learning and supporting behaviours such as complying with prescribed medication and non-prescribed remedies; monitoring symptoms; lifestyle adjustments such as dietary change, alcohol restriction, and smoking cessation; exercise and weight loss; and related preventive activities (e.g. oral and body hygiene, sufficient rest, etc.). A critical issue is online SMI sustainability. This is not just financial viability and cost effectiveness, but motivating patients to adopt and then to continue using SMIs indefinitely to help reduce the risks associated with their chronic illnesses. This paper reviews the literature on online SMIs, including how they can be implemented in a sustainable manner, technology support for SMIs through personal health record systems and online fixed or mobile applications, and complexities that can arise from patient age-related issues.

Keywords: Health self-management, chronically ill patients, online patient support, sustainability, age-related patient issues, cognitive impairment

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INTRODUCTION

Direct medical care costs for chronic disease account for over 40% of Canadian healthcare expenditures¹, so the use of health self-management to shift more healthcare responsibility to the chronically ill themselves has become a major consideration in controlling healthcare costs. The goal of health self-management is to improve health status and health behaviour, reduce utilization of the healthcare system^{2,3} and improve patient quality of life in a more normal environment at work or at home. Expecting patients who have been diagnosed with a chronic illness to self-manage their illnesses by modifying their life styles with no additional ongoing support has been found not to be effective for most diseases (particularly for Canadians aged 50+ years)⁴, so it is critical to find ways to provide and promote cost effective support. One approach is to provide online patient-centred support through a collaborative care approach that empowers patients to manage their own chronic illnesses, supported by their circle of care⁵. If carefully designed and implemented, this can be more effective than the traditional care model⁶⁻⁸, resulting in better management and decision making by patients.

Health self-management involves recognition and evaluation of the importance of changes in symptoms, and implementing adjustments to treatment⁹. It depends upon patient judgment and decision making, supported by access to healthcare professionals, education, skill acquisition and being able to adjust their actions according to feedback¹⁰. Self-management tasks include: Medical Management, involving tasks to treat a condition through a special diet, taking medication, etc.; Behaviour Change, adopting or creating new behaviors that help to improve illness symptoms; and Emotional Management, dealing with emotions often caused by chronic disease, such as fear, frustration, anger and depression¹¹.

Online self-management interventions (SMIs) can play a major role in chronic care. They include the encouragement of behaviours such as complying with prescribed medication and non-prescribed remedies as well as monitoring symptoms, and lifestyle adjustments such as dietary change; alcohol restriction and smoking cessation; exercise and weight loss; and preventive behaviours (e.g. oral and body hygiene, sufficient rest, etc.)¹². Factors that may complicate this process include: having multiple conditions; anxiety and depression; age-related issues; impaired cognition; sleep disturbances; poor health literacy; and problems with the healthcare system¹².

An important issue in online health self-management is sustainability. This is not just financial viability and cost effectiveness, but the motivation of patients to continue the intervention indefinitely. Otherwise investment in self-management support is wasted and patient health suffers unnecessarily. How to motivate patients and reduce attrition rates is often ignored in online health self-management, and high attrition rates have been reported in the few studies that actually measured them^{13,14}. Motivating patients to continue relevant activities must therefore become an integral aspect of online health self-management.

This paper is directed towards answering the following questions:

- a) Are online systems effective in supporting self-management interventions for chronic illness?
- b) What role can mobile applications play in supporting self-management interventions? If so, what technologies can be used, and what roles can they play?
- c) Can online and mobile applications be effective for supporting older patients with chronic illnesses? What are the barriers to the use of such applications, and how can they be addressed?

SELF-MANAGEMENT INTERVENTIONS

Self-Management Interventions (SMIs) for chronic illnesses imply day to day patient responsibility including: taking medications, making lifestyle changes, and taking preventive actions¹⁵. For an SMI to be effective, patients need not only adhere to treatment guidelines but also must monitor their conditions and make cognitive, behavioural, and emotional changes necessary to maintain an acceptable quality of life. The psychological and social dimensions of chronic illnesses differ according to the illness, so there is no “one size fits all” approach to a chronic disease SMI. For example, the objectives of care for asthma may focus on monitoring symptoms and better medication adherence, while diabetes and arthritis SMIs may focus more on behavioural changes such as lifestyle and cognition¹⁵.

Self-management plans and goals are derived through collaborations between patients and their physicians. Patients can use these plans and goals independently to make frequent daily decisions in managing their conditions, resulting in improvements in managing certain chronic diseases¹⁶. If an online health self-management system is developed that is grounded in the chronic care model¹⁷ and utilizes the patient’s personal health record (PHR), it can provide the basis for improved patient-centred care^{8,18,19}. The system should link to the patient’s circle of care through secure electronic communications, preventive healthcare reminders, and disease specific tools such as education, community support, and motivators such as online recreation and amusement. Patient-oriented decision support has also been shown to be effective for patient self-management²⁰⁻²².

Behavioural issues in both the prevention and management of chronic diseases are closely related. While chronic diseases are the most common illnesses to treat, many are also preventable. Common risk factors of major chronic diseases such as heart disease, stroke, diabetes, arthritis, asthma, and osteoporosis include obesity, physical inactivity, unhealthy diet, tobacco, alcohol, hypertension, and high cholesterol²³. Initiatives on the self-management of specific chronic diseases (e.g. heart-healthy diets) relate also to the prevention of diseases in currently healthy individuals.

Fundamentally, an effective online SMI requires of the patient²⁴: self-monitoring (e.g. daily weight measurement), the ability and approval through empowerment to change treatment appropriately, the personality to take control of one's own treatment, and a physician who is comfortable with empowering the patient. For some patients and physicians, this may be quite natural but for others it requires a major cultural change. Tools that support SMIs include²³: a) Information and education about the disease, its causes and effects, strategies to forestall its progress and prevent disease complications, and effective treatments; b) Training in managing the disease, including monitoring symptoms (e.g. blood pressure and weight), problem-solving and coping techniques, developing confidence in disease SMIs; c) Behaviour modification programs such as exercise programs and smoking cessation; d) Counseling, advice and supportive services to help patients to cope emotionally with their conditions; e) Care partners who can assist in patient self-management activities; f) Access to health and social resources in the community; for sustainability we add g) Motivating patients to continue to adhere to their SMI regimens. An online system can provide all these tools, to complement the beneficial effects of physician-prescribed treatment regimens.

Personal Health Record systems (PHRs)

To improve the likelihood that patients and their families and/or caregivers have access to informed knowledge that could assist in self-management of conditions and diseases, they must have access to relevant information about their own medical histories, normally through Personal Health Record (PHR) systems, along with access to education and other support, and links to others in their Circle of Care. PHRs have the potential to change (and possibly improve) patient-provider relationships, enhance patient and shared decision making, and enable the healthcare system to evolve towards a more personalized medical model²⁵. A survey of Canadian consumers and physicians²⁶ indicated that physicians appear to be positive towards the adoption of PHRs. A recent survey of 400 Canadian consumers, who self-identified as suffering from chronic illness or disability, indicated that 83% were in favour of regularly monitoring and maintaining records about their health²⁷. Previous studies in the United States have also indicated a great deal of public interest in PHRs. A major motivation is that over 70% of U.S. consumers believe that having access to PHRs would improve the quality of their healthcare²⁸, although there is no convincing evidence that this is the case. The greatest interest in PHRs is among the chronically ill, frequent users of healthcare, and caregivers for elderly parents²⁹. Among American consumers saying they are not interested in using PHRs, more than 55% indicated that worries about privacy and confidentiality affected their reluctance. About 90% of these consumers surveyed felt that the provision of privacy, record access and user remedies would be significant factors in agreeing to use an online PHR service. Their interest in using such a service depended upon the PHR service's sponsoring organization, with the services that individuals currently use or that are available locally ranked the highest²⁸.

PHRs can be supported in paper or electronic format. Paper PHRs are seldom used except by individual patients to record data temporarily, or by patients who do not have Internet access. Paper PHRs are basically paper diaries in which individuals can maintain records of their health status and support activities. Electronic PHRs can be supported through several different architectures, including standalone (smart cards, PC based systems, etc.), tethered (linked to family physician, hospital, or other institutional systems), or integrated (portal-based systems that also link to the patient's other medical records from family physicians, labs, hospital, or other sources)³⁰. The focus of this paper will assume the use of electronic PHRs for providing online support to health self-management patients. A large variety of commercial PHR products are currently available. Although one study found 91 different PHR products in use by firms, institutions, or governments and/or available commercially³¹, only 7% of American adults use PHRs. Primary care physician Electronic Medical Record systems (EMRs) are often used as sources of information for patient PHRs, and primary care physicians play a predominant role in advising and guiding patients with advice and support of education and health self-management³². PHRs can play a major role in providing repositories for patient information and data as well as functionalities they can include to support patient health self-management (see Table 1).

Table 1 Data Recommended for Inclusion in PHRs³³

Data	Data Sources					
	Patient	Care-giver	PCP	Other Physicians	EMR	PHR Support
Personal information	X	X				
Problem lists	X	X			X	
Procedures, hospitalizations	X			X	X	
Major illnesses	X	X	X	X	X	
Provider list	X		X	X	X	
Allergies	X				X	
Home monitor data	X	X				
Family history	X				X	
Social history, lifestyle	X				X	
Preventive health recommendations			X	X		
Immunizations	X				X	
Examinations, diagnoses			X	X	X	
Medications	X				X	
Laboratory tests, appointments	X				X	
Notes	X	X	X	X	X	
Educational content and links*						X
Training in system use*						X
Decision support capability*						X
Behaviour modification programs*						X
Community of interest links*						X
Communications to Circle of Care*						X
Motivational (recreation, learning)*						X

Note: PCP – Primary Care Physician; *Self-management functionalities added for this paper

Sustainability, Attrition, and Motivation

Sustainability is a term that is used in a variety of ways, with different meanings, but we will adopt the United Nations definition “development that meets the needs of the present without compromising the ability of future generations to meet their own needs”³⁴. Sustainability is basically rooted in economics. How does healthcare relate to this? For a community to be sustainable, its human resources must be maintained and protected. Sustainability on the community level is tied to the health of its population. A healthy community can better care for the environment, contribute to economic development, and promote social equity. If humans remain healthy, economic resources are available for other purposes, such as environmental protection, economic growth, and social welfare, instead of being diverted to healthcare or lost because of an unproductive workforce. In terms of the discussion in this paper, sustainability of an innovation that supports health self-management means that a) it is feasible and cost-effective in comparison with alternatives, b) it contributes to improved health and better quality of life of its adopters, and c) it will be used on an on-going basis by those who can benefit from its use.

Reported attrition rates from online support SMIs vary widely. Attrition rates have been reported from as low as 3% for an interactive web-based intervention that included telephone counseling, to an enormous rate of 99% in a panic disorder self-help program³⁵, although the small number who continued through the entire 12 week program experienced significant improvements. A rate of 65% was reported for a web-based smoking cessation program that lacked personalized follow-up³⁶. Etter³⁷ also reported an attrition rate of 65% in responses to a follow-up questionnaire for a smoking cessation program involving close to 12,000 participants over a 2.5 month period. Attrition factors are closely related to adherence, and they tend to be complex³⁸, but they must be addressed effectively if the benefits of SMIs are to be maximized. One objective of a self-management intervention should be to maximize the motivation of patients to adopt and continue with SMI behaviours for the long term. For example, there may be possible benefits from booster sessions to reinforce long term changes¹⁵. An intensive and repetitive approach can be used to motivate lifestyle changes, and close relatives of patients and other caregivers help by encouraging healthy lifestyles^{39,40}. The continuing use of online self-management can be encouraged by a supportive online network of professionals and peers⁴¹, and interest could also be stimulated by online health education, news, and entertainment.

Yu et al.⁴² reviewed 57 studies of web-compatible tools that have been developed for supporting diabetes patients, for their clinical usefulness, sustainability, and usability. Studies were included that described implementations of electronic audiovisual tools for educating patients, care givers, or clinicians about diabetes management and assessed a psychological, behavioral, or clinical outcome. Mobile device applications were excluded from Yu’s study. Tools that were studied showed inconsistent effects on psychological and clinical outcomes including HbA1c and weight. Although 12 reported interventions resulted in positive outcomes, this was not moderated by clinical usefulness nor usability. Few tools were found that met the criteria of this study for effectiveness, usefulness, sustainability, and usability. Priority areas arising from

this study included identifying strategies to minimize website attrition and enabling users to make informed decisions by reporting website quality indicators.

Eysenbach⁴³ has noted that eHealth trials tend to be prone to participant dropouts. He suggests that what is needed is a “law of attrition” to explain dropouts. He also suggests that most eHealth researchers fail to report high trial dropout rates, although this may be a natural and typical feature of such trials. In fact, measures reported could report differential dropouts or usage rates between two interventions (and presumably between interventions and controls) as “usability efficacy”. Eysenbach argues that a “science of attrition” is needed so dropout data could be reported in a meaningful manner. This is certainly a valid point that should be pursued further. But one could argue that what is also needed is more research into the reasons for attrition, so it could be combated successfully. There is a need to determine how people can be motivated to adopt and continue to use a system that will clearly help them to maintain healthier and more productive lives, and reduce the chances that they will decide to reject such a system. It is not well understood why the goal of better health is not enough to motivate people, although there are techniques to predict in advance whether patients will adopt and continue with beneficial healthcare behaviors⁴⁴. If patient motivation to adopt an innovation were understood, resulting reductions in attrition rates would lead to improved outcomes from such trials. These reductions would also lead to the development of more sustainable systems that would be more likely to be adopted and would contribute to patient self-management beyond the termination of clinical trials. When these systems are adopted and used continuously by more patients, more lives would be saved and the health and quality of life of patients would be improved over the long term, at less cost to the healthcare system. Hence the term “sustainable” applies to such systems.

An area of research that provides much promise in promoting sustainable health self-management systems is the use of psychological theories of behavior change to model individual health actions such as self-management of health⁴⁵. A number of theories have been proposed to explain why people take or do not take health-related actions. Although there are many such theories, three relevant ones include: Social Cognitive Theory, the Transtheoretical (Stages of Change) Model, and the Health Belief Model⁴⁶. The intent of applying these theories is to influence the design of support systems for specific chronic diseases that assist patients, not just to understand and manage their diseases, but to provide self-rewarding feedback that will reinforce patient desires to continue healthy behaviours. Supporting activities may include education, coaching, interactions with other patients with that disease, scheduling doctor appointments, as well as monitoring diet, weight, exercise, blood pressure, heart rates, blood glucose, etc. There is not enough space here to describe how each of these three models might be used to understand how patients can best be encouraged to continue healthy behaviours or to modify undesirable life styles such as smoking and over-eating. However, for example, Social Cognitive Theory links constructs such as social persuasion, outcome expectancies, behavioural capability, environmental situations, and self-efficacy to health behavior and reinforcement by experience, consequences, and self-rewards. These theories can be used to suggest the design of

interactive web sites and virtual communities. Another theory that has found widespread acceptance in information systems and eHealth research⁴⁷ is the Technology Adoption Model. This model is well grounded and has been validated multiple times. It can be used to predict adoption and also to predict whether adopters will continue to use it, after an initial trial period.

In order to improve outcomes from SMIs, behaviour modification must be successful, and this should also lead to improved sustainability. Suitable theories that have been applied in behaviour modification^{48,49} include Social Learning Theory⁵⁰, Theory of Planned Behaviour⁵¹, and the Stages of Change Model⁵².

ONLINE SUPPORT FOR CHRONIC DISEASE MANAGEMENT

The advantages of online network support for chronic disease patients include portability, timeliness, efficiency, and scalability, with few limitations due to geography or mobility⁵³. Such systems can accommodate remote access from both desktop computers and mobile devices (the latter especially for those currently employed and/or otherwise active). Through online and decision support⁵⁴ for patient-centred care, changes in healthcare practice can often help to meet practice and patient goals. For example, research has demonstrated improvements in diabetes outcomes and chronic illness self-management when behavioural support is forthcoming from relevant technologies, improving dietary practices, physical activity, and adherence to medication regimens⁵⁵. King et al⁵³ indicate the need for focus groups and social media that will identify the most acceptable support activities. It is known, for example, that social activities are particularly important for older people, with health benefits that may include less chance of mortality, disability, and depression, and better cognitive and health-related behaviours⁵⁶. Studies targeting multiple co-morbidities of chronic illness along with depression or mental stress have also been successful in relieving psychological symptoms^{57,58}.

The use of online social networking has been growing, and this can either augment or replace face-to-face social activities. Online support groups have been shown to have positive impacts on behavioural and clinical outcomes^{2,59}. To improve health outcomes, online behavioural change programs need to consider patient age and gender⁶⁰, ethnicity⁶¹, and literacy levels⁶². Barriers to online SMIs include fear of loss of privacy, intrusiveness, cost, and loss of interest⁵³. Interest in continuing with online support programs is enhanced by providing patients with frequent, tailored, interesting, encouraging, and nonjudgmental approaches to providing feedback. Self-monitoring features, such as tracking weight, exercise, and diet can improve engagement and goal achievement⁵³. Contact from healthcare providers, social support networks, and caregivers plays an important role in the success of online chronic care⁶³. The use of gaming technologies has been found to be effective in education, preventive behaviours, and in maintaining interest, particularly among adolescents⁴⁸.

Mobile Support for Chronically Ill Patients

Mistry⁶⁴ undertook a systematic review of studies of the cost-effectiveness of telemedicine and telecare from 1990 until September 2010, and found that there is no conclusive evidence that telemedicine and telecare interventions are cost-effective compared to conventional health care. At the same time, the author suggested that telemedicine is a very broad term, and reviews need to be categorized since it unrealistic to make sweeping generalizations about the overall cost-effectiveness of telemedicine. That is, in some categories telemedicine may be cost-effective, while in others it may not^{65,66}. For example, a systematic review and meta-analysis in 2008 by DelliFraine and Dansky⁶⁵ found that telehealth had a moderate, positive and significant effect on clinical outcomes in general, but that outcomes were positive for heart disease and psychiatric conditions but not for diabetes. Paré et al⁶⁶ studied telehomecare services for 95 patients with various chronic diseases over a 21-month period, and found significant benefits from the program: reductions in number of hospitalizations, length of average hospital stay, and number of emergency room visits. However, the number of home visits by nurses increased both during and after the telemonitoring intervention. The program resulted in annualized savings of over CDN \$1,557 per patient, a net gain of 41% as compared to traditional home care.

There has been rapid growth in the use of smartphones by consumers interested in gathering healthcare information or using smartphone apps for tracking and managing health. A 2012 Pew survey⁶⁷ found that half of U.S. adults own smartphones. One in three of these users have used their smartphones to look for health information, and 19% have used smartphone apps for healthcare. These are used primarily to monitor exercise, diet and weight. One of the problems facing those who seriously want to use mobile support for health self-management is that the consumer uses of mobile technology tend to be over-hyped⁶⁸, leading to excessive expectations by the consuming public. Although there are many excellent non-invasive mobile applications for monitoring physiological metrics relevant to a number of chronic diseases⁶⁹(Ch.4, Ch.8), these need to be put to the test in proper randomized controlled trials before their use can be well understood and justified medically. Basically, the characteristics of recommended care and good health outcomes for people with chronic illnesses include active participation, collaboration, and data sharing among participants. These activities are the same as those seen in online social networks (OSNs) such as Facebook. Therefore, OSNs seem to be a natural environment to promote such social interactions among patients.

A successful pilot study with 15 diabetic patients by Roblin⁷⁰, used cellular technology to mediate interactions among adults with Type 2 diabetes and their supporters (family members and friends) through text messages, to motivate regular blood glucose self-monitoring. Some of the patients reported improved self-monitoring and their supporters indicated increased psychological understanding and support that could benefit patient lifestyles and health outcomes. A somewhat similar study with 47 diabetic patients⁷¹ used automated text messaging to remind patients about checking blood glucose and office appointments over a three month period. Daily diabetes management activities of some patients improved and a majority of them

provided blood glucose measures online. Patient-provider communications also improved. Also, text messaging is an inexpensive method to encourage patient adherence.

A recent study in the University Health Network in Toronto, Canada provided smartphone access to diabetic patients in a randomized controlled trial (55 participants over the ages of 30 in each arm of the trial) to evaluate the impact of regularly monitoring and recording blood pressure⁷². Monitoring devices were provided only to the intervention participants (self-care group), and full adherence was defined as a minimum of eight readings per week. Their findings were very promising in that there was a significant reduction in systolic blood pressure of the intervention group by the end of one year. However, there was a negative effect from worsened depression in the self-care group, and they also noted a decline in readings per week over the study period, indicating a fatigue effect for this intervention. Another study has addressed the use of relational agents for chronic disease self-management⁷³. Relational agents are computational artifacts that, if designed carefully, can build long term socio-emotional relationships with users, simulating face-to-face conversations with patients so that a variety of verbal and non-verbal channels can be used to communicate therapeutic information and maintain a continuing relationship with the patient. Such a system, interacting with the patient over a hand-held device, could provide motivational counseling, for example, to promote physical activity, or to monitor vital signs and provide warnings if they are out of normal range. Agents may need to be tailored to the personal characteristics of the individual so they are not ignored or turned off over the long term, with resulting loss of effectiveness.

One meta-analysis⁷⁴ of 25 randomized controlled trials (RCTs) with either telemonitoring or structured telephone support of non-invasive remote models of specialized disease-management interventions for congestive heart failure included a total of 8323 patients. This analysis excluded studies that involved additional home or clinic visits, and reviewed primary outcomes (mortality and hospitalizations) and secondary outcomes (cost, length of stay, and quality of life). Findings were that telemonitoring reduced all-cause mortality and that structured telephone support showed a similar but non-significant trend. Both types of interventions reduced heart failure-related hospitalizations, and improved quality of life, reduced costs, and acceptability to patients. Improvements in prescribing, patient knowledge and self-care were also noted. In a systematic review of 25 controlled studies of cell phones and text messaging interventions involving over 38,000 patients, Krishna et al⁷⁵ found significant improvements in adherence with medication regimens, asthma symptoms, HbA1C, stress levels, rates of smoking cessation, and self-efficacy. There were also fewer failed appointments, quicker diagnosis and treatment, and better teaching and training. Electronic monitoring devices have been suggested for monitoring patient adherence to taking medications. These are very simple to implement and for patients to use, and may be helpful in overcoming non-adherence caused by forgetfulness. They mainly capture patient adherence to the device rather than to taking medications, and tend to be less accurate than pill counting⁷⁶.

As in other studies related to health self-management, cost-effectiveness of trials of telemedicine support must be known to determine whether a net benefit arises from the introduction of telemedicine in specific situations⁷⁷. Most research targeting telemedicine is oriented towards feasibility and technical studies. Decision makers who rely on such studies therefore may not have the cost data needed to make decisions on the adoption of such systems. For these reasons, it may not be impossible to determine whether such systems are sustainable, and as a result proposals that may be cost effective may be discarded or those that are not may be implemented with resulting negative net benefits. However, one review of telemedicine studies that included economic analyses found that that 13 of 23 interventions were good to fair quality⁷⁸, based on assessment criteria proposed by Drummond et al⁷⁹, Ch. 3.

Commercial Internet Support for Patients

Commercial Internet operations that provide online support for chronic disease patients have sprung up in recent years. For example, WebMD <http://www.webmd.com/> provides information and applications for a number of chronic diseases, ranging from advice to disease symptoms to community support networks. This is a major operation, involving more than 700 employees. It appears to be supported primarily by advertising revenue, which quickly becomes obvious to visitors to the site. Another well-known site is Patients Like Me <http://www.patientslikeme.com/> which has the primary purpose of linking patients to others with similar problems, in community-of-interest groups. There are many others, including sites managed by well-known clinics and hospitals such as the Mayo Clinic, Johns Hopkins Medical Center, etc. A primary consideration in visiting any such sites is whether the information or services being provided are trustworthy, and whether data gathered by site will be shared with marketing firms. Visitors tend to rely on the reputation of the organization operating the site, although when one is desperately looking for a solution to an illness, checking on the trustworthiness and reliability of an organization and the information it provides takes on lesser importance.

OLDER CHRONICALLY ILL PATIENTS

Relationship Between Chronic Illness and Cognitive Impairment

The existence and degree of cognitive impairment that often occurs with older patients is important to understand, because this can have a negative effect on the ability of patients to self-manage chronic disease⁸⁰⁻⁸². Mild cognitive impairment (MCI) is a condition that lies on the boundary between normal aging and dementia (e.g. Alzheimer's disease), and patients with MCI are at risk of developing dementia⁸³. Evidence of MCI includes: Memory complaints by patient, family, or physician, but patient has no dementia, is involved in normal activities of daily living, and has normal global cognitive function. Objective tests such as the Montreal Cognitive Assessment (MoCA)⁸⁴ and the Mini-Mental State Examination (MMSE) are used to determine whether a patient has memory or other cognitive function impairments⁸³.

The relationship between the incidence of chronic illness and cognitive impairment in older patients has been known for years, although no satisfactory explanation nor cause and effect relationship has been forthcoming as yet. The relationship has been demonstrated for many chronic illnesses, and the following will describe a few related confirmative studies. For example, a study⁸⁵ that involved 9679 American women aged 65 and older found that the 682 women in this group with Type 2 diabetes had lower baseline scores on cognitive measures than those who did not have diabetes. In addition, measures of cognitive function three to five years later showed that women who had diabetes for 15 or more years had a 57% to 114% greater risk of major cognitive decline than those who did not have diabetes. A more recent systematic review has confirmed that Type 2 diabetes mellitus is indeed associated with increased risk of MCM or dementia⁸⁶. Another study of 4678 Japanese-American men living in Hawaii who had originally participated in a heart health program in 1965-1968, involved checking their cognitive function in 1991-1993, at an average age of 78 years⁸⁷. Findings from this study were that an increased level of midlife systolic blood pressure is a significant predictor of reduced cognitive function in later life. Another more detailed and systematic review of specific cognitive impairments in cardiac patients investigated the link between echocardiographic and cognitive measures⁸⁸. This study confirmed that lower cardiac output and worse left ventricular diastolic function are linked to cognitive executive function deficits. In yet another study of 80 patients⁸⁹, average age 62.5 years, with chronic kidney disease (CKD) at severity stages III and IV but not on dialysis, a relationship was found between the severity of CKD and cognitive function. Impairment of cognitive function in this group increased with the severity of CKD. These results and others were confirmed by a more recent meta-analysis that assessed the impact of CKD on cognitive decline⁹⁰. This research suggested that CKD is indeed a significant and independent risk factor in the development of cognitive decline.

Finally, medications may also play a role in cognitive function changes. For example, statins are one of the most widely used and effective medications for reducing blood cholesterol levels⁹¹, but there are some indications that they may also affect cognitive function in a complex manner. A recent announcement by the U.S. Food and Drug Administration⁹² requires a warning label for statins about their potential for rare cases of confusion or memory loss, and a possible increased risk of Type 2 diabetes.

While physical activity can be effective in combating the effects of chronic illness^{12,23,93}, it has also been demonstrated that it can mitigate the potential for cognitive impairment. For example, one study⁹⁴ involved 6434 Canadian men and women aged 65 and older, who were cognitively normal at baseline, with a five year follow-up. Compared with no exercise, physical activity in this group was associated with lower risks of cognitive impairment, Alzheimer's disease, and other types of dementia. Another study of 18766 American women in the age group 70 to 81 years over a time frame of 15 years⁹⁵ found that long term regular physical activity, including walking, was significantly associated with better cognitive function and less cognitive decline in older women. A recent systematic review⁹⁶ also suggested that physical activity tends to protect

against future risk of dementia and Alzheimer's disease. However, the optimal level of physical activity for risk reduction was not accurately defined in this study. For the reasons stated here, it is obviously critical that online health self-management support should include a functionality that encourages exercise by the patient. In many situations, this can help to protect against developing further complications from the chronic disease⁹⁷.

Figure 1 shows the incidence of mild cognitive impairment and dementia in Canada, for people aged 65 or more. It is clear that a considerable percentage of older patients with chronic disease(s) may have some symptoms of mild cognitive impairment or dementia, reducing the likelihood that these patients can successfully self-manage their illnesses or actively use online support. It is also evident from the previous paragraph that chronically ill patients who get regular physical exercise at all ages will be better able to combat the onset of cognitive impairment, thus giving them a more normal life as well as making them more capable of managing their own chronic illnesses.

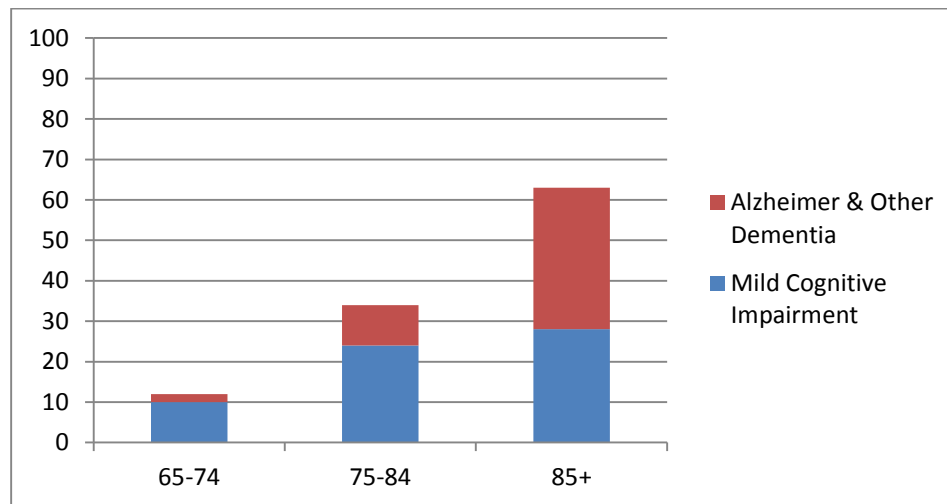


Figure 1 Percentage Prevalence of Cognitive Impairment in Canada by Age Group (Adapted from⁹⁸)

Self-Management Support for Older Chronically Ill Patients

Caution is advised when planning to provide online services, whether mobile or stationary, for older chronically ill patients. In addition to possibly being afflicted by mild cognitive impairment or dementia, older patients are also much more likely to be afflicted with chronic disease(s) and therefore are the main population target for chronic disease treatment. As shown in Fig. 2⁹⁹, the proportion of the population with no chronic illness falls from 75% at age 12-14 to 21% at ages 65-69, and even less for older patients. In fact, Fig. 2 also shows that the proportion of people with more than one chronic disease begins to grow at middle age and older. A multiplicity of chronic diseases is more difficult to treat effectively than a single chronic disease¹⁰⁰. In addition, older age groups have considerably less access to the Internet and are less likely to be Internet users than people in younger age groups (Table 2). It has already been pointed out that older patients with chronic diseases are likely to have some degree of cognitive

impairment, making it even more difficult for them to be trained to self-manage their chronic diseases, particularly using online support.

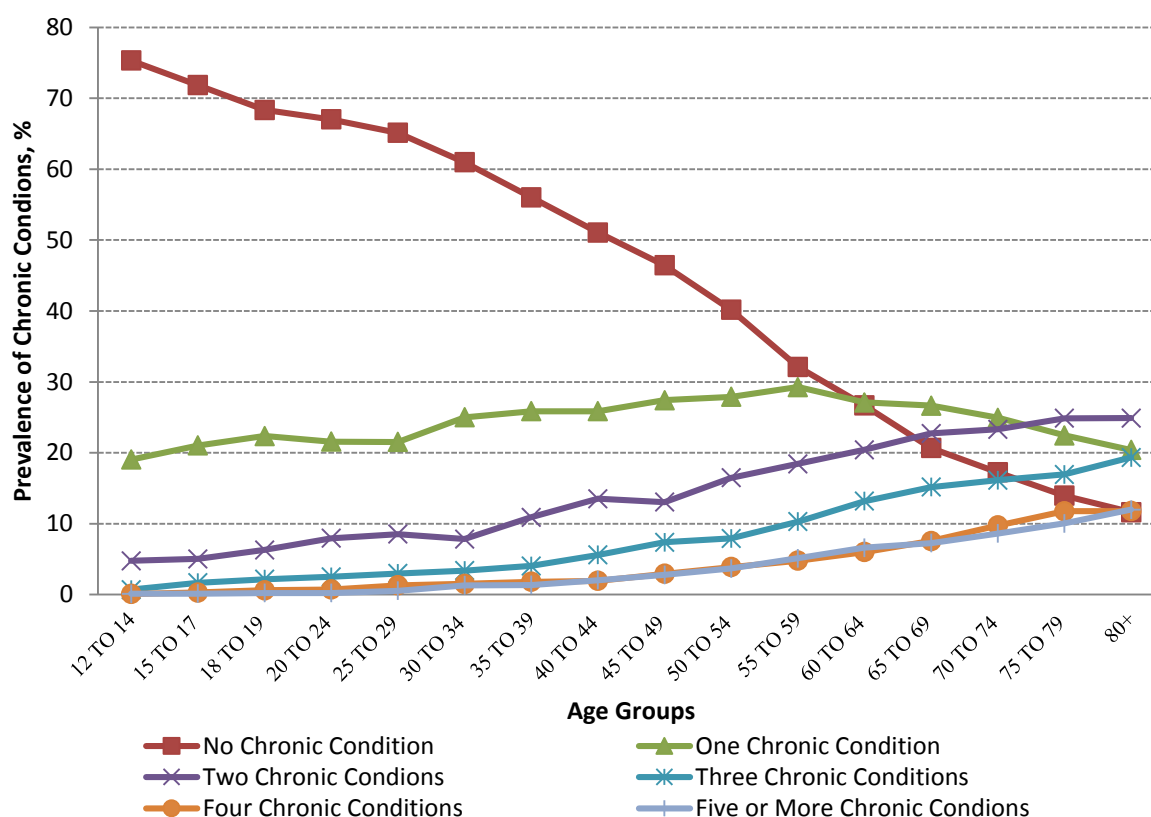


Figure 2. Prevalence of Chronic Conditions by Age Groups, Canada 2009-2010
(Adapted from⁹⁹)

Table 2 shows the results of a Statistics Canada survey of Canadians in 2009¹⁰¹, showing the relative difference in the percentage of Canadians with Internet access, across age groups. The substantial increase in Internet access by people aged 65 or older between 2007 and 2009 shows the strong effect of the baby boomer generation who have grown accustomed to regular Internet use for work and recreation, as they begin to replace the older generation above age 65.

Table 2. Percentage of Canadians Accessing the Internet From Any Location
(Adapted from¹⁰¹)

Age Group	2007	2009
Internet users aged 16 years and over	73.2	80.3
Internet users aged 34 years and under	93.1	96.5
Internet users aged 35 to 54 years	79.8	87.8
Internet users aged 55 to 64 years	60.8	71.1
Internet users aged 65 years and over	28.8	40.7

Age related issues are a major problem for health self-management, particularly when online technology support is provided. Limitations to online support for older patients with low self-efficacy measures or limited cognitive abilities can be partially overcome by considering, where possible, dyads of patients and caregivers, one or both of whom are regular technology users. To demonstrate that this has possibilities when considering online support, consider for example a recent study of heart failure patients¹⁰². Here, a survey of 41 patient and caregiver dyads (see Table 3) found that online or mobile patient support could be improved if access to the service were managed by a dyad, since caregiver partners tended to be younger and much more likely to be Internet and/or mobile phone users. The difference between average caregiver and patient ages is at least partially due to the fact that caregivers of relatively old patients are likely to be their offspring. This has very real possibilities for online self-management support for older patients, but caution is advised since significant psychological strains may result from such a relationship, and it will likely require training and regular coaching support¹⁰³⁻¹⁰⁶ to make this approach work well.

Table 3. Statistics for 41 Patient-Caregiver Dyads (Adapted from¹⁰²)

	Patient	Caregiver
Average Age	79	60
Home Internet Users (%)	21	67
Mobile Phone Users (%)	30	79

DISCUSSION AND CONCLUSIONS

In the introduction to this paper, three questions were posed. Based on the material presented in this paper, we can now offer at least partial answers to these questions.

a) Are online systems effective in supporting self-management interventions for chronic illness? In many of the papers reviewed, the answer to this question is a conditional yes for many patients afflicted with chronic illnesses, including co-morbidities such as depression. However, the support must address the specific problems that patients believe are important, and the support must be provided in such a way that it is easy to use, has good feedback, and provides communications for the patient with those who are within the patient's circle of care. Fundamental to its successful use is that it is cost effective in relation to alternatives, and that patients are willing to adopt and to continue using it, resulting in a sustainable benefit to their health. More research is needed to study the psycho-social needs of patients so support systems can be provided that meet their needs and reduce the problems of non-adoption and attrition.

b) What role can mobile applications play in supporting self-management interventions? If so, what technologies can be used, and what roles can they play? It is very clear that mobile applications are the wave of the future in health self-management. It is easy to envisage the day

when health self-management is ubiquitously available through smartphones that manage patient personal health records, stored securely with accompanying functionalities on the devices themselves or on remote secure servers (in “the cloud”). Such systems would possibly link to self-monitoring devices and allow patients to enter confidential data as events occur, such as exercising, eating, taking medications, and other relevant activities. These could be effective for people on the move, either traveling or at work.

c) Can online and mobile applications be effective for supporting older patients with chronic illnesses? What are the barriers to the use of such applications, and how can they be addressed? The aging population as a group suffers disproportionately from the rest of the population from chronic diseases, so their need for self-management assistance is greater. Their problems are exacerbated by the fact that the older old population is more likely to be afflicted by cognitive impairment or dementia, making it less likely that they will be able to manage their own health problems, no matter how that support is offered. In addition, those who have chronic diseases are even more likely to suffer cognitive impairment than people of the same age who do not have chronic disease, thus compounding the problem.

Solutions that address the needs of the aging population with chronic disease include: 1) providing support through dyads of patients and caregivers, where the caregivers are likely to be younger than the patients, are more familiar with using online systems, and do not suffer from cognitive impairment, 2) providing highly simplified and very easily used support to cognitively impaired patients. In the long term, of course, as baby boomers age, fewer and fewer of the older population will be unfamiliar with online technology use, so patients will be more at ease with technology, thus reducing this particular barrier to technology adoption in the future, 3) It is also very clear that there is a lack of a good theoretical basis to explain patient willingness to adopt and to continue using online health self-management support. This void can be addressed by developing suitable psycho-sociological theories and using associated questionnaires during trials of online support systems, to provide statistical evidence that can help in the design of effective online support systems for chronic disease self-management.

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