Chapter 5. Patient Education and Self-management Support

Vignette with a vision of the future

Ten years ago, Thomas was 52 years old, approximately 70 pounds overweight, had type 2 diabetes, hypertension, and osteoarthritis in his knees and hips. For most of his life he had been very active in competitive sports like hockey and baseball. Up to the age of 40 years he had normal weight for men his height and build, but gradually gained this additional weight. He started to have problems with his knees and experienced several injuries requiring arthroscopic surgery. He continued to play these sports because they were important to him but in a modified manner that didnt require running and quick starts and stops. However, he paid the price for continuing and experienced increased pain and mobility problems.

Five years ago he participated in a community self-management program and learned helpful skills and strategies. His priority concerns were how to lose weight and to eat in a way that didnt leave him hungry all the time. He was impressed by this program and became a leader and subsequently led the program four times. He told his doctor about the self-management program and was surprised that the doctor was already familiar with the key concepts such as action planning and problem solving. His doctor also encouraged him to join an online program where he could take the self-management program again, access his medical record, add certain types of information such as his latest HbA1c levels, communicate with peers, receive online newsletters, and find community resources.

Today Thomas continues to manage and cope with diabetes, but feels he has more control. He used the problem solving process and found ways to get 30 minutes of daily exercise by parking three blocks away from the office and using the stairs instead of the elevator, and eating foods that are healthy but dont leave him hungry. For his home he bought a popular video fitness program and enjoys playing it with his wife and grandchildren, and he also joined an online chat room for older men with diabetes. He has lost nearly 40 pounds, has much more energy and has a really great relationship with his doctor who also is happy with the way Thomas is controlling his disease.

Summary

- Self-management is good medicine
- Health care without a strong self-management component does not meet quality standards.
- The best type of education for patients experiencing chronic health conditions should include: a) disease specific education; b) general managing skills (e.g., problem-solving, finding and using resources, working with health care team); and c) use behavioural strategies that increase patients confidence (i.e., self-efficacy) in their ability to engage in behaviours that are needed to manage their condition on a daily basis.
- Self-management support can take place on a one-to-one basis between the patient and health care professional or in-group settings led by either health providers or lay persons, or by using interactive technology like the internet.
- When patients participate in evidence-based self-management programs and interact with health professionals who use self-management support strategies, they become more knowledgeable and have higher self-efficacy. This influences their behaviour as

well as the behaviour of their health providers; patients attain better disease control leading to improved health outcomes and higher patient satisfaction; and better healthcare utilization takes place as well as improved workplace productivity and lower costs.

- Effective self-management support programs not only involve changes at the clinician-patient level but also require change at multiple levels: office environment, health system, policy, and environmental supports.
- Use of multiple modalities has been shown to lead to improved health behaviour outcomes.
- Modern interactive social networking technologies have a boundless potential of enhancing self-management support.

Why is this topic important?

Over the last decade, a dramatic rise in the prevalence of chronic conditions has emerged, altering the way in which care is delivered and received. Presently, one in every three individuals, across the lifespan, is living with a chronic condition (1). The increasing prevalence of chronic conditions will affect at least one-third of developed nations over the next 50 years (2). Coupled with aging populations and rising health care costs, these chronic conditions will create a financial burden that is expected to overwhelm the finite medical and personal resources of any given country. The reality of this global situation will mean that clinicians will be present for only a fraction of the patients life and these people will be living over a long period of time and mostly outside the formal health care system. Importantly, these people have an integral role in managing because the pace of disease progression and nearly all health outcomes are mediated through their own behavior (3).

A promising approach to improving outcomes and reducing health care costs associated with chronic conditions is self-management, whereby individuals, in collaboration with health care professionals assume greater responsibility for health care decisions. In the past, almost all health care and teaching was provided by health care professionals but there is acknowledgement that many of the clinical functions (e.g., monitoring HbA1c, blood pressure and weight) and teaching activities can be effectively carried out by patients. An inherent philosophical re-orientation is taking place whereby health professionals are seeing their relationship with patients as partners and coaches.

The growing emergence of self management support programs not only involve changes at the clinician-patient level but also require change at multiple levels: office environment, health system, policy and environmental supports (4). The bottom line is that self-management is good medicine and health care without a strong self-management component does not meet quality standards.

What do we know?

Probably one the most important aspects of knowledge that has emerged and been synthesized over the last two decades is a general consensus of how self-management is defined and delivered. To date there is no gold standard, universally accepted definition of **self-management**. Rather, several terms are used, sometimes interchangeably, depending on the context and focus of the discussion. Although generally they are meant to describe a similar phenomenon, the terms imply varying specification regarding attributes, roles and responsibilities of both people with chronic health conditions and health care providers. Adams, Grenier, and Corrigan (5, *p.57*) define self-management as the:

tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, social management, and emotional management.

This definition envisions self-management as behaviors, but includes the notion of confidence and embraces medical management as well as role and emotional management by the individual. Using this definition someone who is engaged in self-management:

- has knowledge of his/her condition and /or its management;
- adopts a care plan agreed and negotiated in partnership with health professionals;
- actively shares in decision-making with health professionals;
- monitors and manages signs and symptoms of his/her condition;
- manages the impact of the condition on physical, emotional, occupational and social functioning;
- adopts lifestyles that address risk factors and promotes health by focusing on prevention and early intervention; and
- has access to, and confidence in the ability to use support services (6).

This definition of self-management provides clarity in that the definition focuses on the person with the chronic condition, and further introduces Adams et al. (5) concept of self-management support, which specifies what health care providers can do to encourage self-management. Self-management support is defined as:

the systematic provision of education and supportive interventions by health care staff to increase patients skills and confidence in managing their health problems, including regular assessment or progress and problems, goal setting, and problem solving support (p.57).

By articulating self-management as behaviors and confidence to deal with medical, role, and emotional management and by using the term self-management support to describe what health care providers can do to facilitate it, Adams et al. (5) have brought greater clarity to the picture.

Another factor supporting the decision to use this definition of self-management is that it is congruent with the concept of self-management support incorporated into the Chronic Care Model (7) (Chapter 4).

The model involves two overlapping realms, the community and the health care system, with self-management support as one of the four essential components within the health care system (3). Self-Management / Develop Personal Skills refers to the support of self-management in coping with a disease, but also to the development of personal skills for health and wellness (8).

Ultimately, the model posits that when Informed Activated Patients interact with a Prepared, Proactive, Practice Team the result is improved Functional and Clinical Outcomes. To encourage these outcomes, health authorities provide inputs to strengthen and maximize the efficiency of each component including Self-Management Support.

Difference between patient education and self-management education

Traditionally, disease patient education usually has involved the provision of disease-specific information, teaching specific disease-related skills (e.g., how to monitor

glucose levels and how to use asthma medication), and contingency planning (i.e., what to do if a situation occurs). Self-management focuses more on teaching generalized skills persons can use to manage their condition and include learning how to solve problems, using community resources effectively, working with ones health care team and how to initiate new behaviors. The major differences between patient education and self-management education have been delineated by Bodenheimer, Lorig, Holman, and Grumbach (3):

- Traditional patient education provides information and teaches technical disease-related skills whereas self-management education teaches skills on how to act on problems.
- Problems covered in traditional patient education reflect widespread common problems related to a specific disease, whereas the problems covered in self-management education are identified by the patient.
- Traditional patient education is disease-specific and offers information and technical skills related to the disease. In comparison, self-management education provides problem-solving skills that are relevant to the consequences of chronic conditions in general.
- Traditional patient education is based on the underlying theory that disease-specific knowledge creates behavior change, which in turn produces better outcomes. Self-management education, in contrast, is based on the theory that greater patient confidence in his/her capacity to make life-improving changes yields better clinical outcomes.
- The goal of traditional patient education is compliance whereas the goal in self-management education is increased self-efficacy and improved clinical outcomes.
- In traditional patient education the health professional is the educator, but in self-management education educators may be health professionals, peer leaders or other patients.

Both types of education are essential in assisting patients achieve the best quality of life and independence. However while necessary, disease specific patient education is generally not sufficient for people to manage a lifetime of chronic disease care (9- 12). There is strong evidence that using behavioural strategies that teach self-directed goal-setting and action planning, problem-solving, healthy coping, stress management, self-monitoring and skills to link to community resources have been effectively used in patient education programs and improves outcomes (1022). There is also evidence that using more than one of these strategies increases effectiveness (1214, 16,17).

The evidence makes a strong case that the best type of education for patients experiencing chronic health conditions should include: a) disease specific education; b) general managing skills (e.g., problem-solving, finding and using resources, working with health care team); and c) use of strategies that increase patients confidence (i.e., self-efficacy) in their ability to engage in behaviours that are needed to manage their condition on a daily basis.

Delivering self-management support

Self-management support can take place on a one-to-one basis between the patient and health care professional, or in group settings led by either health providers or lay persons. These activities could happen in person or through Web-based interactive technologies.

In recent years, the main task of managing ones chronic health condition has been shifting to the patient, yet a considerable responsibility still remains with health care professionals who can use their expertise to inform, activate and assist patients in the

self-management of their condition.

Self-management interventions are delivered in a variety of settings and according to Barlow et al. (23) the most popular locations in which health professionals deliver programs are clinical settings (e.g., hospitals). Today a greater emphasis is being focused on health care professionals to deliver self-management support and use behavioural techniques during routine clinic visits to enhance patients abilities to be effective self-managers.

Self-management support provided by health care professionals

The 5As

A unifying conceptual framework used on a one-to-one basis or in groups by health care professionals is known as the 5 As construct (24). The 5 As are *Assess*, *Advise*, *Agree*, *Assist* and *Arrange*. Basically, these are a set of behavioral strategies to encourage patients to engage in self-management, including:

- Establishing rapport with patients to ensure that patients have opportunities to express their priority concerns.
- Setting a visit agenda with patients to ensure that both health professionals and the patients concerns are addressed in the visit.
- Getting patients to complete a Health Risk Appraisal at home to provide an opportunity for patients to obtain independent objective information about their health and what they need to do to address these concerns. The information can be discussed with the health professional.
- Assessing patients readiness to enable the health professionals to use appropriate behavioral change strategies.
- Considering the Ask-Tell-Ask strategy, a technique to ensure that patients get the information they are after, or the Closing the Loop technique, to ensure patients understand the information provided by health professionals.
- Getting patients to make Action Plans is the process by which patients specify a particular behavior they will engage in.
- Teaching the Problem-Solving Process which gives patients a systematic approach to solve problems when they arise in their daily lives.
- Ensuring that Follow-up takes place, facilitating the success of action plans.

These activities, which are not necessarily linear with each step following the other sequentially, have been applied to primary care interventions for a variety of behaviours (25-27).

The goal of the 5 As is to develop a personalized, collaborative action plan that includes specific behavioural goals and a specific plan for overcoming barriers and reaching those goals. The 5 As are elements that are interrelated and are not designed to be used in isolation, and superior results will occur if a combination of interventions are used, especially for complex cases (28).

Professional Associations and major hospitals have used the 5As construct as the basis of their evidence-based Best practice Guidelines in providing self-management support

to adults with chronic health conditions (29) and in caring for children experiencing chronic health conditions (30).

Motivational Interviewing

Motivational interviewing (MI) is a patient-centred, directive method of communication used throughout self-management support with the goal of enhancing motivation to change behaviour by exploring and resolving ambivalence (31-32). With widespread dissemination of a complex innovation such as MI it is likely that reinvention may take place reflecting practitioners particular understanding and style, and this reinvention may further add or remove critical elements. Miller and Rollnick (33) provide clarity with respect to what MI is and is not, specifically:

- MI is collaborative and person-centred;
- MI incorporates reflective listening to guide the resolution of ambivalence about change;
- MI is intended to enhance patients motivation for change (change talk) and does not need to be based on the transtheoretical model of change (i.e., Pre-contemplative Stage);
- MI honours the patients autonomy and should never be used to coerce them into doing what you think they should;
- MI is a complex clinical skill that requires practice to increase proficiency, rather than a formula to be followed step by step ;
- MI is a method to elicit solutions from the patient, rather than providing solutions for them in the assumption that they lack something necessary to be successful; and
- MI is not necessary if the patient is ready for change.

A recent meta-analysis by Rubak (34) evaluated the effectiveness of using MI with patients who had various diseases. They found that MI produced significant effects in some areas (body mass index, total blood cholesterol, systolic blood pressure) but not in others (cigarettes smoked per day and A1C levels).

Lewin et al (35) recommended that MI be used to counsel patients/families on health behaviour change. MI can be effective in brief encounters of fewer than 15 minutes, however, the dose of effectiveness is individualized, assuming that increased use improves the likelihood of favourable outcomes (33). As well, some studies have shown greater efficiency when combined with other treatment methods (36). MI outperforms traditional advice-giving for a broad range of behavioural problems and diseases in approximately 80% of studies (34).

Studies show that any appropriately trained health professional (e.g., physician, nurse, psychologist and dietician) can successfully use MI skills with his or her patients (34). Miller and Rollnick (33) recognize that most health care professionals learn about motivational interviewing through self study or in short one- or two-hour workshops, and state that although this clinical method is simple, it is not as easy to master, requiring repeated practice with feedback and encouragement from knowledgeable guides to facilitate both skill and comfort of use.

Despite the promise that the technique holds for promoting behaviour change, there are few controlled studies evaluating its efficacy with health problems (37,38). This point of view is consistent with that of Bodenheimer and Grumbach (39) that the effectiveness of MI in enhancing physical activity and managing chronic illness is still inconclusive.

The Flinders Program (formerly the Flinders Model)

The Flinders Program (40) was developed at Flinders University in Adelaide, South Australia. This model enables the clinician to use measurement over time to track changes. It involves three main phases, namely:

- An assessment phase, which may involve using three tools: the Partners in Health Scale (41); the Cue and Response Interview, and the Problems and Goals Assessment Scale.
- The development of a self-management care plan where information elicited in the assessment is used to collaboratively develop an individualized self-management care plan. The plan includes the identified issues and key problem; the agreed-upon goals, interventions, a sign-off for patient and clinician and review dates.
- Monitoring and review, initiated by the clinician and using the self-management care plan as its basis. The purpose is to help patient maintain motivation, assist the patient with problem-solving and make changes in the plan if circumstances change.

Research has investigated specific elements of the Flinders Program (41,42), and demonstration projects have investigated effectiveness when using the complete version. These pilots, part of the Australian Statewide Chronic Disease Self-Management Initiative, investigated diabetes in rural aboriginal communities (43); mental health (44), and patients in respiratory rehabilitation (45) and found encouraging outcomes, both statistically and clinically.

Self-management support provided by health professionals and patients

The most familiar and common way that evidence-based self-management support is delivered is through specially designed programs that emerged during the last decade. These include both disease-specific and generalized programs led by health care professionals as well as by lay persons (11,46- 48). A cursory review of recent literature reveals a growth in the development, scope, and evaluation of these programs and includes programs for: adults and children with asthma (49-51), cancer (52), COPD (53), HIV (54), bulimia nervosa (55), chronic kidney disease (56), congestive heart disease (57), dementia (58), low vision (59), macular degeneration (60), mental health (61), and stroke (62). As well, the US National Council on Aging has also recommended several evidenced-based programs which include: *Chronic Disease Self-Management Program* (47), *EnhancedWellness* (63), *EnhancedFitness* (64), *Active Choices* (65), *Active Living Every Day* (66), *Strong for LifeA Matter of Balance* (68), *Healthy IDEAS* (69), *Prevention & Management of Alcohol Problems in Older Adults: A Brief Intervention* (70). These programs have been shown to be effective across a wide range of settings for people with many different types of disease and for people from different cultures and socioeconomic groups(67).

A comprehensive review on the strengths and weaknesses relating to program settings, using professional or lay leaders, using disease specific or generic programs, and group or individual programs, have been published by McGowan and Lorig (71).

These self-management programs provide basic information, teach specific skills, and use strategies to increase patients confidence in their ability to manage their condition (72). Specific skills include: a) *Problem Solving* (learning to identify a problem, generate possible solutions, implement a solution, and evaluate the results); b)

Decision making (learning how to identify warning signals when caring for their symptoms, having suitable guidelines to follow, and making appropriate choices to manage their symptoms properly; c) *Resource utilization* (learning how to find and use resources effectively); d) *Patient - provider relationships* (learning how to build relationships with health care providers); and e) *Taking action* (learning how to carry out a specific behaviour in order to achieve a goal. Patients learn to do this by making short-term, realistic and achievable action plans).

Self-management programs usually employ several strategies to increase the patients self-efficacy to carry out a specific behavior at a future point in time. Bandura (73) defined self-efficacy as: *peoples judgments of their capabilities to organize and execute courses of action required to attain designated types of performances* (p.391). The key contention regarding the role of self-efficacy beliefs is that *"people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true"* (74). The process of developing long and short-term goals, which is known as Guided Mastery, serves as the major means for developing and expanding behavioral competencies (73), and is an effective technique for raising individuals self-efficacy. Other self-efficacy enhancing strategies used in the group programs include: modeling (i.e., persons with chronic health conditions leading the program); reinterpreting physiological signs and symptoms, and persuasion.

A comprehensive framework that is helpful in planning and evaluating the impact of self-management programs and considers several stages of knowledge development and dissemination is the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) framework (4,75). The five dimensions of RE-AIM build on conceptual work by Rogers (76) and Green and Kreuter (77) and focus on the following:

- Reach (proportion and representativeness of the target population willing to participate);
- Effectiveness (impact of the program in terms of outcomes and quality of life);
- Adoption (proportion and representativeness of organizations and staff agreeing to deliver the program);
- Implementation (degree to which interventions are delivered consistently as planned across staff, patients, program components, and time); and
- Maintenance (extent to which behavior change is maintained over the longer term and, at the setting level, the extent to which the program is maintained by the organization).

Traditional evaluations have mainly focused on only one or two dimensions from knowledge development to dissemination. Examining all five dimensions yields a more thorough evaluation, thus giving decision makers more information on which to base their decision to adopt or discontinue a program. The Stanford Patient Education Research Center has satisfactorily addressed the RE-AIM factors in that these programs have been around since the mid 1980s and are currently being delivered in approximately 20 countries. These self-management programs have undergone randomized controlled trials (46 -47, 78), dissemination studies (79), follow-up and cost analysis studies (16), and have demonstrated external validity through successful implementation, producing similar results in different countries and with different populations (80-85). Presently, The US Centers for Disease Control and Prevention are in the process of conducting a meta-analysis of two popular self-management programs developed at the Stanford patient Education Center, namely: The Arthritis Self-Management Program and the Chronic Disease Self-Management Program.

What do we need to know?

A major question that has not been conclusively answered relates to the process of self-management, specifically the process(es) which bring about the beneficial outcomes. The recent evaluation of self-management support programs conducted by RAND (86) suggests a chain of self-management support effect, specifying that: 1) as patients participate in evidence-based self-management programs and interact with health professionals who use self-management support strategies, they become more knowledgeable and have higher self-efficacy; 2) this influences their behaviour as well of the behaviour of their health providers; 3) patients attain better disease control leading to improved health outcomes and higher satisfaction levels; and 4) better healthcare utilization takes place as well as improved workplace productivity and lower costs. Specific aspects within this chain of effect that need further investigation relate to why and how disease control and health outcomes become improved through self-management. The current understanding of how this process unfolds is that when patients learn new knowledge and skills and gain higher self-efficacy in their ability to carry out behaviours to achieve goals, their health status and outcomes improve. The major question warranting further research is what are the core components that are necessary to bring about this improvement? Most self-management research studies showing positive results have utilized multiple strategies, making it difficult to delineate exactly which strategy has been the most effective in contributing to the change in behaviour or in bringing about the improvement in health status (22,39, 87-89).

Another area that needs to be addressed is on the development of realistic strategies and incentives for recruiting, training and retaining peer leaders for the community programs. Sponsoring organizations generally use a variety of recruitment strategies to interest people to become peer leaders. The majority of prospective leaders then successfully complete the necessary training workshops and approximately 60% lead programs. Within this 60% of leaders approximately 10% remain involved and become program champions. While successful in some aspects, there is a need to develop strategies to retain this valuable cadre of trained and skilled volunteers.

The research design commonly used in evaluating self-management interventions has involved longitudinal randomized controlled or a matched- group pre- and post program designs from base-line to four-six months. There has been little research providing information on the sustained effectiveness of these programs for longer periods of time, for example five to ten years. Having this valuable information would assist in determining the need for and types and scope of refresher and reinforcement programs.

The dissemination strategies used with self-management programs has been successful in reaching remote and rural communities and specific populations. However, these strategies may have problems with quality control and program fidelity. As with any program, trained peer leaders and health professionals may personalize and modify specific elements within the program, and observing and monitoring program delivery is difficult. Although quality control mechanisms can be implemented (e.g., program delivered by two leaders, four-day training workshops, and regular contact and support from program coordinators), there may be variation in the delivery. This is a serious concern because participants may not receive the benefits that occur when the intervention is delivered as it was planned.

From an organizational perspective there are ongoing challenges of how to make self-management programs accessible and attractive to the target populations. Successful dissemination strategies can make the programs accessible but people may be reluctant to participate. Multiple venues (small group, telephone, mail, and internet) do exist for these programs but information is needed to determine best combinations and

concentrations given limited resources. Scenarios that may entice members of the target population to participate may include enhancing the choice of available programs (e.g., communities having a menu of self-management programs from which to choose such as: an Online Program, Chronic Disease, Chronic Pain, and Matter of Balance...etc.). Another potential strategy may be to have health professionals recommend and encourage patients to participate. Research has demonstrated that the probability of participating in a community Arthritis Self-Management Program increased 18 times when recommended by a health professional (90). The process of deciding to participate in a program is complex and an examination of marketing strategies used in the business world may shed illumination in this area.

Community self-management programs and the provision of self-management support strategies by health professions need to be combined into the overall health system. The term integration is commonly used to indicate how this combination should take place. However, this term is not easily defined and means something different to those who use it. To some, integration means that health professionals should coordinate the process while to others it may mean a sharing of effort and information to ensure patients receive consistent information and acknowledgement that they have an integral role in managing their health. Focused research on best ways to integrate self-management support activities into overall care would help boost overall effectiveness and ensure that self-management is not considered a disparate and complementary service.

A concern related to the provision of self-management support by health professions deals with ensuring a sustainable remuneration and payment formula for health professionals who use practice time to provide these activities. Consistent and burgeoning research findings are indicating that disease control and health outcomes are improved with self-management support strategies, but a system that negatively impacts ones practice and livelihood will not be welcome or supported. Therefore the development of various administrative and organizational incentives for health professionals to engage in self-management support needs to be developed.

What innovative strategies could fill the gaps?

In addition to the increase of self-management support development and implementation activities, several innovative initiatives are taking place with promising potential. For example, Group Health Cooperative, an American consumer-governed nonprofit health care system that coordinates care and coverage, is implementing new technology to facilitate remote participation in self-management. Online social networking technology is being integrated into MyGroupHealth, a program with health tools and services allowing patients to refill prescriptions, view online medical records, email the health team and schedule appointments. This new technology will enable members to participate in an online self-management program. This integration also enables online program recruitment, a training plan for moderators, evaluation tools and processes, and linkages with other self-management and patient activation resources at Group Health. Another macro-level innovation taking place in the US is that the US Administration on Aging is using a decentralized strategy whereby discretionary grants are provided to support collaborations between aging and public health networks to implement evidence-based self-management programs.

In the United Kingdom, the Chronic Disease Self-Management Program (known as the Expert Patients Programme) is being delivered by the Expert Patients Programme Community Interest Company (EPP CIC), a not-for-profit social enterprise set up to meet a public need and to reinvest profits for the public good. The EPP CIC was established in 2007 to expand the work already undertaken across England in the area

of self-care and self-management. The purpose is to establish the principle of individual self-management and self-care as a recognized public health measure, deliverable in a cost effective and sustained way, increasing the number of courses from 12,000 a year to over 100,000 by 2012.

Another example of an innovative social networking project is being implemented by the Association of Cancer Online Resources, Inc. (ACOR). This association, a non-profit organization, is offering access to 159 mailing lists to provide support, information and community to everyone affected by cancer and related disorders. The aims of ACOR include: providing information and support to cancer patients and those who care for them through the creation and maintenance of cancer-related Internet mailing lists and Web-based resources. This provides subscribers with access to varied and credible information sources through Internet resource development, partnerships with trusted content providers, and improved communication between patients and health care professionals through advocacy in a variety of public forums, including the media and professional journals. Uncontrolled studies have found that participants report enhancement of self-esteem and improvement in comfort level in dealing with health professionals (91), feel assisted in finding information, obtaining support, formulating questions to ask health care providers, and become more active partners in their care decisions (92).

In the past most self-management support activity has focused on individuals experiencing chronic health conditions, there is a growing notion that there may be a possibility of applying such programs to the prevention of chronic illnesses, in that more than 50 such conditions include risk factors of poor diet, sedentary lifestyle and smoking.

Today we are experiencing tremendous growth in the conceptualization of collaborative working paradigms that have been fueled by the Internet and Web 2.0, along with social networking support tools. This has unbridled potential in developing global interventions to promote successful sharing of experiences and the validation of alternative language versions of successfully validated protocols and tools across countries. Of particular interest, given its major role in social support, is the emergence of "many-to-many" communication tools such as Twitter (http://twitter.com) and Google Wave (http://ww.wave.google.com), which could transform self-management, particularly through the use of mobile telecommunication devices. We are now entering a fascinating era, which we could call Self-Management 2.0, defined as "self-management based on social support through new technologies" (http://ww.globalalliancesms.org). Those responsible for health policy, patients' associations and caregivers have an opportunity to foster the coordination of experts and international project management and to make successful self-management support and education a global reality.

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Comments to the whole document

- 26 Mar 2010 12:35 **Esther Gil-Zorzo** commented, on

En mi opinión no se deberían contraponer el Self_management (muy anglosajón) y la educación (mas dela escuela centroeuropea). Ambas son complementarias e incluso forman parte una de la otra.

El tratamiento que se hace de la educación como algo antiguo y escaso no corresponde con la realidad ni las corrientes europeas.

Seria mas correcto describir cada una de ellas y que el lector decida cuando y como aplicarlas

Echo de menos ejemplos prácticos de programas y resultados de los mismos. Esto no solo ayudaría al lector a una mejor comprensión, sino que además podría favorecer la implementación de los mismos

Habría que ampliar más las características, ventajas… de las intervenciones grupales. Añadiendo además la evidencia existente sobre las mismas

Serviría de mucho ilustrar todo esto aplicándolo al caso que se describe al principio

Yo añadiría algunas lecturas recomendadas y añadiría unas conclusiones

Comments by section

Summary

- 30 Mar 2010 18:50 **Antonia Herraiz** ✉commented, on

Desde mi punto de vista en la aplicación del modelo de self-management deberíamos tener en cuenta los siguientes aspectos:

Las características socioeconómicas de la población diana y las políticas publicas de información y de salud que se aplican en los diferentes países, ambos factores van a incidir de forma indirecta en la toma de decisiones del paciente y en su salud.

Con relación a la evaluación de intervenciones educativas en pacientes crónicos, se ha visto que algunos pacientes no son capaces de completar las actividades educativas iniciadas [1], éstos se corresponden con un determinado perfil de pacientes con sobrepeso o con déficit en sus hábitos saludables(tabaco,etc). Deberíamos analizar las necesidades de estos grupos de pacientes para ser capaces de adaptar el modelo de self-management o en su caso conocer los limites de su aplicabilidad.

La familia y amigos del paciente, son elementos que deberemos tener en cuenta en la utilización del modelo de self-management, algunos trabajos muestran su impacto en la adhesión en el seguimiento de programas de pacientes crónicos [2].

Otros elementos a tener en cuenta son, las políticas públicas de información, la publicidad trata de inducir el consumo de los pacientes y en ocasiones puede producir conflictos en la toma de decisiones de estos, los profesionales deberemos manejar una comunicación adecuada y

satisfactoria para los pacientes. Un meta-análisis estudia diferentes modelos de comunicación y los resultados alcanzados por los pacientes [3].

Otros factores a analizar son, la aplicación en algunos países europeos de políticas públicas de salud, como son la reducción de sal o grasas trans y/o saturadas en los alimentos, así como la promoción de menús saludables en los restaurantes.[4]. La diferente aplicación de la ley en la limitación del consumo de tabaco, es otro dato a tener en cuenta.

Por último, el impacto de la HES (historia electrónica de salud) y la posibilidad de compartir ésta con el paciente sin duda va a influir en el desarrollo del modelo del self-management.[5]

1 Toft U,Kristoffersen L,Aadahl M,et al.Diet and exercise intervention in a general population-mediators of participation and adherente:the Inter99 study.European Journal of Public Health.2006;17:455-463.

2 Effectiveness of diabetes self-management education intervention Elements: A meta-analysis. Canadian Journal of Diabetes.2009;33:18-26.

3 Roter DL, Hall JA.Physician Communications and patient adherente to treatement: a meta-analysis. Medical Care. 2009;47:826-834.

4 Agencia española se seguridad alimentaria. http://www.aesan.msps.es/AESAN/web/notas_prensa/pan_menos_sal.shtml

5 Basch E.The Missing Voice of Patients in Drug-Safety reporting.N Engl J Med.2010;362:865-869.

- 26 Mar 2010 12:31 **Esther Gil-Zorzo** ✉commented, on

Sugiero cambiar "good medicine" por buen tratamiento, pues no es una medicina sino un arma terapéutica

No contraponer educación individual y grupal; cambiar "or" por or/and

- Modificar en todos los sitios que aparece
- Añadir la importancia del trabajo en equipo
- Añadir que el programa debe ir dirigido también a familiares y amigos
- Añadir el acompañamiento terapéutico/pedagógico

- 16 Mar 2010 05:44 **Manuel Serrano Gil** commented, on

- "*The best type of education for patients experiencing chronic health conditions should include: a) disease specific education; b) general managing skills (e.g., problem-solving, finding and using resources, working with health care team); and c) use behavioural strategies that increase patients' confidence (i.e., self-efficacy[1]) in their ability to engage in behaviours that are needed to manage their condition on a daily basis.*
- *Self-management support can take place on a one-to-one basis between the patient and health care professional or in-group settings led by either health providers or lay*

persons, or by using interactive technology like the internet[2]*. (...)*

- *When patients participate in evidence-based self-management programs and interact with health professionals who use self-management support strategies, they become more knowledgeable and have higher self-efficacy.*(mentioned already two paragraphs earlier[1]) *(...)*
- *Modern interactive social networking technologies* (mentioned already in previous paragraph) [2] *have a boundless potential of enhancing self-management support."*

I would mention something about the role of the expert patient as health provider, social and family support and the challenge to engage the Community (as in GASMS Summary)

- 11 Mar 2010 19:52 Maria Carmen Griñán Martínez commented, on

In Europe there are many countries that are trying to treat chronic diseases, we can say that health systems are moving away from the traditional model of patient care multimorbidity, giving importance to the role of patient and proposes a comprehensive approach to respond to more effective care from different health systems. This is one of the great challenges of the European systems from which it is proposing a new model of patient care through the management and management of their disease.

On how to deal with the adoption of this model begins to offer: quality primary care, the existence of well-coordinated multidisciplinary teams together (secondary care); of implementing guidelines and evidence-based practices, as well as making plans of patient care where the patient has a proactive role to her illness.

Management plans and training of patients should be coordinated by primary care physicians and nurses treating the patient. These plans are a useful resource for acquiring knowledge and health habits that promote increased autonomy and management of chronic diseases. These action plans set out the strategies and implications of the patient in their own healthcare. Developing an action plan should be coordinated way and should express the prescription personalized way.

An action plan should include: treatment and maintenance, identification of symptoms and guidelines to follow to solve common problems, treatment in case of crisis assessment and evaluation of one's environment action plan.

Numerous studies and publications reflect the benefits for the patient to practice and resource use management plans for their own health, among which I note the related published research that documented that cardiac rehabilitation / secondary prevention improves patient outcomes in coronary heart disease mortality and morbidity in a proportion similar to that obtained with aspirin, β blockers and cholesterol-lowering drugs (statins therapy) (Thomas, 2007) [1].

Other researchers have evaluated such as relapse prevention in coronary heart disease when they have followed management plans, they conclude: "The secondary prevention programs affect the processes of care (risk factor profiles and use of proven therapies) and functional status or quality of life of patients and reduces heart attacks by 17% at follow-up of 12 months. The mortality benefits associated with participation in secondary prevention programs (15% overall and 47% in two years follow-up) is clearly apparent with longer follow-up. (Clark, Hartling, Vandermeer, Findlater and McAlister, 2005) [2].

We can also mention another study that reviews the publications on the outcomes of education provided at health centers to patients who have been admitted with cardiovascular disease, where these authors indicate the best time to start a health education (Auer, Gaume, Rodondi , Cornuz and Ghali, 2008) [3].

[1] Thomas, R. J. (2007). Cardiac rehabilitation/secondary prevention programs: a raft for the rapids: Why have we missed the boat? Cirulation, 116, 1644-1646.

[2] Clark, A. M., Hartling, L., Vandermeeer, B., & McAliser, F. A. (2005). Meta-analysis: Secondary prevenction programs for patients with coronary artery disease. Annals of Internal Medicine, 143, 659-672.

[3] Auer, R., Gaume, J., Rodondi, N., & Cornuz, J. G. W. (2008). Efficacy of in-hospital multidimensional interventions of secundary prevention after acute coronary syndrome: A study review and meta-anlysis. Circulation, 117, 3109-3117.

Why is this topic important?

- 16 Mar 2010 05:52 **Manuel Serrano Gil** commented, on

Perhaps here, to introduce the figure 1 (Schaeffer ref) or 2 (Brownson ref) at GASMS chapter (related to reference 4) for the Chronic Care Model based in Self Management, as proposed by the Mc Coll Institute:

1. Schaefer J, Miller D, Goldstein M, Simmons L. Partnering in Self-Management Support: A Toolkit for Clinicians. Cambridge, MA: Institute for Healthcare Improvement. 2009

2. Brownson CA, Miller D, Crespo R, et al. A quality improvement tool to assess selfmanagement support in primary care. Jt Comm J Qual Patient Saf. 2007 Jul;33(7):408-416

- 15 Mar 2010 14:24 Jackie Bender commented, on

I would recommend adding to paragraph that describes the characteristics of effective self-management programs the following additional key factor:

and d) social environmental factors (such as peer role models and support networks) that help in the initiation and maintenance of the desired behavioural changes.

- 11 Mar 2010 20:09 Maria Carmen Griñán Martínez commented, on

Kru Research published in 2009 an article entitled **"Patients Rising: How to reach empowered, digital health consumers"** [1] which lays down the end of the paternalism of traditional medicine, a system in which the doctor knew the whole family and enjoyed full confidence. Kru Research reveals that: 50% of patients not taking medication as prescribed; doctors only raise the side effects of certain treatments for 35% of the time, so that one third of patients undergoing surgery may mind only a risk factor involved in the intervention, in addition, half of primary care physicians are

expected to reduce or cease their practice in the next 3 years.

With the advent of the Internet emerges and accelerates the concept of participatory medicine, with patients who seek information on the network, sharing data and opinions and want to participate actively in the selection of treatment.

[1] Kru Research (2009). Patients Rising: How to Reach Empowered, Digital Health Consumers. Kru Research [15 December 2009].

Available at: http://www.kruresearch.com/library/patients_rising2.pdf

What do we know?

- 15 Mar 2010 15:41 Jackie Bender commented, on

I think we should highlight in this introductory section the importance of self-management programs for the individual as well (we could draw from subsequent sections to do so).

As is, the rationale for self-management in this chapter seems to be largely presented from the perspective of benefits to the health care system (e.g. reduced costs).

11 Mar 2010 20:42 Maria Carmen Griñán Martínez commented, on

Consult study Ewart, Taylor, Reese and DeBuskl (1983)[1] which argued that a sustained health care is possible through a knowledgeable staff management program within the assumptions of the theory of Bandura's social learning: the concept of self-efficacy ".

[1] Ewart, C. K., Taylor, C. B., & Reese, L. B. D. R. F. (1983). Effects of early port-myocardial infarction exercise testing on self-perception and subsequent physical activity. American Journal of Cardiology, 51, 1076-1080.

Difference between patient education and self-mana

- 16 Mar 2010 05:55 **Manuel Serrano Gil** commented, on

Here I would include a table to clarify differences:

Tabla: Diferencias entre los conceptos de educación sanitaria y educación en el autocuidado

	Educación sanitaria	**Educación en autocuidado**

Contenido	Información y habilidades sobre la enfermedad	Habilidades de cómo resolver problemas
Significado	Un problema significa mal control de la enfermedad	El paciente identifica problemas relacionados con la enfermedad y su manejo diario
Relación educación/enfermedad	Educación basada en el tipo de enfermedad	Educación dirigida a los problemas funcionales del enfermo crónico
Teoría subyacente	La información es la que provoca el cambio conductual	Muchos factores influyen en los resultados clínicos
Quién es el educador?	Un profesional sanitario	Profesional sanitario o paciente, frecuentemente en grupos

Taken from: Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA. 2002 Nov 20;288(19):2469-2475.

- 15 Mar 2010 15:38 Jackie Bender commented, on

I think it is important to discuss (probably following the definition of self-management) the theoretical underpinnings of the concept of self-management and related self-management programs.

important theories to highlight are:

- **Theory of self-determination-** intrinsic versus extrinsic motivation and the degree to which an individuals behaviour is self-motivated and self-determined (Deci & Ryan, 2002).

- **Social Cognitive Theory** (Bandura)

Social cognitive theory (SCT) as defned by Bandura provides a useful framework for understanding, predicting and changing human behaviour. It has evolved as a popular

theory to explain both individual and group behaviours and has guided the development of numerous health promotion and self-management programs.

SCT explains human behavior in terms of a triadic, dynamic and reciprocal interaction between the characteristics of a person, the behavior of that person and the environment in which the behavior is performed.

The core constructs include: environmental and situational factors; knowledge and skills required to perform the behavior; the person's self-efficacy or confidence in performing the behavior; outcome expectations, the anticipatory factors that influence behaviors; outcome expectancies, the values that a person places on a particular outcome; self-management and regulation of the behavior; observational learning used to acquire the behavior; behavioral rewards and reinforcements; and emotional coping responses.

A critical component of SCT is **self-efficacy**, defined as the perceived belief or confidence in one's ability to perform a particular activity including confidence in overcoming obstacles to performing that activity. Self-efficacy can affect health behavior directly and exerts an influence on the other determinants of the SCT. It is considered to be one of the most important prerequisites for the initiation and maintenance of changes in health behaviour.

Bandura argues that to be effective a health promotion program must contain four key components. The first component is informational- individuals should be informed of the health risks and benefits of different lifestyle habits. The second component should address the social and self-management skills necessary to translate that knowledge into effective preventative practices. The third component should build a sense of self-efficacy to perform the healthier behaviors in the face of difficulties and setbacks. The final component should create the social supports necessary for the initiation and maintenance of the desired personal changes.

1. Bandura A. Self-efficacy: The exercise of control. USA: W.H. Freeman and Company:1997.
2. Bandura A. Health Promotion by Social Cognitive Means. Health Educ Behav. 2004;31:143-64.

I would be happy to provide more information about the theory behind self-management programs if desired.

- 12 Mar 2010 19:51 Jennifer Jones commented, on

I think it would be good to include something here on Therapeutic Patient Education, which is focused on self-management and encompasses much of what is in this chapter including motivational interviewing. There is more to add on this but here is what I have pieced together (you may consider expanding this-I can help with this if needed):

Over the past 10 years there has been a movement toward "therapeutic pateint education" (TPE) which is defined by the WHO as a set of structured activities which consists in "helping the patient and his family to acquire knowledge and competencies on the disease and its treatment, in order to better collaborate with the caregivers, and

to improve his quality of life". TPE focuses very specifically on setting goals and developing the skills required for effective self-management of chronic disease. As such it is an essential component for the efficient self management and quality of care of all long-term diseases and conditions.

While increasing knowledge is one important aspect of TPE, the main aim is to increase awareness of the issues that they face and must manage and to motivate patients to actually incorporate the self-management and self-care behaviours they are taught [Assal]. Attention to resistance to change and ambivalence are both fundamental to TPE and these must be assessed, discussed openly and negotiated. TPE takes a patient-oriented approach to promoting self-management, as opposed to a professionally-led model, in that patients, with the support of their health care professionals, work to develop and commit to their own strategies through goal setting so that they end up with a very tailored approach that suits their preferences. Thus the health care provider effectively becomes a "coach" that, in addition to teaching, negotiates with, motivates and accompanies their patients. As such, TPE is a concordance rather than a compliance model.

TPE is complemented by motivational interviewing and cognitive-behavioural approaches which help to prepare the patient and provide support during the change process.

There is evidence that TPE can result in a number of benefits to the patient including better quality of life, greater therapeutic compliance, a reduction in complications, decreased anxiety and a reduction in the number of acute or emergency situations [Gagnayre; Ivernois]. TPE has been successfully implemented in a number of chronic conditions including diabetes (Assal), bronchial asthma [Gagnayre], other pulmonary diseases (COPD) [Bourbeau], sleep apnoea syndrome [Engleman; Golay], cardiovascular diseases [Eriksson]. In addition, it is increasing being applied in cancer, which is now viewed as a chronic disease [Grahn; De Wit; Maung]

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// De Wit R., van Dam F., Zandbelt L., van Buuren A., van der Heijden K., Leenhouts G. & Loonstra S. (1997) A pain education program for chronic cancer pain patients: follow-up results from a randomized controlled trial. Pain 73, 55–69.

// Grahn G., Danielson M. & Ulander K. (1999) Learning to live with cancer in European countries. Cancer Nursing 23, 213–221.

- 6 Mar 2010 06:55 **Juan Carlos Arbonies Ortiz** commented, on

Muy buena sección .

Me ha gustado ver explcítitas las diferencias entre la educación tradicional y la educación para la autogestión.

Como sugerencia, una tabal donde se vieran las diferencias entre ambas estrategias y los aspectos comunes

Gracias

Delivering self-management support

- 16 Mar 2010 05:58 **Manuel Serrano Gil** commented, on

"The 5A's"

- *Considering the "Ask-Tell-Ask" strategy, a technique to ensure that patients get the information they are after, or the "Closing the Loop"* technique, to ensure patients understand the information provided by health professionals.*

*Reference: Schillinger D, Piette J, Grumbach K, et al. Closing the loop: Physician communication with diabetic patients who have low health literacy. Arch Intern Med.

2003 Jan 13;163(1):83-90.

- 13 Mar 2010 21:47 **Antonia Herraiz Mallebrera** commented, on

Chapter 5 is a comprehensive and complete writing

it offers a clear and understandable of patient self-managemente, the impact on health, patients, health professionals and health services.

Self-management means that health profesional team have change their view of patients. Teams and patients have to share together patient care plans. Professionals have learn to prioritize according to needs patient.

The challenges of profesionals are knowing the patients needs and goals, sharing information and guides that will improve the confidence and comunication between patients and team. Also they have explored patiens´ beliefs and improving access to health and community services.

- 6 Mar 2010 07:38 **Juan Carlos Arbonies Ortiz** commented, on

Puede servir este trabajo sobre entrevista motivacional en las enfermedades crónicas.

Motivational interviewing-based health coaching as a
chronic care interventionjep_1300 171..179
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- 6 Mar 2010 07:32 **Juan Carlos Arbonies ortiz** commented, on

Convendría explicar más claramente la técnica del bucle.

Gracias

- 6 Mar 2010 07:30 **Juan Carlos Arbonies Ortiz** commented, on

Las 5 A,s pueden traducirse en español de la manera siguiente:

Averiguar, Aconsejar, Analizar la voluntad de cambiar, Ayudar en el intento, Acordar seguimiento.

- 6 Mar 2010 07:08 **Juan Carlos Arboniés Ortiz** commented, on

En mi estado (España),la mayoría de los profesionales de la salud hemos sido educados en el **modelo paternalista** de relación profesional de salud -paciente , que señala al paciente (por su beneficio)lo que tiene que hacer para conservar o restaurar su salud.Al paciente a su vez se le ha otorgado el Rol pasivo de cumplimineto de las indicaciones del profesional de salud.

Este modelo sirve muy poco para las enfermedades crónicas donde el paciente , experto en su vida, necesita adaptar sus hábitos de vida a las nuevas necesidades de salud.

Es por ello que es importante un cambio, para que los profesionales de salud se formen en la toma de decisiones compartidas con los pacientes y éstos adquieran mayor protagonismo en el control de su salud.

Self-management support provided by health profess

- 16 Mar 2010 05:59 **Manuel Serrano Gil** commented, on

En ocasiones se han utilizado con éxito escalas para valorar el grado de capacitación del paciente (33), activación del paciente (34) o su predisposición sobre el autocuidado como la *Medida de Activación de Paciente*, que se ha relacionado con el grado de conocimiento del paciente, su nivel de autoeficacia y como predictor de adquisición de habilidades de autocuidado (35)

These referentes were provided by GASMS contributors Funell MM, Anderson Rm Schaeffer J and Miller D

33. Funnell MM, Anderson RM (2003). Patient Empowerment: A Look Back, Look Ahead. Diabetes Educ. May-Jun;29(3):454-8, 460, 462 passim.

34. Simmons L, Baker NJ, Schaefer J, Miller D, Anders S. Activation of patients for successful self-management. J Ambul Care Manage. 2009 Jan-Mar;32(1):16-23.

35. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004 Aug;39(4 Pt 1):1005-26

What do we need to know?

- 16 Mar 2010 06:03 **Manuel Serrano Gil** commented, on

"A major question that has not been conclusively answered relates to the process of self-management, specifically the process(es) which bring about the beneficial outcomes... This is more that we do now not the what we need to know: "*The recent evaluation of self-management support programs conducted by RAND (86) suggests a "chain of self-management support effect", specifying that: 1) as patients participate in evidence-based self-management programs and interact with health professionals who use self-management support strategies, they become more knowledgeable and have higher self-efficacy; 2) this influences their behaviour as well of the behaviour of their health providers; 3) patients attain better disease control leading to improved health outcomes and higher satisfaction levels; and 4) better healthcare utilization takes place as well as improved workplace productivity and lower costs".* From here is OK for this section: "*Specific aspects within this "chain of effect" that need further investigation relate to...*

"*From an organizational perspective there are ongoing challenges* (the following is for the following section: innovations to fill the gap) *of how to make self-management programs accessible and attractive to the target populations. Successful dissemination strategies can make the programs accessible but people may be reluctant to participate. Multiple venues (small group, telephone, mail, and internet) do exist for these programs but information is needed to determine best combinations and concentrations given limited resources. Scenarios that may entice members of the target population to participate may include enhancing the choice of available programs (e.g., communities having a menu of self-management programs from which to choose such as: an Online Program, Chronic Disease, Chronic Pain, and Matter of Balance...etc.).*

- 15 Mar 2010 15:49 Jackie Bender commented, on

We should also mention that peer-led self-management programs have also **proven effective for people with multiple, confluent chronic diseases** (?Lorig et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. Medical Care, 37 (1), 1999; 5-14).

- 15 Mar 2010 15:45 Jackie Bender commented, on

In the introduction to this section, we should define the different providers of self-management support (e.g. health care professionals, allied health professionals, other patients, family and friends).

We should highlight the important role of other patients, chronic disease sufferers as role models and support providers making reference to the importance of social factors as per the social cognitive theory and the evolution of successful peer-led self-management programs (e.g. Lorig's Stanford Self-Management Programs and the UK's EPP).

- 12 Mar 2010 20:02 Jennifer Jones commented, on

"There has been little research providing information on the sustained effectiveness of these programs for longer periods of time, for example five to ten years. Having this valuable information would assist in determining the need for and types and scope of

refresher and reinforcement programs." I would very strongly agree with this comment and you may want to expand on the research questions here. We know that much of the data on patient education and self-management interventions(i.e exercise interventions) are professionally led and while they show short term benefit, pateints likely do not sustain these activities once the study is over. It would be helpful to discuss stratgies for promoting sustainability. A TPE interventions with patient-oriented approachs can help to promote this. Technology can support this. Continuous feedback, boosters and peer-support can all play an important role.

- 9 Mar 2010 16:04 **Antonia Herraiz Mallebrera** commented, on

In my point of view, Family and Friends play an important role in patient self-management behaviors performance. Some authors showed that selft-management behavior interventions may need differentially emphasize familiar and friends support, self-efficacy or profesional support depending on the self-management behavior targeret for improvement.

Rosland, A,Kieffer E,Israel B, et col. When is Social Support important? The Asspciation of Family and Professional Support with Specific Diabetes Self-management Behaviors. J Gen Intern Med 2008; 23(12):1992-9.

What innovative strategies could fill the gaps?

- 19 Mar 2010 18:01 **Manuel Armayones** ✉commented, on

It is necessary to analyze what are the learning strategies used by patients in their transformation to e-patients. How a patient learns to manage his own illness? "A patient can learn to be as efficient in its self as another who has been" formed "by the professionals or even by other patients? And if so, what strategies and what technical means? What Internet applications? The answers to these questions raise a possible scenario of "self-learning" in which professionals have to promote "things happen".
The analysis of both the personal characteristics of e-patients, learning strategies used by those not involved in any training program is essential if we cover a phenomenon as complex as the learning process for self-care skills so autonomous (and therefore more sustainable health systems)
This will make it possible to "teach to learn" to some users and even design and content materials that are situated in a strategic network through web positioning methodologies to increase the chances of being located by the citizens.

- 19 Mar 2010 17:36 **Manuel Armayones** commented, on

The increase in social networks among these patients indicates that there is demand, but often are private companies that offer the service, and few networks linked to public institutions.
A social network for patients sponsored by the public and the medical records related to shared or personal health records (PHR) could lead users to assume the role of suppliers of information useful for the inves
gations of certain types of diseases, including rare diseases. In this respect, we should encourage the use of standards that allow interoperability of data that patients choose to share on social networks specializing (always under informed consent).

- 16 Mar 2010 06:12 **Manuel Serrano Gil** commented, on

After 3rd paragraph:

I would add here the case of New Health Partnerships (www.newhealthpartnerships.org), using Breakthrough Series College Methodology for an Online Collaborative in Self Management Support:, lead by Dorianne Miller, one of the contributors to the GASMS chapter.

- 16 Mar 2010 06:05 **Manuel Serrano Gil** commented, on

These references were provided by Anne Rogers, Anne Kennedy and Jane Cooper, from the Expert Patient Programme, working at the GASMS group for chapter 5:

Richardson G, Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Gardner C, Gately C and Rogers A. Cost Effectiveness of the Expert Patients Program (EPP) for Patients with Chronic Conditions. Journal of Epidemiology and Community Health, 62:361-367, 2008

Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Richardson G, Gardner C, Gately C, Rogers A. The Effectiveness and Cost Effectiveness of a National Lay-led Self Care Support Program for Patients with Long-term Conditions: A Pragmatic Randomized Controlled Trial. Journal of Epidemiology and Community Health, 61(3), 254-61, 2007

Cooper, J. (2001) Partnerships for Successful Self-management. The Living with Long-term Illness (LILL) Project Report. The Long-Term Medical Conditions Alliance, London

- 12 Mar 2010 19:56 Jennifer Jones commented, on

This is an interesting paper that you may want to cite:

Armstrong AW, Watson AJ, Makredes M, Frangos JE, Kimball AB, Kvedar JC.Text-message reminders to improve sunscreen use: a randomized, controlled trial using electronic monitoring. Arch Dermatol. 2009 Nov;145(11):1230-6.

- 6 Mar 2010 08:00 **Juan Carlos Arbonies Ortiz** commented, on

Creo que la estrategia debe ser sistémica , multifactorial y adaptada a cada contexto.

Una estrategia debe combinar mensajes a la población que promocionen el autocuidado y la autogestión con estrategias de formación a los profesionales de la salud para adapatarse a las tomas de decisiones compartidas con estrategias sociales basadas en redes de ayuda y apoyo entre iguales.

Creo que es importante además utilizar los diferentes modelos teniendo claro el objetivo común que es mejorar el nivel de salud del paciente y su calidad de vida

References (click here to access).

- 15 Mar 2010 19:41 Jackie Bender commented, on

Yes, there are indeed many existing and emerging health communities that offer a venue for supportive health exchange among chronic disease sufferers as well as tools to support self-management and behaviour change.

We may want to make a distinction between mailing lists (like those offered by ACOR) and the newer social networking platforms, some of which provide health behaviour change tools specifically for self-management.

Some examples of social networking sites for health purposes (that have not already been mentioned) include:

WellSphere http://www.wellsphere.com/about.s- A platform of personalized information, social support and a suite of tools to improve and manage your health.

WebMD http://www.webmd.com/ - Health information, tools for managing your health and support.

MD Junction http://www.mdjunction.com/ - A social network for health purposes.

- 14 Mar 2010 16:51 Maria Carmen Griñán Martínez commented, on

Virtual Communities for Health:

http://www.patientslikeme.com

According to the platform itself, in March 2009 had over 11,000 registered users from multiple sclerosis, 8,000 users with mood disorders, 3500 with amyotrophic lateral sclerosis users, 3000 users with Parkinson's disease and 2,000 users with HIV . The company was named one of the top 15 companies that will change the world "in Business 2.0 and CNN.

http://www.patientopinion.org.uk

It is the web portal where patients from the National Health Service (NHS) (UK health service) may come to share their particular experiences and events due to the contact you have had with the various network services of your health.

http://www.revolutionhealth.com

Created by Steve Case: founder of America Online (AOL), is a clear example of the new wave of web 2.0 platforms that are intended to provide a significant change in the health world by using the Internet and new technologies.

http://www.forumclinic.org

The program aims to enhance the autonomy of patients, and provide contrasting information about each type of disease and the efficacy of treatments that will be

applied if either having a preventative or curative nature. Forumclínic is an initiative led by professionals in hospitals and primary care Corporación Sanitaria Clínic, Hospital Clínic de Barcelona.

http://www.disaboom.com

The platform was born with the will to generate enough interest to generate greater visibility to the sector of personal autonomy and quality of life. Disaboom was founded in 2007 by J. Glen House, a young man who despite having become a quadriplegic at the age of 20 years as a result of a skiing accident, managed to start a career in medicine and graduate successfully.

http://blog.trusera.com

The platform eagerly began his career in June 2008 by involving users in 150 countries, has been forced in less than a year to close its doors by funding problems. Trusera canceled its service in late April 2009 and today continues to seek resources to enable the reopening.

http://www.doctrs.com

It aims to facilitate effective communication between health professionals across the network. The platform enables the promotion of events or creating group discussions among physicians and other health professionals.

http://www.sermo.com

It is a community dedicated solely to physicians.

http://www.quantiamd.com

Today QuantiaMD already offers its users access to its online community through mobile devices like the iPhone. This enables professionals to launch interactive presentations and clinical updates, respond to polls, publish content and review comments and ratings, among many other features.

http://www.healthcommunities.com

Healthcommunities currently houses 30 channels of medical information, having consolidated until an extensive network of professionals in the portal. As a service to those professionals are offered a practical platform for creating and maintaining their websites. As regards the scope of patients, these are helped to identify and locate different doctors, in turn adding relevant information about your services.

http://www.scivee.tv

The tool allows you to upload videos, audio-visual material with associated scientific literature (text, images), create podcasts. The platform offers tutorials on multimedia content creation.

http://www.innocentive.com

It is a platform of "crowdsourcing," a neologism that first appeared in the magazine

about technology "Wired" to define a knowledge-seeking phenomenon that has spread through ICT.

https://www.google.com/health

The platform offers the possibility that the user can register at the history of its medical center your personal health information, so that if you have been prescribed medications from another center, your regular doctor may be current and can anticipate risks of interaction.

http://www.healthvault.com

Microsoft is working with healthcare professionals, hospitals, pharmacies, mutual, device manufacturers making and monitoring vital signs, etc.. Although Microsoft's bid is clear and in line with current trends in health services, there is still very large percentage of citizens who fear for their privacy when disclosing such data to a company.

http://www.sugarstats.com

Online application that provides its users of analytical capabilities, so you get an interesting return by exploiting information and graphic representation of data that have previously entered. The platform is designed for diabetics and patients directed to their own condition.

http://www.webcitation.org

WebCite does not completely solve the preservation of contents, in fact, the platform often makes it difficult to replicate the complexity of interactions that had the original pages.

http://www.connotea.org

This service is free of "social bookmarking" and online reference management. The platform, based on "Delicious" was launched in late 2004 and particularized use to the academic community.

http://www.scirus.com

It is a form of scientific information in the network. The tool provides full access to journals, collections, reports, abstracts, patents, newspapers, web portals and leading universities and business associations between different reference sites.

http://www.plosone.org

It is published in open access format for the "Public Library of Science", an organization that aims to facilitate global access to the field of medical and scientific literature.

- 11 Mar 2010 22:39 Maria Carmen Griñán Martínez commented, on

Examples:

1. - "EHealth and new models for the attention": Promoting the self-care via

the Internet: the care of patients with chronic diseases and implementation of collaborative work in healthcare in the health professionals. A personal experience: Social Networks: Self-care via the Internet "and" Spanamed. "

"Everyone knows that" education is a social fact "as it, since many years, is Conceived, from the perspective of the societies. The social fact is shown by an external Coercive power exerted on the individuals and Whose essential characteristic is the dissemination of it that occurs within the group.

Education is similar in all societies, since the same is given following the traditions, customs, explicit or implicit rules, within the framework of institutions, families, groups and during each of these moments educate the educators and the children are educated, and, as the process is the same at any time we are learning something, even when we are adult.

Throughout our lives we are taught the ways of being healthy, how to care, exercise, how to take a balanced diet, take care of our body, etc.. The same as education is a social fact, de-learning in health is also a social fact, and occurs when one is already adult, when the des-learning begins.

On the other hand, since the new technologies we are seeing a new trend in health /: the informed patient and skilled in his / her illness / taking into account the current various transformations of health care, and that the Internet offers lots of information to its users, and it is now when it is appropriate to Assess Whether this environment offers tools to care for and teach how to take care of one.

We have gone from asking our doctor, to ask others about what happens to our health, and we do this in a new telematic environment, where the new Web 2.0 goes beyond the various health organizations.

This communication is about how to apply a new proposal about the Pedagogy of Self-Care (support and promotion of self-care) as a model of health care through tools provided by "Free and Open Source Software" to verify if the Internet can be a facilitator To promote self-care in patients with chronic illnesses, health professionals and provider of means to develop joint work on health.

Materials and methods

"It is a proposal for the implementation of self-care in health prevention, its causes and effects in chronically ill persons, from a new social and professional perspective, patient-focused and under the / New Model of Attention of Chronic Care adapted by the World Health Organization for the creation of "the innovative profile of care for chronic conditions" / (2003), and using the tools offered by open source software, Incorporating as actors, patients, healthy people who want to Improve their healthy habits and health professionals through the use of open social networks and with applications that Facilitate collaborative work among health professionals".

Conclusion

The Internet offers through open programs and social networks in particular through applied to the health, an enabling environment for health care: information, prevention and self-help for users. The patients get more involved than the health professionals. The participation from the health professionals in Ireland has a long way to go.

[1] Griñán Martínez, M (2009). "EHealth and new models for the attention": Promoting

the self-care via the Internet: the care of patients with chronic diseases and implementation of collaborative work in healthcare in the health professionals. A personal experience: Social Networks: Self-care via the Internet "and" Spanamed. "IV (Assessment conducted for the authorship of the module mHealth: access to health information and quality of life "in the Master of ICT and Health Systems UOC).

Available:http://www.cibersociedad.net/congres2009/po/coms/fomentar-el-autocuidado-de-la-salud-a-traves-de--internet-la-atencion-a-pacientes-con-enfermedades-cronicas-e-implementacion-de-trabajos-de-colaboracion-en-los-profesionales-de-la-salud/654/

2 .- *"Nyaya Health Organization implemented several simple strategies of Web 2.0 while doing their work of health care in rural areas of Nepal. This initiative helped the company improve its transparency, receiving critical feedback from outside experts and through comparison with alternative budget proposals for the provision of care, pharmaceutical supplies, clinical protocols and public health programs.*

The work developed by Nyaya Health in Nepal is an example of how to implement technology freely accessible, useful and easy to use. The article presents five tools for the implementation of such platforms: a) inclusion of quantitative performance data and logistical protocols a free gateway, b) a database of unidentified patients, c) a geo through-space real-time mapping, d) a blog and e) a public budget and detailed "

[2] Maru DS-R, Sharma A, Andrews J, Basu S, Thapa J, et al. (2009). Global Health Delivery 2.0: Using Open-Access Technologies for Transparency and Operations. Research. PLoS Med 6 (12): e1000158. doi: 10.1371/journal.pmed.1000158.

Available:http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000158

3 .- *"A study in the Netherlands, examines the implementation of an electronic program to complement and extend the usual care that midwives provide to pregnant women, the program allows pregnant women registered to receive monthly e-mail and through , links to questionnaires and additional information on healthy lifestyles, appropriate to their stage of pregnancy. The strength of this study is the approach to the issue both from the perspective of health professionals (midwives), and from the point of view of the user (pregnant women)".*

[3] Moniek van Zutphen, MSc; E Ivon Milder, PhD, Wanda J. Bemelmans, PhD. (2009). Integrating an eHealth Program for Pregnant Women in Midwifery Care: A Feasibility Study Among Midwives and Program Users. Journal of Medical Internet Research.

Available: http://www.jmir.org/2009/1/e7/HTML

4 .- *"Inspire and Bristol-Myers recently started a community called Advance Breast Cancer Community for information and a social network (community support) for people with advanced breast cancer. These online communities offer benefits to support groups or family members who would otherwise not participate".*

[4] Shah, Shahid N. (2008). Tech-savvy A Physician's View of Patient Social Networks. The Healthcare IT Guy.

Available at: http://www.healthcareguy.com/index.php/archives/447

5 .- "*As the Internet has evolved to Web 2.0, it is natural for technology experts*

envision the Web 2.0, known as the Semantic Web (Semantic Web) The Semantic Web defines the meaning of information and services available online; in this way can meet the needs of people who use the content. Understanding the Semantic Web will bring to any person seeking information related to health care much more about what you are looking for.

However, the realization of this site is several years away. In the current trip of Health 2.0, those who have chosen to use social networks to manage their health and get different types of support found in the near future, an increase in information tools and methods available. In addition, users of the Health 2.0, through its collective wisdom, determine the value in their daily lives. "

[5] Sarasohn-Kahn, Jane (2008). The Wisdom of Patients: Health Care Meets Online Social Media. California Health Foundation [19 December 2008].

Available at:http://www.chcf.org/documents/chronicdisease/HealthCareSocialMedia.pdf