Do-It-Yourself Health Care:

A Three-Step Approach to Supporting Patient Self-Management in Clinical Practice

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Abstract— **Implementation issues plague the uptake and effectiveness of self-management programs in clinical practice. Using a participatory design, we developed an innovative three-step approach to support patient self-management in the field. This approach is based on existing evidence-based techniques and is supported by a Web-based patient portal. The focus of this online patient portal is threefold: firstly, patients are taught the skills and helped to build the confidence to adequately self-manage their disease in the home-environment. Secondly, professionals are provided with the tools and techniques to guide and monitor this process. Thirdly, the portal allows for data sharing, long-term progress monitoring and efficient communication between different health care providers. The authors are currently in the process of evaluating this approach and assessing the uptake, usability and usefulness in clinical practice.**

Keywords-self-management; health care; e-health; implementation; participatory design; patient portal

I. INTRODUCTION

Support is growing for a new conceptualization of health that views health as 'the ability to adapt and self-manage' [1]. This definition is process-oriented and encourages people to take an active role in managing their own health. Self-management programs aim to support patients in coping pro-actively with being (chronically) ill. Such programs focus on building the skills and confidence necessary to make informed decisions, engage in health promoting activities and manage the impact of the illness on life. Research shows that supporting self-management has beneficial effects on people's health behaviors, quality of life, clinical symptoms and use of health care resources [2]. However, the wide dissemination and uptake of self-management initiatives in clinical practice lags behind [3]-[5]. Next to financial, managerial and technical problems, there are two important reasons for the problematic uptake and implementation of self-management in practice. Firstly, adequate self-management requires behavior change on multiple levels: patients need the skills and confidence to learn how to 'adapt and self-manage' their illness, and professionals need the motivation and tools to build a collaborative partnership with their patients and families. Most self-management programs, however, focus on providing skills training for patients, but do not provide any such training for professionals [6]. Secondly, most self-management programs are offered in isolation from the chronic care system, meaning that self-management skills, activities and (electronic) tools for support are not integrated by the multiple partners involved in long-term disease management or embedded in the day-to-day routines of care [6].

In an attempt to address these issues, we have developed an innovative approach to aid self-management in practice that focuses on (a) providing patients with a set of tools and techniques to help them build their confidence, manage the impact of their illness on their lives and engage in healthy behaviors, (b) providing health care professionals with a set of tools and techniques to help them transform the patient-caregiver relationship and (c) aiding collaboration between primary and secondary health care providers using an overarching electronic self-management support system. This approach joins several theories of health behavior change [7]-[9] and is based on existing evidence-based techniques and interventions [7][10]-[12] and is supported by online self-management tools.

This paper is organized as follows. Section II gives the theoretical and conceptual background of the three-step approach to self-management. Part A in Section II goes into finer detail with respect to the development of the Web-based patient portal. Part B addresses the use of the self-management approach and patient portal in clinical practice. Part C describes the evaluation of the approach. The conclusions close the article.

II. A THREE-STEP APPROACH TO SELF-MANAGEMENT

Central to our approach is the idea that self-management is an interactive, 'staged' process – rather than a set of skills used in isolation [7]-[12]. Each stage, or step, commands patients to obtain specific knowledge, learn specific skills and form adaptive cognitions. It supports patients to move through these series of stages and requires health care professionals to employ different methods for behavioral change, tailor the mode and level of intensity of communication, and offer varying settings in which to practice self-management skills. We propose that full self-management may be achieved in three distinct steps, the first of which is termed 'self-confidence'. High levels of

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self-efficacy are a prerequisite for behavior change [8]. Thus, in this first phase, self-management support focuses on empowering patients and enhancing self-control by means of education, skills training and by offering patients a safe and controlled environment in which to explore and extend their boundaries. In this stage patients will communicate frequently with health professionals, and practice their newly learned skills mostly in a controlled, face-to-face setting (e.g., rehabilitation or health (care) center). The second phase, which is termed 'self-regulation', focuses on guiding patients in self-regulating their (new) behaviors and learning them to monitor relevant risk factors and parameters for the management of their disease [10]-[12]. Support for behavior change in this phase focuses on learning patients how to set salient and achievable goals, practice the skills they need to achieve these goals in real-life situations, and overcome barriers to change [10]-[12]. Patients will still communicate regularly with health professionals in this stage, but face-to-face contact will be alternated with online and/or telephone contact (e.g., e-coaching). The third and final phase is the 'self-management' phase in which patients draw upon their skills and experiences to adequately manage their risk factors and embed their healthy behavior in day-to-day life. Self-management support in this stage focuses on leveraging the skills developed and integrating new behaviors and skills in the home-environment [7]. This means that communication with health care professionals in this stage will be almost solely internet-or telephone-based and that the frequency of contact will gradually fade-out.

A. Development of a Web-Based Patient Portal

As we have a strong background in cardiology and since there is a clear need to help cardiac patients in maintaining adequate self-management over time, we have developed and pilot-tested our three-step approach in close dialogue with patients in cardiac rehabilitation. Using both qualitative and quantitative methods, we first assessed cardiac patients' as well as health care professionals' needs and preferences regarding self-management. Such participatory design of (online) self-management programs is thought to increase implementation success and uptake rates in practice [13]. Structured interviews were carried out with 13 patients and 5 health care professionals [14]. Both patients and professionals confirmed the need for a more systematic approach to aiding self-management in practice. Patients indicated that they would appreciate online access to their personal health information in addition to face-to-face contact. Health care professionals valued efficient communication and stressed the importance of being able to track patients' progress over time. Moreover, they indicated a need for tools and techniques to help them ask motivational questions to aid patients in the process of behavior change. On the basis of this input a mock-up version of a Web-based patient portal to support self-management (MyHealthePortal) was developed. Using a questionnaire, patients' needs and preferences as well as factors associated with intention to use this Web-based patient portal were assessed [15]. The questionnaire was filled out by 113 cardiac rehabilitation patients (34% females and 66% males, mean age 63 years). Patients especially valued being able to objectively monitor their progress, and being able to obtain adequate feedback from health care professionals on progress, lifestyle behaviors and relevant risk factors. Furthermore, they indicated a need for low-threshold communication with professionals [15]. The vast majority (97%) of patients used the internet several times a week and 69% indicated that they strongly intended to use the Web-based patient portal [15]. On the basis of this input, the mock-up version was improved. The look and feel and the different functionalities of this updated version were assessed in three patients by means of a qualitative thinking aloud study. The Web-based patient portal was rated as useful, but several design-related problems (e.g., consistency with other systems, error management, visibility of system status) appeared to impact ease-of-use. These problems were addressed and the design was updated accordingly; screenshots of 'MyHealthePortal' are displayed in Fig. 1.

B. Do-It-Yourself Health Care

MyHealthePortal is currently used in 'blended' (i.e., using a combination of online support and face-to-face contact) forms of cardiac rehabilitation. It allows both patients and health care professionals to set salient goals that are linked to patients' life goals, choose suitable face-to-face treatment modalities that will help support these goals, and monitor progress on both objective (e.g., blood pressure, cholesterol, weight, physical activity etc.) and subjective (e.g., well-being, self-reported goal progress etc.) outcome measures. The patient portal dashboard visually displays the journey through the three steps of behavior change and the actual progress on outcomes. The program is inherently empowering, as the patients themselves – as opposed to the clinician – determine their own curriculum and (learn how to) indicate to health care professionals what it is they need to move from one stage to the next. Progress towards self-set goals is rewarded by bonus points, which can be exchanged for lifestyle-related gadgets. Such elements have been shown to increase adherence to and effectiveness of interventions [16]. The Web-based portal also allows patients to continue with self-monitoring their dietary habits, exercise and smoking behavior, blood pressure, body weight and cholesterol after termination of the program. Not only does continuous monitoring and feedback prevent relapse into old lifestyles [7], the portal also allows electronic input of data from various devices (such as blood pressure monitors, weight scales and activity trackers) and sharing of this data between different levels of the health care system. Thus, the portal smooths the transition from primary to secondary care (and vice-versa), and aids the interoperability of health care providers and systems.

The Web-based portal also acts as a powerful tool to help health care professionals shape the patient-caregiver relationship. The three-step approach to full self-management is reflected in a behavior-change 'ladder': a series of small behavior change steps that ultimately lead to full self-management of the behavior. A series of questions

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based on motivational interviewing techniques guide health care professionals in their communication with the patient; thus, professionals have the tools to assess the stage the patient is in with regards to a specific behavior, discuss motivation to change with the patient and help the patient determine what their next step might be and what they need in order to take this step. Moreover, the Web-based portal allows health care providers involved in different levels of care to guide and monitor this process in the long-term, share data and communicate efficiently about the patient's progress.

C. Practice-Based Implementation-Evaluation

The authors are currently in the process of implementing and evaluating our approach in a number of cardiac rehabilitation centers in the Netherlands. We feel that our three-step approach to full self-management and the do-it-yourself patient portal are applicable to other areas in which lifestyle modification plays an important role, such as cardiovascular risk management, diabetes and chronic obstructive pulmonary disease management.

In order to evaluate actual use in the field and to obtain feedback on both the user experience and on clinically relevant outcomes measures, we aim to include several approaches. First of all, Rapid Application Development Processes, such as the Agile methodology, can be used for iterative usability evaluations. Thus, the patient portal can be continuously updated and the user experience improved.

Secondly, in order to evaluate which components of the self-management approach impact upon important outcomes, such as cardiac risk factors and health behaviors, we suggest an alternative to the randomized controlled trial (RCT) design. RCT designs typically evaluate the efficacy of an intervention - which can be defined as the effectiveness of an intervention under 'ideal conditions'. When a (behavioral) intervention is subsequently implemented in clinical practice, the residual effect may be much smaller as a result of delivery and compliance issues [17]. Therefore, alternatives to RCT-designs have been suggested that have greater ecological validity and greater generalizability as they are intertwined with the process of implementation [18]. So-called 'multivariate testing' (or 'split testing') methods are widely used to compare which of several versions of a Website performs better in terms of conversion rates [19]. We suggest that the concept of A/B testing may also be applied to comparing different versions of a behavioral intervention. For example, by comparing automated versus human coaching, text-message reminders versus online reminders, automatic registration of behavior versus self-monitoring etc., the content of the intervention can be optimized. Performance indicators would be progress in terms of the three self-management steps (e.g., move from self-confidence to self-regulation), and actual behavior shown (e.g., physical activity, smoking, diet etc.). When carried out in multiple settings and across a large group of participants, A/B testing will be able to project the impact of our approach in real-life situations, as well as allow for ongoing development and innovation. Thus, the 'optimal intervention' (for a specific setting) can be determined from a range of evidence-based behavior-change methods and supportive tools. Furthermore, uptake and implementation issues can be tackled whilst they are occurring.

III. CONCLUSIONS

This paper argues that adequate self-management requires (1) gaining the self-confidence to change behavior(s), (2) monitoring and self-regulating the new behavior(s), ultimately leading to (3) embedding the new behavior(s) in daily life. In order to support this process, a Web-based patient portal has been developed, which allows progress and outcome monitoring, and personal coaching. The portal provides tools and techniques for the professional to monitor patient-progress and give motivational feedback. The authors are currently implementing and evaluating this approach in cardiac rehabilitation.

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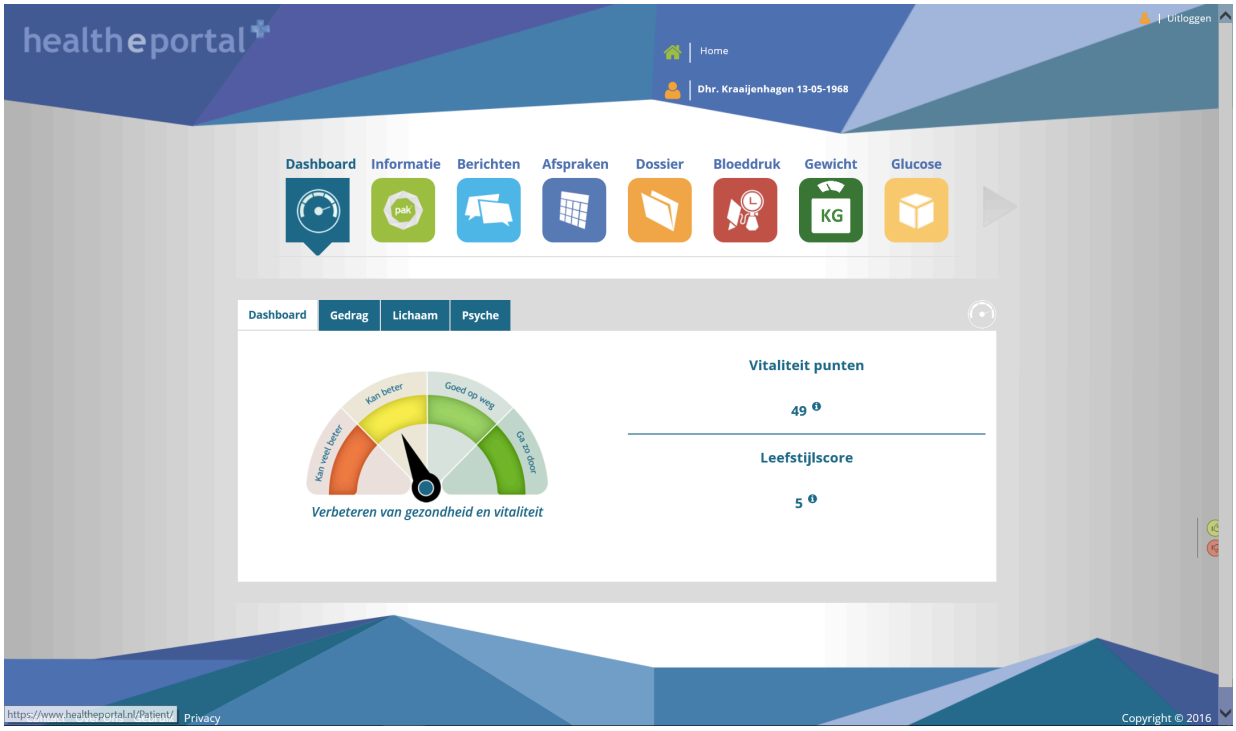

Figure 1. Screenshot of 'MyHealthePortal'