

Managing Self-Management in Healthcare: from a Systemic Perspective

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Abstract— Self-management among patients, especially chronically ill patients, has shown to be crucial for their ability to adjust lifestyle, increase empowerment and maintain a satisfactory quality of life. The use of the Internet and ICT tools support self-management on different levels. With the new and improved patient role, the patient becomes more actively involved in decisions and treatments. More personalized care and support become also possible. The question is how enhanced emphasis on self-management affects healthcare. By taking a systemic perspective, this paper elaborates on the complexity of self-management and on healthcare management issues related to self-management. It proposes a holistic view on managing self-management in healthcare.

Keywords-self-management; ICT tools; complexity; control; management; systemic; viable; holistic.

I. INTRODUCTION

The patient role is becoming more self-managing. Self-management among patients, especially those with chronic diseases, has shown to be crucial for their wellbeing [1]. Self-management includes taking care of the body and disease, adapting in order to carry out daily activities, managing changed life conditions and roles, and also emotional changes and uncertainty about the future. Self-management brings with it a new patient role in which the patient becomes more active. The patients can be said to act as "prosumers of wellness rather than passive consumers" [2, p. 180]. Greater empowerment is detected among patients who engage in online support groups [3][4], and power is also somehow slightly shifted from the healthcare system to the patient [4].

A sense of control and social belonging are important to all people, but for patients with chronic and severe diseases, this imposes a certain challenge [3]. When becoming a long-term patient, you need to redefine your role and adjust living conditions or lifestyle. This can lead to a feeling of being outside the norm and alienated, why interaction in groups of patient peers becomes important [3]. Through peer interaction, experiences, skills and inspiration can be shared among patients and others with similar health concerns [3]–[5]. This kind of interaction takes place independently of formal healthcare but can be supported by it.

Self-management can help patients develop a sense of control over their situation, and to influence on practical conditions and interventions. Increased patient involvement implies a new approach from the healthcare system and the healthcare professionals [2]. The change concerns attitudes and

approaches to care, and to the relations between patient and doctor; it is very much a conceptual change. It also demands for new ways of using ICT for communication and interventions [6]. For effective self-management, conversations between the healthcare and the patients are important [6]. It is also in the conversations that conditions for interventions and self-management tools are decided upon. Allowing the patients to be more in control implicates that these conversations are emphasized. However, it is a challenge for the healthcare to manage the idea of patient-centric care and the support of self-management among the patients. Healthcare management is to be further explored in this respect.

This paper will investigate the concept of self-management from a systemic perspective. The perspective helps us regard the complexity and viability of self-management, and how to manage it. The following section, Section 2, addresses the concept of self-management and complexity in relation to self-management. Thereafter, in Section 3, different types of self-management tools are introduced. In Section 4, a holistic view on how to manage self-management is proposed, and the last section, Section 5, concludes and points out a way forward.

II. SELF-MANAGEMENT

Self-management has been identified 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, role management, and emotional management." [7, p. 3]. Another way to address self-management is to refer to "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life." [8, p. 178].

Examples of activities included in self-management programs are: how to deal with frustration and pain, what exercises to do, how to take medication, effective ways to communicate with relatives, friends and health professionals, what food/nutrition that is recommended, and how to evaluate new treatments [1]. Encouraging the patient to be more self-managing, and thereby involved in the healthcare more actively, has shown to be helpful for several care goals, for example, increased patient satisfaction, development of healthy behaviors and improved wellbeing of patients [1][8].

Self-management support includes also educational components, teaching the patients about self-management skills [1] [9]. Examples of key skills for the patients are problem solving skills, including communicating with close ones and healthcare professionals, day-to-day decision making skills, such as knowing when to exercise and when not to. Other examples are skills to access relevant resources, to build relationships with healthcare providers, and the ability to make short term action plans and carry them out [9].

A. Self-Management and Complexity

Whenever a person is to handle a situation, and the involved tasks, he or she needs to adjust to the situation and to the complexity it holds. As mentioned previously, for self-management, the tasks include “gaining confidence to deal with medical management, role management, and emotional management” [7, p. 3]. When considering this from a systemic perspective, to manage the situation and its tasks, the person amplifies his or her abilities and skills and attenuates the situation through models and filtering of information [10]-[12]. Both amplification and attenuation are needed to manage the situations we meet (see Fig. 1). How much we are to amplify and attenuate depends on the relation between ourselves and the situation, considering the tasks involved. In everyday situations that we manage without great efforts, we maneuver and adjust often without being conscious about it.

However, we often become overwhelmed by situations due to the imbalance between our own individual complexity and the complexity of the situation [11]. This is especially evident when we face a new or more complex situation. Management of situations unfamiliar or difficult to us requires that we develop relevant models and skills. We need also to look for adequate performance criteria and performance goals [11][12]. Learning can be seen as a struggle with insufficient variety, forcing us to enhance our performance [12]. However, if the desired outcomes are recognized as impossible to achieve, they may have to be changed [12]. Otherwise, they will lead to errors and failures in performance all the time.

The practice of self-management must also consider that given a limited knowledge of the patient, a certain type of self-management may lead to more harm than good. One crucial thing for successful health treatment is that the patient takes his or her medicine as described, for example. The patient may forget to take the medicine, or perhaps takes it too often. One of the most common risks in this area, documented in the medical literature, is the overdose of prescribed medications among diabetic patients [13]. Another example is the corticosteroids and bronchodilators, generally used by chronic obstructive pulmonary disease (COPD) patients during the exacerbation phase. Once again, the risk is the abuse of this treatment, i.e., the patient goes on a light distress and even if it is not needed, he or she uses the bronchodilator. Conversely, if a patient does not use a bronchodilator when needed, he or she will go on a respiratory distress.

There is a need for balance between the desired outcomes, patient’s current abilities and the situation at hand. Based on this, appropriate levels, or types, of self-management will be necessary to decide upon. What the patient is able to manage

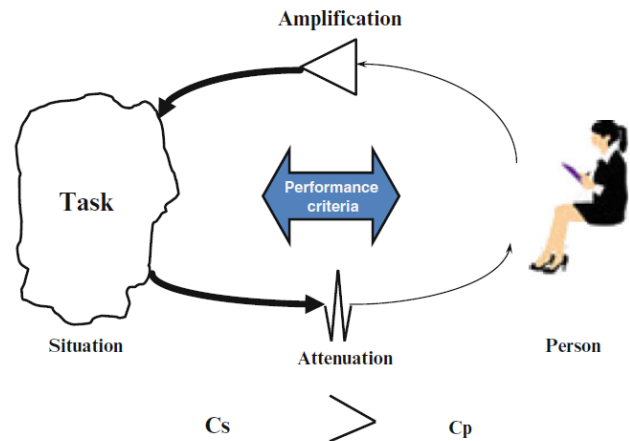


Figure 1. Managing the complexity of a situation [11, p. 55]

at a certain time, and what needs to be managed by the healthcare professionals, is crucial to have a continuous dialogue about.

B. Self-Management and Changed Relations

To enhance self-management of patient groups, especially those with chronic diseases, puts new demands on the healthcare system and the care professionals. The relation between patients and the healthcare provider is to be more characterized by collaboration, with frequent and productive conversations [2]. In comparison with the traditional relation between the patient and the healthcare provider, the collaborative relation is less characterized by the doctor telling the patient what to do and more about combining the different types of expertise that the doctor and the patients possess [1]. The patient is to become part of the conversations and participate in setting goals and developing care plans. While the physician is expert in medicine, the patient is the expert regarding his or her life, situations in daily life, history and past abilities. To include the different expertise, and to let the patient not only be in the centre but also an active participant, physicians and other health professionals are expected to have two-way conversations with the patients about goals, treatments, possible side-effects of medication and evaluations of treatments.

The emphasis on self-management and collaboration makes patient education a necessary activity of the healthcare system: to help the patients with the practical tools so they can manage more easily and be more involved in the interventions and also as independent as possible [1][9].

III. ICT-SUPPORT FOR DIFFERENT TYPES OF SELF-MANAGEMENT

Greater patient participation and control can be achieved through available ICT tools [3][4][6]. There is a wide range of ICT-based self-management tools, spanning from online self-help groups that allow for an autonomous patient role, to home surveillance systems that let the patient take a subordinate role due to the nature of the health conditions [6]. For patients who need home surveillance for their safety, there are video camera surveillance and sensor-based surveillance systems that can

facilitate this. In these situations, the patient's role is subordinate, and it is crucial that the systems do not violate the patient privacy or become too controlling. In order for these systems to be regarded as self-management tools at all, the patient has to be in charge of how the systems are used [6].

In between the autonomous and the subordinate roles, there are ICT tools supporting a structured patient role. Examples of these are interactive telemedicine consultation and messaging systems, allowing for patient-doctor communication to be more continuous. Other tools for the structured role are blood glucose meters, weight scales, apnea monitors and neurological monitors. There are also tools that let the patient be included in communication, education and decision making processes together with healthcare professionals. These ICT tools address the collaborative dimension of the patient role [6].

A. Online Self-Help Groups

The most autonomous type of self-management tool is the online self-help communities and self-help books [6]. These tools let groups of patients communicate, learn and act independently of the healthcare professionals. Online self-help groups let patients exchange knowledge and experiences, and the groups support the participants in helping each other develop new skills and attitudes. Previous studies have shown how self-help groups for patients with severe illnesses contribute to increased empowerment and improved ability to approach the healthcare with their health concerns [3] [4]. One example of a web-based community platform for different patient groups is PatientsLikeMe in which patients can share experiences, and the system can also aggregate the information as to serve the participants with decision support [2]. If you want to know about the experienced side effects of a certain medicine, for example, you can search for this in the online community and get aggregated data from hundreds of patients who are taking the medicine. Healthcare becomes then more than merely a patient-centric healthcare; it is also about patients co-creating healthcare and wellness [2].

Another example is WeAreUs, an online health community for supporting conversations between patients, families and related stakeholders. This platform also contributes to a kind of collective intelligence through aggregated tracking and gathering of group information [2]. A further example is the NetDoctor sites in Europe with different areas for information from the healthcare, ask-the-expert systems (Q&As) and conversations in web-based communities for self-help groups.

There are also self-help groups for people who suffer from lifestyle problems, such as unhealthy eating habits, too little physical exercise, smoking and abuse of alcohol, for example. The online communities on lifestyle issues are valuable for prevention purposes, but they are also important for people with chronic diseases, such as diabetic. Another example is stress management through conversations in online communities with the aim to prevent dysfunction due to negative stress exposure [14]. Social support is important when trying to develop new habits and behaviors that last [15] [16]. Also, in comparison with advice from healthcare

professionals, the self-help groups have shown to offer complementary and more practical hands-on advice [17].

B. Discussion on ICT-Support for Self-management

For all these tools supporting self-management, it is important that they serve the purpose of allowing the patient as much own control and independence as possible. As mentioned before, even tools that facilitate subordinate patient roles, like the surveillance systems, should not violate the patient privacy or become too controlling. The choice and combination of self-management tools depend on the nature of patient conditions and the decision made by the patient, the doctor and the healthcare institution together. Especially for patients with chronic and multiple diseases, the negotiation about self-management tools, and how they are to be used, is crucial for their wellbeing. Also, if the nature of the health condition changes in character and the patient's health status deteriorate or progress gradually, the communication concerning the tools will have to be continuous. In addition, the learning curve is a factor that needs to be considered.

There are different kinds of knowledge and skills that the patient needs to possess, one is to know how to use the ICT tools for self-management. The more in control of the ICT tools the patient becomes, the more likely it is that he or she will use the technology. The emphasis on self-management makes patient education a necessary component of the healthcare system, to help patients with the practical tools and the practices they need. Patient education includes introduction to self-help groups for peer communication and how to use an apnea monitor, for example.

If we assume that self-management is critical and that we have to figure out the patient, in the context of remote monitoring, we need to move beyond traditional roles. Obviously, until the patient manage to self-medicate, the problem with under- and overdosing is inevitable. But surprisingly in home-care and remote monitoring, this kind of risk is often not managed through the software and telemedicine platforms. What can we then put in place to mitigate the risk of such events from occurring? Most of the clinical picture of the patient involves trying to record in an as accurate as possible manner all the doses taken. However, the situation may be complicated by the fact that the overdose (or a too low dose) in emergency situations may be adequate. The typical example is a diabetic patient where the proportion of glucose in the blood exceeds a certain level for which it is necessary to add an extra dose of insulin, in order to bring it back to normal levels. In this case, the patient knows through the symptoms (e.g., headache) that something is going on. By measuring blood sugar level, this can be verified before adjusting and putting in an additional dose of insulin. In this case, we have an additional medication that is not scheduled, i.e., it deviates from the daily doses of insulin. The majority of current diabetic control software applications allow the patient to simply record additional measurements of glucose and additional insulin medication.

Some improvements could be done by a simple real time alert system for the clinician that is following the patient. The use case will be the following. The patient receives his or her

medical drug prescription on the home monitoring platform. If, for some reason, there is an additional drug intake registered by the software, an alert should be sent to the clinical care alerting that the patient is overdosing. However, this simple suggestion could be further improved, and a global refactoring of traditional remote monitoring systems should be done in order to archive also the possibility of having a patient that is not only self-medicating but who is also an active part of the cure and able to make decisions with the clinician.

IV. PROPOSAL OF A HOLISTIC VIEW ON MANAGING SELF-MANAGEMENT

This section will explore the systemic perspective of self-management further. A systemic model, the viable systems model, will be introduced, as well as applied and discussed.

With a systemic or holistic approach, systems are regarded as a set of interrelated parts that form a whole with certain systems goals [18][19]. The mutual relations and communication between the parts of the system are as important as the parts themselves, since the whole system is greater than the sum of the constituent parts. A characteristic of living systems is their ability to alter and adapt to new conditions and demands of situations in the environment, in order to maintain viable.

The patient care can be regarded as a living system with the different care components seen together, as interrelated, and with certain goals of patient recovery, health and wellbeing. This includes considering self-management components and the healthcare activities, provided by formal givers, together, in which the different actors and their activities affect each other as well as the outcomes.

In Fig. 2, the viable systems model by Stafford Beer is illustrated [10]. It shows the relations between overall management (the upper square) and the operations (the System 1 circles) being managed. Management is divided into three different subsystems: System 3 is responsible for planning for the System 1 to function well, to distribute resources and to follow up the results. System 2 manages oscillation of System 1 and tries to enhance the togetherness of the different operations of System 1. System 4 deals with changes of the system, and looks for changes in the environment for the system to consider and adjust to. System 5 is the one that makes sure that there is a balance between internal stability and change, i.e., any conflicts between System 3 and System 4 is handled by System 5.

The environment is important for the system, since it provides the context and conditions that the system has to adjust to. In the case of the care of the patient, there are regulations, treatments, development of ICT tools, other patients, work and social environments of the patient, daily situations that the patient has to deal with, and so on. As can be seen in the figure, some parts of the overall environment are better known by the operations of System 1 than management of the top level. This goes for work and social environment, and specific situations that the patient experiences, for example. Variety is to be adjusted to this and should be taken into account when planning for patient care,

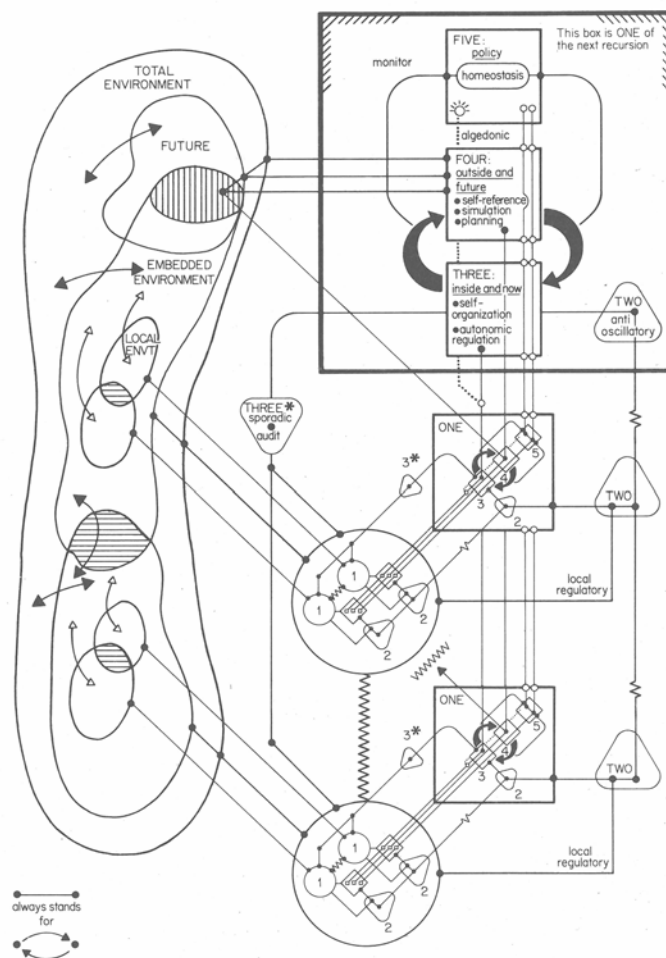


Figure 2. The viable systems model [10, p. 136]

especially the self-management activities. However, as shown earlier, there are also new types of ICT tools that offer possibilities for patients to interact with peers, and help them make use of the collective intelligence of the self-help group. This increases the patients' variety and their ability to have conversations with the healthcare about treatments as well.

A. Self-Management as Part of the Whole

The viable systems model by Stafford Beer can be used to deal with the concerns of integrated self-management in the total patient care. System 1 is the operational part that needs to be managed as a whole. In the patient care system, this System 1 consists of all activities necessary for a patient's health care and wellbeing. Looking into System 1, we find the different operations, such as medication/treatment programs, surgery and aftercare, such as treatments by physiotherapist, for example. In addition, we need to include self-management as one integrated operation. All the operations should be managed as a whole and get resources to work well. This is managed by System 3. It is also dependent on System 2, i.e., the one trying to avoid oscillation from occurring in System 1. In our case, System 2 would be someone who regulates and

makes sure that there are common health-related concepts and understanding among the operations, and who schedules different care activities so that they are performed in line with one another. System 4 contributes by managing change, and it can suggest addition of care activities or ICT-support to the operations.

In order for the healthcare to manage the situation, in which self-management becomes a natural part of the patient care, the ideas behind self-management need to be well-known to the healthcare. In addition, the use of self-management tools has to be embedded in the everyday healthcare practices. Since self-management includes a demand for education of the patients and their close ones, this will also have to be part of healthcare management.

To have two-way conversations with patients and to let them take part in decision-making situations leads to an increase in complexity in the patient – healthcare relation. More variables will have to be handled. For a well-working overall system for patient care, the health and wellbeing of the patient, i.e., seen from several perspectives, should be present to both the healthcare professionals and the patients.

B. The Viable Self-Management System

In the previous section, we addressed the whole care system in which self-management was one integrated part. If we focus on self-management, i.e., the next recursive level down, we will find different self-management operations. Among the operations of the System 1 of self-management, there are different types of activities and ICT tools appropriate for a certain patient (lifestyle self-help groups and monitoring of blood sugar, for example). As mentioned before, the types of self-management tools relevant for a certain patient should be discussed on a continuous basis due to changes in the patient's health status (both progress and deterioration) and his or her experienced wellbeing. In managing the system for self-management, we therefore find planning and evaluation of self-management operations. While System 3 plans and follows-up the outcome of the different self-management activities, System 4 looks for new ways of supporting self-management for the patient. This calls for ongoing processes of planning, evaluation and for scanning the environment for new tools and situations to be managed by the patient. To keep a balance in the self-management system, System 5 resolves any conflicts between stability (System 3) and change (System 4).

V. CONCLUSIONS AND FUTURE WORK

In this paper, we have discussed self-management for increased health and wellbeing among patients. Since self-management has shown to be of great importance to patients, it has to be an integrated part of today's healthcare. The complexity of patients and their situation is to be addressed. Evaluation of self-management tools will also be needed. If embedded in the healthcare, this will allow for continuous evaluations of the set of ICT tools for a certain patient, including suggestions for improvements in the self-management support. We have therefore proposed a systemic approach to managing self-management based on the viable

systems model by Stafford Beer. This view offers different roles and functions necessary to ensure that self-management is viable and also well integrated in the overall care system.

When self-management becomes a natural part of healthcare, the healthcare system has to further develop criteria for measuring effectiveness. Adequate level of control and inclusion in decision-making, experienced wellbeing of the patient, together with health status, are examples of criteria related to self-management. Future research work will focus on how to measure effectiveness, when patients and their close ones come to play a greater role in the care process, and when self-management through ICT tools are being further explored and implemented.

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