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Information Technology to Support Self-Management in Chronic Care

A Systematic Review

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Abstract

Informed individuals who are actively engaged in managing the daily challenges of their chronic disease are the change agents in a healthcare system that is presently unresponsive to the needs of this growing population. The application of information technology (IT) to support self-management extends the reach of the provider organization by linking patients to the exchange of health information and facilitating self-management activities. This systematic review of the literature was conducted to illuminate the application of IT that is enabling consumer self-management and healthcare provider support of that self-management. Research in self-management IT is being conducted to determine the effectiveness of various tools in improving self-management performance and health outcomes. A significant area of inquiry focuses on self-management technologies to support the chronic care model (CCM) conceived by Wagner and colleagues.

Results indicate that most research is focused on the use of IT by individuals for self-education and self-monitoring, with a small number of studies exploring applications to enable collaboration of providers and individuals in self-management planning and activities. Changes in patient adherence and levels of knowledge were the most popular outcome variables measured, with reports of significant improvements in both areas. However, limitations in study design have led to inconclusive results regarding the effect of IT-based self-management tools on patient adherence and clinical outcomes. This systematic review affirms the importance of extending the IT infrastructure of the healthcare system to support the self-management activities of individuals striving to manage their chronic disease.

By the year 2020, there will be 157 million people in the US living with chronic illness, an increase of almost 20% in 16 years.[1] This ominous trend threatens to overwhelm a healthcare delivery system engineered to treat acute episodes of care; the growing chronic disease population demands ongoing care management of psychosocial and medical problems.[2-4] Effecting system change to improve chronic care management rests with those individuals who are taking control of their health and healthcare. A patient-centered model, in which patients with chronic diseases master self-management skills with the support of their providers,

will lead to higher quality of, and lower costs for, healthcare.[5,6] Disease education, mastery in solving the everyday problems that arise with a chronic illness, and building self-confidence in managing one's health form the nucleus of self-management activities.[5,7] Informed individuals who are actively and competently engaged in managing the daily challenges of their chronic disease are the change agents in a healthcare system that is presently unresponsive to the needs of this growing population.

Integrated clinical processes operating across the healthcare continuum for an extended time are critical to successful chronic care management. A robust information technology (IT) infrastructure enables this level of clinical integration by supporting access to and sharing of health information among members of multi-disciplinary care teams.[8] The application of IT to support self-management extends the reach of clinical integration by linking the patient into the exchange of health information, thereby fostering collaborative activities among patients and clinicians. This model of IT-based self-management (i.e. 'self-management systems') represents a fundamental characteristic of the individual-centered healthcare system. Ultimately, the availability of a portable and electronic medical record (EMR) that is owned by the individual and accessible to authorized providers empowers consumers and improves clinical decision making.[9] With this type of collaborative information system infrastructure, providers are able to extend their practice to support self-management, facilitate patient involvement in the setting of goals to improve health outcomes, and foster the development of a patient who is more actively engaged in managing his or her own health.[5]

To what extent is IT being applied to facilitate self-management of chronic diseases? Pertinent literature reviews[10-12] reveal substantive evidence that health IT is associated with improvements in patients' knowledge of their chronic illness and certain clinical outcomes. A comprehensive systematic review[11] reported enhanced knowledge, significant and positive effects on clinical outcomes, and improved social support when patients were end-users of IT applications; these programs featured tools that supported self-management and not just presentation of health information. A subsequent review,[10] limited to populations with diabetes mellitus, reinforced the findings of Murray et al.[11] of improved hemoglobin levels in association with the use of interactive applications. These analyses, along with a review of telemonitoring studies[12] were consistent in their conclusions that the effect of health IT on clinical outcomes is limited.

These systematic reviews illuminate the growing body of evidence on the benefits of patient-centered health IT in the management of chronic illnesses. However, the studies presented share a common limitation in the scope of the computer applications included. Where an interactive property of the system exists, in most cases the primary focus is the patient's interaction with the tool. Telemonitoring systems are particularly narrow in scope, supporting the reporting of patient information to the provider, but not vice versa.[12] The limitations of the systems covered is revealed in the Cochrane systematic review,[11] in which the authors pointed out the need for better understanding of the effect of interactive health communication applications on the patient-provider relationship. A related issue is the need to examine the extent to which a patient is engaged in the overall care management process.[10] Hence, the intent of this systematic review is to present a different perspective on health IT for self-management, where collaboration between providers and patients is a key attribute that is scrutinized in the analysis. Improving an individual's self-management performance requires recognition of the need for collaboration between the patient and provider. Self-management support is a partnership between the provider and the patient, enabling resolution of patient-defined problems, participatory decision making, and self-education that is focused on the development of problem-solving skills and self-efficacy.[5] Therefore, the scope of health IT for this literature search deliberately includes applications used by the provider, the patient, or both to advance these key factors of self-management performance. As a result, this systematic review contains minimal overlap with the previously cited literature reviews.

This systematic review of the literature was conducted to determine the extent to which IT is applied to enable consumer self-management and healthcare provider support of these activities. Results from three lines of enquiry within academic papers reporting studies of self-management systems are presented.

First, a variety of self-management systems are currently in use, distinguished by whether the principal end-user of the application is the healthcare consumer or provider. This orientation determines the types of functions supported and the extent of online interaction between patients and providers. Therefore, the analysis initially explores the relative popularity of each orientation and the attributes of self-management systems.

Second, the review analyzes the significance of self-management tools in a healthcare systems context. This is particularly important because self-management support and IT can be evident but are not necessarily being used together or as part of a broader system of chronic care management. Thus, the second perspective of this review is an exploration of the extent to which research in the use of self-management technologies is being conducted to support the systems-oriented chronic care model (CCM) conceived by Wagner and colleagues.[2,13] The CCM is the foundation of an emerging paradigm for chronic care management within healthcare provider organizations. Research on IT-based self-management to advance the CCM is of particular importance because self-management and IT are essential elements of this model and the CCM exemplifies the conjoint characteristic of the patient and provider in self-management.

Table I. Keywords and combinations used for the self-management and self-care literature searches

Keyword	Combinations															
Chronic care domain																
Self-management	✓	✓	✓	✓	✓	✓	✓	✓								
Self-care									✓	✓	✓	✓	✓	✓	✓	✓
Disease management	✓		✓		✓		✓		✓		✓		✓		✓	
Chronic care		✓		✓		✓		✓		✓		✓		✓		✓
Information technology domain																
Web	✓	✓							✓	✓						
Information systems			✓	✓							✓	✓				
Informatics					✓	✓							✓	✓		
Personal health record							✓	✓							✓	✓

The third area of enquiry focuses on the measurement of the performance of self-management systems described in the selected studies in terms of improving self-management capabilities and health outcomes. Associations between the target end user of the tool (i.e. tool orientation), level of online interaction, and changes in self-management performance are explored.

Finally, the findings from these lines of enquiry provide the basis for discussion of the implications and future directions for research in self-management systems for chronic care management.

1. Search and Analysis Methods

1.1 Search Procedure

A systematic search of English-language peer-reviewed articles was conducted to locate papers in which a major topic was the use of IT to support self-management activities of individuals with chronic diseases. Seven electronic databases (MEDLINE, CINAHL Plus, EBSCO Electronic Database Description, Academic Search Premier, Business Source Premier, Health Source: Nursing/Academic Edition, and Computers and Applied Sciences Online) were searched for articles published between 1 April 1997 and 31 March 2007. Search algorithms were constructed using the keywords from the chronic care domain combined with keywords from the IT domain (tables I and II). Three separate searches were conducted, with 'self-care,' 'self-management,' and 'self-education' each serving as the primary keyword for a particular search. Thus, an inherent restriction of this literature search is that any article selected for consideration must have at least one of these three terms in the title, abstract, or text; show the keywords used as parameter values; and include the various combinations employed for the searches. A multi-step evaluation process was employed (figure 1).

First, abstracts of all articles matching the search terms and returned by the electronic database search engine were reviewed for possible inclusion. For the small number of results where an abstract was unavailable, the entire article was reviewed for possible selection. Articles were subsequently selected for a complete review and assessment if the abstract indicated a full-length paper describing an original study or theoretical model of IT applications in disease management or self-management, as well as logical extensions of these categories (e.g. chronic care management, self-care). Editorials, letters, reviews, symposium proceedings, and papers where peer review was not indicated in either the search results or the article itself were excluded.

Table II. Keywords and combinations used for the self-education literature searches

Keyword	Combinations							
Chronic care domain								
Self-education	✓	✓	✓	✓	✓	✓	✓	✓
Disease management	✓		✓		✓		✓	
Chronic care		✓		✓		✓		✓
Information technology domain								
Web	✓	✓						
Information systems			✓	✓				
Informatics					✓	✓		
Personal health record							✓	✓

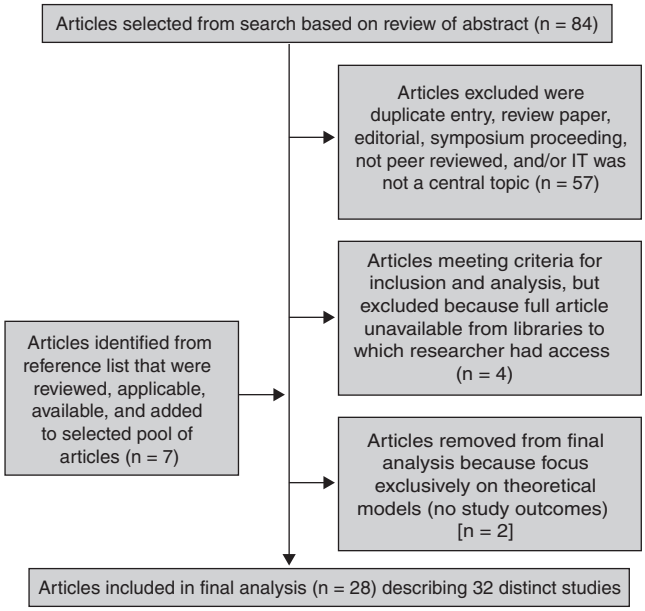

Fig. 1. Process for evaluating articles published between 1 April 1997 and 31 March 2007. **IT** = information technology.

Execution of the three search iterations – after filtering for the exclusions previously noted – yielded 84 articles. The subsequent abstract or article evaluation reduced the pool to 27 articles for a complete review. Four of the chosen papers were excluded because the complete article could not be procured. A review of the reference lists of the remaining 23 articles yielded an additional seven papers. Two articles were not included in the final analysis because they described theoretical models without discussing study outcomes. A total of 28 articles representing 32 distinct studies comprised the final repository used for the analysis.

1.2 Analysis Process

A qualitative and structured approach to compiling, analyzing, and synthesizing the results of the review was taken. Using an open coding process[14] to populate a codebook containing all selected articles, categories were defined to identify the study and organize salient data according to the four perspectives of the systematic review described earlier (see the supplementary material ['ArticlePlus'] at http://diseasemanagement.adisonline.com). These categories of the codebook are represented by the last four columns in the synopsis of selected articles. Because of the relatively small number of studies meeting the search criteria, the reporting of results from the systematic review does not attempt to rank-order the studies by any criterion. Rather, the review strives to ensure all studies from the selected articles with findings that are notable and relevant to one or more of the perspectives of the review are described.

2. The Role of Self-Management in the Chronic Care Model (CCM)

The CCM is a system specification for the practice of chronic disease management. Healthcare organizations, embedded in the larger community system, provide the core care delivery and information systems infrastructure to support multi-disciplinary care teams collaborating with chronically ill patients.[2] The foundation of the CCM is the symbiotic relationships between patients who are actively engaged in the management of their health, and the care team members. A care team leverages knowledge of the patient's health and evidence-based practices in delivering proactive interventions. Patients respond by enhancing understanding of their disease, actively participating in care planning, and engaging in activities toward the goal of improved health outcomes. The six major components of the CCM, described and visually depicted extensively in the literature characterize a system in which information is flowing across organizational boundaries to promote the accumulation of knowledge by care teams and patients as they work together to improve health outcomes.[2,3,5,13]

The relationships between the different CCM components involved in fostering an informed and activated patient reveal the significance of IT to self-management. Self-management support, in particular, transverses community resources as well as the health system, suggesting that individuals draw from multiple sources throughout the community to self-manage their health.[2] By interacting with these resources, patients become more informed and empowered. They actively participate in setting goals to manage their disease, develop a plan of action, engage in a myriad of self-care activities, and solve problems that arise during everyday life. In order to facilitate this interaction and develop self-management capabilities, patients and their multi-disciplinary care teams access a shared repository of comprehensive health information.[9] Wagner et al.[3] acknowledge the importance of sharing information with patients and the lack of attention this issue receives in the CCM with their admission, "… [patients] may be unaware of the guidelines that describe best care, and we should work to change that, and they may be totally unaware of how we keep information to provide that care." Furthermore, patients and their providers need to continuously monitor the patient's level of knowledge, problem-solving skills, and self-confidence in order to identify areas for improvement.[15] Thus, to achieve the informed and activated patient depicted in the CCM, the clinical information systems must be extended to individuals who are self-managing their health.

The major attributes of the CCM self-management component were used to classify and analyze the various types of self-management systems described in the literature: (i) problem identification; (ii) goal setting; (iii) care planning; (iv) problem solving; (v) self-monitoring; and (vi) self-education.[2,3] Self-management systems may support more than one of these functions,

Table III. Summary of study characteristics[a]

Characteristics	n (%)
Articles	28
Studies	32 (100)
Type of study	
case study	9 (28)
randomized controlled trial	6 (19)
survey	6 (19)
quasi-experimental	4 (13)
pre-experimental (pilots)	2 (6)
other qualitative	2 (6)
mixed methods	2 (6)
phenomenological	1 (3)
Target disease	
diabetes mellitus	17 (53)
general chronic disease population	5 (16)
heart failure	4 (13)
asthma	3 (9)
cancer	2 (6)
kidney failure	1 (3)
multiple sclerosis	1 (3)

a Percentage total of studies targeting particular diseases is greater than 100% because two studies targeted multiple, specific diseases.

resulting in many of the systems reviewed appearing in more than one classification. An overarching principle of self-management support – implicit in the productive interactions between the individual and care team at the foundation of the CCM – is the collaborative process. Enveloping all attributes of self-management is the active participation of the patient, his or her family members, and the care team, especially the primary care physician.[3,16] Providers acknowledge the patient's experience with the disease and perception of the problems being confronted.[5] Consequentially, the self-management functions identified earlier are responsibilities shared by the patient and care team members. Patients also have access to patient-centered activities (e.g. support groups) that extend beyond the care team.[17]

The ongoing development of self-management skills and capabilities is critical to the individual's ability to set goals and manage problems. Self-management education programs enhance understanding of the disease, problem-solving skills, and confidence.[16] Mastery of these three areas is also a predictor of self-management performance, a finding that inspired the creation of the patient activation measure (PAM) for assessing an individual's level of knowledge, skills, and self-efficacy.[15,18] Although not a direct extension of the CCM, the PAM reflects the self-management education attributes of the CCM and is therefore an appropriate measure of the model's informed and activated patient. Furthermore, the PAM is useful for evaluating the effectiveness of self-management interventions.[15,19] For these reasons, the PAM served as an important point of reference in the analysis of studies that investigated the variables knowledge, problem-solving skills, or self-efficacy.

3. Characteristics of Studies of Self-Management Systems

An overview of the types and designs of self-management systems studies reported in the articles reviewed provides insight into the current state of self-management systems in chronic care management. The literature reveals a body of research that is relatively immature in terms of breadth of diseases covered, depth of evidence, and rigor of study designs. Table III presents a summary of the selected studies by research design and target disease. Case studies were the most popular study design, and randomized controlled studies the second. An increase in the number of scientific pre-/post-test projects reported in the literature is expected, as several pilot and quasi-experimental studies reviewed were described as preludes to more rigorous randomized controlled trials.

Diabetes is the chronic disease generating the most interest in research of the use of self-management systems, with 53% (17) of the studies targeting this disease. After diabetes, a significant drop-off in the frequency of studies targeting a particular disease is apparent. Heart failure and asthma were the focus of four and three studies, respectively. The other chronic diseases represented in the articles involved two or less studies per disease. Five studies explored the use of IT-based self-management tools by the general chronic disease population. The results from all studies were analyzed to (i) determine if the study objectives included application of the CCM; (ii) assess the capabilities and type of online interaction supported by the IT implementation; and (iii) define/assess/study the performance measures used and outcomes reported.

4. Major Attributes of Self-Management Systems

Numerous approaches and application architectures were used to support self-management activities. Providers were the principal end-users targeted by particular applications in seven studies,[20-26] especially where self-management support functions were an extension of EMR systems or disease registries. Self-management education and self-monitoring applications are typically designed with the patient targeted as the end-user. The various types of self-management applications and levels of online interaction identified in the systematic review are summarized in tables IV and V, respectively. Studies of the use of IT for self-management education comprise the bulk of the research being conducted, with patient self-monitoring also receiving a significant amount of attention. Surprisingly, collaboration of patients

Table IV. Types of self-management applications

Description	Studies (n)
Self-management education	
Internet access to health information	8
Online forums and discussion boards	7
Secure online communications	5
Interactive learning modules	3
Patient monitoring, electronic diaries, and health risk assessments	11
Patient registry with reminders to providers and/or patients	6
Provider-based electronic medical records	
Provider alerts	5
Collaborative care planning with care teams and patients	2

and their personal providers in a web-based environment where health information is shared appears in just six studies.[20,27-31] Decision support and clinical information systems are provided by the healthcare organization to support the activities of the care provider team.[20-24,27,28] However, a relatively small subset of the research in these articles included the granting of access of the clinical information system to the patient for collaboration with clinicians in care management planning and activities. Self-management support that is part of a provider-oriented clinical information system – an attribute of the CCM often included in studies of CCM adoption by physician organizations[32-34] – are found in a very small proportion of the articles in this review. In contrast to the aforementioned studies on CCM adoption – where a provider orientation of IT applications dominates – this systematic review reveals that the use of IT for self-management is undertaken with the principal goals of informing and activating patients themselves.

In line with the lack of collaborative self-management tools, research of online interaction between clinicians and patients for self-management support appears in less than one-third of the articles; the majority of the system implementations feature no online interaction between patients and clinicians (64% of articles). Communication between patients and their peers was a component of the intervention in five articles.[29,30,35-37] These results suggest that the use of IT to engage patients by integrating them into the care management process is not a significant area of interest. Instead, the focus is on leveraging IT mainly to develop a more informed healthcare consumer.

5. Application of the CCM

The CCM serves as the basis for 19% of the studies reviewed. IT deployed at Intermountain Healthcare supports all major elements of the CCM. Care team performance is measured in accordance with a set of measures based on the CCM. The integration of care managers and IT into the primary care workflow is viewed as critical to the successful implementation of CCM at this organization.[20] The Veterans Health Administration adopted the self-management support, care guidelines, and integrated clinical design of the CCM to demonstrate the value of a robust IT infrastructure in the chronic care management of the organization's multiple sclerosis population.[27] A small primary care practice implemented automated disease registries and quality measures in support of the CCM.[25] Community health outreach initiatives are using the CCM in the development of information system applications to support the chronically ill.[21,38] In those cases where the CCM is discussed, it serves as a blueprint for implementation of an integrated approach to chronic care management or, at the very least, a minimum specification for activities. All cases where the CCM is applied suggest that clinical IT provides the critical infrastructure deemed necessary to achieve clinical integration for coordination of care.[8]

Although research indicates a correlation between the use of IT applications and care management processes to support chronic care, most organizations treating chronic disease populations do not have this important infrastructure in place.[32] Adoption of the computerized clinical guidelines needed to drive a robust disease registry and reminders system is low.[2] The lack of clinical guidelines may also explain why studies indicate less than one-third of physician organizations that are implementing components of the CCM are also deploying automated reminders or systems reporting feedback on performance.[32] Another contributing factor to the dearth of clinical IT use in CCM field studies may be the vagueness and lack of specificity regarding the capabilities and design of IT to support the CCM. With few exceptions, notably the cogent description of an integrated disease registry and reminder system by Bodenheimer et al.,[5] a blueprint for clinical IT to support the CCM featuring clarity and depth comparable to the description of the CCM self-management support component[16] is not evident in the literature.

Scant attention is given to patients' use of the CCM clinical information system. The descriptions of computer systems found in articles on CCM theory and application are overwhelmingly provider centric. IT is applied to help providers implementing the CCM monitor key health status measures at the individual and

Table V. Levels of online interactions[a]

Level	Articles (n)
None	18
Between patients	5
Between patients and clinical resources (other than personal physician or assigned care team)	4
Between patients, their personal physicians, or assigned care teams	4

a The total number of articles is more than 28 because three articles supported patient-patient and patient-clinician online interactions.

population levels.[25] Feedback to physicians consists of reports on their compliance with care guidelines and progress on population health status.[3,5] These descriptions of the CCM are silent regarding the use of clinical information systems for patient self-reporting of progress – an important type of feedback to providers. Internet communication between patients and their providers has been included as part of an index for measuring implementation of the CCM, but no description of its attributes or benefits has been provided.[33] A study of large physician organizations implementing processes in support of the CCM revealed that only a small minority exchanged information electronically with patients.[34] In summary, although self-management support and clinical information systems are major components of the CCM (described as a systems approach to care[2]) a clear connection between IT and self-management in the model has yet to be developed.

6. Measuring Self-Management System Performance

Measuring change in individuals' health status through the use of IT is an essential characteristic of significant health improvement initiatives.[8,9] A relentless focus on measurable outcomes by multi-disciplinary teams armed with the information technologies to improve and measure results characterizes the high-performance, consumer-driven healthcare organization.[6] Hence, the value of IT-based self-management tools in healthcare system change efforts is a function of the ability of these technologies to influence health outcomes while measuring any resultant improvements.

Changes in measurable self-management or health status indicators were reported in 50% of the articles, with four studies examining the relationship between the introduction of IT and clinical outcomes.[22,26,28,39] Adherence with prescribed regimens for testing (seven studies[21,22,28,39-42]) and improvement in knowledge level (four studies[40,41,43,44]) were the most common self-management outcome measures examined. Patients with diabetes were the indirect beneficiaries of providers using an EMR to facilitate self-management support; increases in the frequency of blood glucose testing,[20,22,26,28,39] and in two cases, eye and foot exams, were observed.[22,39] The quantitative study with the largest sample of diabetic patients (n = 11 992) demonstrated that individuals using a particular internet-based disease self-management program were more likely to have been tested for blood glucose control than those who did not participate in the program.[40] All the referenced studies relied on convenience samples, raising the possibility that the observed improvements in adherence were not representative of the overall diabetes population.[45] A subset of these studies also measured change in hemoglobin A_{1c} levels among participants; four studies observed reductions,[26,28,39,40] although arguably the most rigorous analysis indicated no significant difference as a result of EMR usage.[22] The lack of a true experimental design among these studies has lead to inconclusive results regarding the effect of IT-based self-management tools on clinical outcomes.

All three major components of the PAM are found in research on the impact of access to disease-specific information using IT. First, the level of knowledge was measured in two studies where patients accessed the internet for health information not specifically provided by their physicians.[44,46] In these cases, participants reported that internet resources on the chronic disease of interest had a major and positive impact on comprehension. The results also revealed that health information obtained from the internet influenced patients' interactions with their providers even when online patient-clinician communications were not part of the experience.[43,47] Web-based self-management education (independent of other elements of IT for self-management) fosters development of the informed and activated individual. Studies of patient access to health information via the internet and participation in virtual health communities reveal increases in the participants' knowledge of their disease and perceived social support;[29,43] knowledge and social support are intermediate agents affecting self-management performance.[15,29,48] More specific interventions in the form of web-based education modules[46] and interactive computer games[44] that are designed to achieve particular self-education objectives have also been associated with improvements in participants' knowledge of their disease. Patient activation was demonstrated in a study by Dickerson et al.,[47] in which patients with cancer used the internet to obtain information about their disease independent from the physicians providing direct consultation. These alternate sources helped patients with retention, affirmation, and validation of their provider recommendations. Studies of pediatric patients with asthma or diabetes reported by Lieberman[44] showed statistically significant improvements in their knowledge of their disease and increased levels of self-confidence in their ability to self-manage their condition, i.e. the self-efficacy component of the PAM.[44]

The results from these studies support the notion that use of the internet changes the balance of knowledge, with consumers in many instances being more knowledgeable about their specific health situation than providers.[49] Providing individuals with education on self-care management nurtures the development of 'health activists' who alter the patient-provider relationship by taking responsibility for closely watching their health status.[6] In summary, web-based self-education tools are among the most fundamental interventions for developing individuals who are empowered and engaged in managing their chronic illness.

Two phenomena, observed in multiple studies, diminish the positive impact of web-based self-management education. First, the extent of improvement is associated with frequency of usage.[35,36] In the Atherton study,[35] use of the MyAsthma™[50] self-management tool needed to exceed a certain threshold before significant improvement was observed. This relationship between

usage and change in self-management measures suggests participants' self-motivation is an important factor. Second, relatively high levels of participant attrition were observed,[29,36,37] an indication that the benefits of improvements in self-management are limited to a segment of the chronically ill population who already possess a certain level of self-management capabilities, a shadow system of support, or, more likely, a combination of these factors.

The third component of the PAM, self-management skills, was also represented in three studies measuring specific change in participant abilities from pre- to post-test. The quality-of-life measurement of individuals with asthma by Atherton[35] showed a statistically significant improvement in participants' management of symptoms and ability to respond to environmental triggers. Lieberman et al.[37] observed a reduction in depression levels in patients with cancer and an improvement in their ability to cope with pain. A randomized controlled study demonstrated that being able to obtain emotional support, advice, and information from others was associated with a significantly higher level of perceived social support by participants.[29] This suggests improvements in participants' ability to leverage their social support networks from the use of self-management systems.

Evidence from the small number of self-management systems that supported the sharing of clinical information between patients and their care providers affirms the importance of the care team in an individual's efforts to improve their self-management performance. Care managers engage patients in collaborative care planning and mobilize the appropriate team members to assist patients with all facets of self-management, including motivational coaching.[20,28,51] Where care management teams using self-management applications are in place, significant improvement in patient compliance with recommended interventions occurs.[20,22] With feedback and ongoing support from clinicians monitoring a patient's progress, sustainable improvement in self-management behavior is possible.[51]

IT plays a vital role in the collaboration of care management teams and patients towards improved self-management. Electronic access to a comprehensive profile of patients' health histories and treatments (coupled with recommended interventions derived from care guidelines) enhances the multi-disciplinary team's capacity for supporting individual and population-based chronic care management.[2,17,52] Individuals in need of active chronic care management are efficiently identified by scanning clinical databases for indicators of undiagnosed or untreated disease and engaging individuals in electronic health-risk self-assessments.[26,27,38,40] Reminders of recommended care and self-management activities that are based on care guidelines and information in the EMR are automatically sent to patients.[23,25,28] Use of computer-generated reminders is more cost effective than traditional interventions initiated by clinicians, and therefore increases the scalability of an organization's care management operations.[52] These applications exemplify the leveraging of IT to extend the care management capabilities of the provider organization, thereby helping to overcome the resource limitations often cited as a barrier to developing self-management support programs.[34,53]

To what extent do patients need to be connected to the IT used by the care team for improvements in patient activation measures? The literature review reveals that shared access of clinical information is limited. Although all studies in the review with elements of the CCM report IT-based tools generating feedback to the care provider are a significant component,[20,21,25,27,38] only one system includes patient interaction.[27] Providing patients with a view of their EMR is uncommon because of providers' concerns about privacy and security.[23] However, the IT-based care management processes previously discussed still benefit patients. A higher level of compliance with routine testing is attributed to reminder letters and other forms of guides sent to patients.[23,40] At the conclusion of a visit, clinicians provide patients with a health summary report to take home as a guide for self-management activities.[20] These forms of communication between providers and their patients, while not collaborative or interactive, serve to motivate and stimulate patients to continue with their self-management plans.

A more continuous feedback loop for care management among clinicians and patients occurs with the use of biometric devices, web applications, and interactive voice technologies accessible from an individual's home for the collection and monitoring of health data.[28,30,31,35,36,41,51] These self-management systems capture and track the weight, vital signs, medications taken, and other key measures of a patient's health status. Electronic diaries are used to supplement this data with self-reporting of adherence challenges, non-medical activities, and other information useful to the care manager.[28,51] Feedback on exceptional results, such as abnormal readings or adherence variances, prompts patients to take self-care actions. Chronic care system applications designed primarily to support the information needs of clinicians contribute to a more informed and activated patient.

The patient reminders, summary reports, and self-reporting functions described in the literature enable the provider to reach out to patients and stimulate self-management activities. These computer-generated interventions are manifestations of care guidelines, which are the basis for continuous improvement in health outcomes through enhanced care management,[32] and promote patient adherence to plans.[49] Furthermore, the self-monitoring technologies link patients with their clinicians, a critical integrative element in the quest to coordinate clinical care across the continuum and foster collaborative activities.[8] Patient outreach applications such as reminders and self-monitoring facilitate productive interactions between patients and their care team, increasing the level of individuals' knowledge about their health condition and providing clinicians with information to manage care

proactively. These systems with their various levels of provider-patient communication processes are building blocks of an IT infrastructure that will eventually enable individuals and all members of their health support network to share a common view of care guidelines in the context of a comprehensive personal health record.

7. Summary of Key Findings, Implications, and Future Directions

Findings of the positive influence that patient-centered health IT has on factors affecting self-management performance from this systematic review affirm those of previous literature reviews.[10-12] Patient knowledge of his or her disease and adherence with prescribed regimens are important measures of health status showing improvement when patients are supported by interactive health applications, telemonitoring, and similar types of systems. The integrated framework of this particular systematic review (encompassing self-management tools, implementation of the CCM, and the interaction of patients with their care providers) offers a fresh perspective on the research reported in the literature. Meaningful findings from this review, their implications, and areas of future research are summarized below.

Health IT applications specifically designed for use by the provider – most evident where the CCM is also part of the care management processes – are a significant dimension of self-management. Disease registries, care reminder systems, and similar provider-centric applications to support self-management programs need to be included when evaluating the benefits of health IT on self-management performance. Unfortunately, this review also suggests that efforts to support the CCM with health IT are being conducted separately from tools supporting patient access to health information and self-management tools. This evolution is incongruent with the CCM, which presents interactions between the patient and care team as a foundational process.[2] The significance of an integrated approach to health IT for self-management is reinforced by studies that indicate care management teams – when supported by IT – are an important factor in improving patient adherence.

Another key finding is the importance of frequent and persistent use of the self-management tool. Attrition of participants appears to be a significant challenge in studies involving patients as participants. Omission of these factors from research on the benefit of IT-based self-management tools may result in the level of use of a tool or attrition becoming confounding variables or an undesirable source of bias in a study's results. In addition to measuring participant use and tracking attrition, acquiring knowledge on the factors contributing to participant attrition is an important area of future research.

The lack of integration of IT-based self-management tools and the clinical information systems used by providers discovered in this review are especially a cause for concern. The CCM emphasizes collaboration of informed, activated patients and prepared, proactive practice teams.[3] An emphasis on care management tools for the provider that lack capabilities to enable patient self-reporting and communications with the care team inhibits the productive interaction called for in the CCM. This may be a reason for the lack of any substantive differences in self-management performance in the studies using elements of the CCM compared with the study sample as a whole. Likewise, use of self-education tools independent of the care management processes – particularly care planning activities – fails to facilitate the feedback and reinforcement mechanisms that encourage patient learning. Future research should build on the few studies noted where patients have access to the same clinical information system as their providers. Study of the differential impact of self-management systems using provider-patient communications is needed to increase understanding on the importance of having a shared IT infrastructure in the CCM.

Assessing the value of IT-based self-management tools through the lens of the patient activation measure also has significant implications for the role of IT in developing informed, activated patients. Evidence of IT-based self-management applications as an intervention that is associated with improved levels of knowledge, skills, and self-efficacy – the three variables of the PAM – appears throughout this systematic review. Considering the growing evidence of the PAM as a valid and reliable measure of an informed and activated individual, applying the PAM scale to evaluate the impact of IT-based self-management tools is a logical progression of research in this area. Findings from this line of enquiry will contribute to the knowledge of the impact IT can have on the informed and activated patient in the CCM.

7.1 Study Limitations

This systematic review has three limitations. First, the review, interpretation, and analysis were conducted by a single researcher who has experience in the development of web-based collaborative self-management tools. A detailed description of the analysis and interpretation of the studies is provided in the supplementary material for the purposes of verification and to assess applicability to other situations.[14] Second, randomized controlled studies are under-represented in the review. The results and subsequent analysis reflect studies with wide variations in the quality of scientific design. Third, a widely accepted definition of what constitutes an IT-based self-management system does not exist in the literature. The breadth of applications covered in this review may be viewed as too broad – encompassing basic access of health information via the internet to sophisticated EMR systems – resulting in different conclusions than if a narrower scope of applications was reviewed.

8. Conclusions

This systematic review affirms the importance of extending the IT infrastructure of the healthcare system to support the self-management activities of individuals striving to control their chronic disease. High leverage change to the current healthcare system is possible with recognition of the individual as having the primary role in chronic care management. By providing people with chronic disease with the tools and support to self-manage their conditions, individuals become more knowledgeable about their health situation and are more apt to adhere to self-care practices that lead to better outcomes. IT becomes an integrative element of the CCM, enabling patients and their providers to collaborate on ways to optimize self-management performance. In essence, incremental change through the application of IT to extend the capabilities of the provider organization and raise the level of involvement of consumers in managing their health can yield significant improvements in chronic care management. The individual who is enabled by IT for the sharing of health information and self-management is a key link in the clinical integration necessary for effective chronic care management. For these reasons, coupled with the growing evidence of measurable benefits of these tools, IT-based self-management interventions are practical and realistic changes that can lead to major and sustainable enhancements in the healthcare system's ability to manage the chronically ill population.

Furthermore, self-management education – where individuals have access to health information and online discussion forums via the internet – fosters development of the informed patient, which is a prerequisite to active engagement in monitoring and improving one's health. When self-management support is an integral component of the broader IT infrastructure, the value of collaboration among clinicians and their patients is realized in the form of more sustained engagement of individuals. Increased levels of knowledge and self-efficacy, enhanced problem-solving skills, and higher levels of adherence to prescribed regimens are intermediate measures of improved health outcomes holding the most promise for future research and development in the use of IT for self-management. Although the current state of health IT falls short of a comprehensive electronic health record enabling a clinically integrated health system, self-management systems provide a critical piece of the puzzle for an organized system of coordinated chronic care management.

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