Design for Self-Management
Lessons learned from design for behavior change

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ABSTRACT

Self-management of chronic illness is a well-researched subject, however in spite of all this knowledge there seems to be little practical knowledge or use of this information in a design context. At the same time the research area of behavior and behavior change is well explored and has in recent years been the subject of some focus through the development of a new field of design research; design for behavior change, or persuasive design. Can we learn from the development of this field and the experience from project case studies to facilitate the evolvement of a field of design for self-care in chronic illness? The aim of this article is to explore the potential of using design guidelines derived from persuasive technology case studies in the design of self-management technology. As persuasive technology and self-management share a goal of facilitating behavior change and to systematize data from the user’s everyday life to help them reach their goals the guidelines for the design of persuasive technology are relevant to self-management technology and should be considered in the design process. Additionally five theory-based design strategies for self-management technology content are proposed.

KEYWORDS: Self-management, chronic illness, design, persuasive technology.

1. INTRODUCTION

Chronic illnesses, in addition to the disease specific symptoms, have several shared challenges that can severely limit quality of life for those that suffer from disease. Because of dietary restriction, lacking knowledge, stigma, medication routines, debilitations, embarrassing symptoms or side effects and more, many already struggling with managing pain, sense of loss and the cognitive load of dealing with it all find themselves isolated, confused and disappointed. Most patients want to be in control of their illness [1], however not many know how to gain control or have the necessary knowledge and understanding of the necessary behavior changes to successfully manage their condition [2].

Managing chronic illness in large part falls to the patient as it is necessary to find ways to structure management of the illness in a way that minimizes the negative effect on the individual’s quality of life as well as minimizing the time spent in health care facilities and resource use [2-4]. Products and technology for self-management has existed for some time, such as devices to measure blood sugar at home, but has gained more focus and interest in the light of the pressing need for a more diverse healthcare system as populations grow and grow old [2, 5]. Whereas healthcare professionals are naturally occupied with curing disease and symptom management, individuals living with chronic disease tend to see their illness only as one element of the entity that is their daily lives [6]. As for most people, daily life for the chronically ill is a compilation of social interactions, work and duties, activities and emotions, in which the experience of the illness needs to fit in somewhere. It is the totality of all these elements and the experience of everyday life that decides how the quality of life is judged. A holistic view of healthcare where the everyday life of individuals is the starting point is necessary if
technologies that facilitate self-management are to be successful and appreciated [6, 7]. However, although this need has been highlighted and requests for more research on methods has been made, little has been explored that treats support for the self-management of chronic illness specifically.

Self-management of chronic illness is a fairly well researched subject, in addition to research on the experience and self-image of the chronically ill.

In spite of all this knowledge there seems to be little practical knowledge or use of this information in a design context. At the same time the research area of behavior and behavior change is well explored and has in recent years been the subject of some focus through the development of a new field of design research; design for behavior change, or persuasive design. This field has become a promising method for encouraging healthier or more desirable behavior, which corresponds to the central focus of many self-management strategies. In the early years of the field focus has stayed with making healthier choices to prevent poor health or disease, however there is a potential to make more direct use of the methods to also aid the management of already existing long term or chronic illness although current knowledge is limited in this area. The question for this article is; can we learn from the development of this field and the experience from project case studies to facilitate the evolution of a field of design for self-care in chronic illness?

1.1 Method

The aim of this article is to explore the potential of using design guidelines derived from persuasive technology case studies in the design of self-management technology. The article is based on the summary of two very different fields of study. The first is a summary of the self-management literature to outline a set of elements that could or should be present in the design of related technology. Only articles on self-management as a treatment strategy for chronic disease have been included. The second is a summary of the literature on persuasive technology in a design context. Here only articles that seek to establish and try strategies, requirements or guidelines for the design of persuasive technology have been included. Persuasive technology was chosen as a subset from the wider category of design for behavior change because of the many practical applications and case studies available in the research literature.

1.2 Structure

The second section of the article contains the findings from the review of self-management literature and seeks to establish some core elements in self-management strategies that can be used to evaluate the relevance of the persuasive technology findings. These are presented in section three. In section four the finding from both fields are compared and evaluated and a set of design strategies for self-management technology are suggested in section five based on this evaluation and the review findings. In section six I discuss the findings and related concerns.

2. SELF-MANAGEMENT OF CHRONIC ILLNESS

Self-management, within the social sciences, is the process of minimizing the negative effects of (chronic) illness on everyday life by adopting a conscious attitude to choices that affect it [3]. Individuals with chronic diseases inescapably self-manage their illnesses every day, deciding what to eat, whether to exercise and when to take their medications, when and how to seek help and more [4, 8]. However, self-management of chronic diseases can take a lot of effort and willpower to establish for many patients, especially as they often struggle with a lack of understanding of the disease characteristics and the necessary self-management behaviors [2].

Various term are used for self-management in the scientific literature, the most common being self-management, self-care and self-help. According to Barlow et al. [3], “self-management refers 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” which is the definition used for this paper. Self-help also falls under this definition [9, 10], while self-care is defined as the process and practices of managing health and wellness goals in terms of general physical and psychological health benefits [2, 4]. Self-management approaches can be split in two general categories, those who focus on medication and symptom management and those that draw on social, cognitive and behavioral theories that usually focus on managing psychosocial consequences, lifestyle, social support and communication. The first category is necessarily mostly disease specific, whereas the second is more generic in its approach [3].

Although self-management at some level is inescapable [4, 8], the degree to which an individual wishes and/or has the ability to take on responsibility for their health differs greatly. Interest in personal involvement can vary, but even being involved only at the most basic level still hold some expectancy of being able to choose between alternative options or strategies that would take their individual needs and lifestyles into account [1]. For the scope of this article only self-management as a conscious choice and process to achieve better health through improved mastery of disease and related health issues will be considered.

2.1 The process of self-management

The process of developing a system of self-management practices begins with the individual’s awareness of the disease and the search for information to confirm their symptoms, or look for symptoms that match an unfamiliar or unexpected diagnosis [2]. Becoming aware of and accepting the diagnosis is the first element of the discovery of their illness, followed by a period of learning to live with the disease [11]. The patient will then rotate between these phases, switching back and forth between gathering information to deepen their understanding of their condition and implementing new information and experience into the daily self-management [1, 12].

After learning the basics of their chronic condition and accepting it’s permanency patients are required to in some way adjusting their lives unless they choose to live in denial of the disease. Adjusting their lives in this first stage can involve making time for treatment or having to rearrange their schedules to allow for doctors’ appointments or manage their medication [1]. Finally, it means having made the basic necessary adjustments and beginning to grasp the basic consequences of living with chronic disease. The experience and outcome of chronic illness is the conscious choice to take or not take control of the situation and their own role in managing their health [12].

Leading up to a conscious decision to take control are usually four “key insights”: understanding and accepting that the condition is forever, realizing that “textbook” treatments and prescriptions are inadequate or inappropriate, that they as the “owner” of the disease are the experts of their own experience and that they in fact already have some base from which to make decisions and lastly that if they do not take control no one else will do it [4]. From these insights arises a confidence that they can take control and a feeling of responsibility, on behalf of themselves and others, for taking action. This conscious decision is a central factor in the outcome of chronic disease in terms of health experience [12].

2.2 The Components of Self-Management

Self-management is a system of continuous decision-making regarding medication, treatment options, symptom management, general health promoting activities, attitudes and beliefs, education, social support and everyday practices such as work, caring for your family and hanging out with friends [3]. To make these decisions individuals build confidence by assessing their responsibility for themselves and others, as well as recalling previous experiences with making lifestyle changes and the awareness of stories of other people that had managed successfully in similar situations [4]. In addition, sufferers of chronic illness often have to deal with feelings
of anger, frustration or sadness because of their new situation, as well as managing expectations and motivation to stay on track even if their condition deteriorates or progress is slow. Corbin and Strauss organize these self-management tasks into three categories: 1) medical management, including medication, treatment and symptom management, 2) social role management, in both professional and private settings, and 3) emotional management [13]. Looking more closely at the most prominent elements, the selected literature points to the following central components:

**Understanding**
When faced with a new diagnosis, the individual will be faced with a great information demand. Searching for evidence of the disease through symptom descriptions and trying to piece together an understanding of the central mechanisms of the disease, expected side effects and the outlook for the future is a primary concern [1], and this knowledge is often constructed in collaboration between the individual and relevant health professionals [7]. However, this minimum of knowledge and understanding is seldom enough to fill the demand for information, and a realizing the limitations of this very basic knowledge can be a motivation for taking more responsibility in the self-education of living with a disease. In addition to clinical knowledge, a conscious decision to take control often includes a decision to or increased focus on listening to the body through self-monitoring, learning its individual responses and forming personal health goals in accordance with these cues [3]. In conclusion, gaining disease specific knowledge is central to the self-management process [1].

**Individualization**
Realizing that the standard definitions and practices of the prescribed treatment related to their disease is inadequate, or does not fit the individual’s lifestyle, is common as understanding of the disease grows [4]. Others may live with several chronic illnesses or other health impairments that require a high degree of individualization to coordinate the best options for dealing with multiple and sometimes conflicting advice [2]. Thus, a central component of self-management is the adaption of medication practices and treatment options to fit in the everyday life and demands of the individual.

**Network building**
Some individuals will shop for healthcare practitioners that will take their personal expertise seriously and build their own personal self-management network including social support networks of family and friends as well as self-help and support groups and practitioners of alternative healthcare, treatment facilities and other relevant stakeholders. Self-help and support groups are often initially visited initially for learning but will often evolve to support mostly social purposes, providing a safe environment where the health condition is a shared experience rather than something identifying the individual as sick or different [3]. To coordinate the different actors can be challenging, especially in transferring information [5], and motivation to expand or develop a self-management network is often also rooted in the decision to take control of the situation [3].

**Renegotiating everyday activities**
In chronic disease, individuals will often be forced to reevaluate their everyday activities and as some become impossible to continue, others become difficult or require support, and yet others are challenged as new practices related to the management of symptoms, treatment or health preserving measures take up more time and energy [14]. Many find it necessary to balance the demands of self-management against the activities that make the effort to manage disease worth it, and renegotiate their priorities when it comes to what activities are essential to their quality of life and which might be abandoned or reduced to make room for new demands on their time and focus [1].

**Renegotiating social roles**
Another aspect of the impact disease can have on everyday life is the way it potentially
affects the social roles an individual inhabits through the course of a day [14]. In addition to the new role as patient or impaired the management of and emotional impact of living with chronic illness can necessitate a renegotiation of existing roles [15]. For instance, being a care provider for an elderly or impaired relative can be an important part of an individuals identity that might be challenged by reduced capability or time as they struggle to manage their own health challenges, or an identity as the strong and invincible father that ensures his children are always safe and warm can be challenged by the demands of disease. As with the activities we shape our lives with, it might be necessary to balance the effort of keeping these roles intact against the importance they play in the individual’s self-image [14].

Self-care
Most patient that have made a conscious decision the manage their disease also engage in self-care, or activities to improve or maintain general health and wellness as well as possibly seeking alternative treatment options [1, 3]. Such activities will be a necessary part of successful self-management for many chronic conditions, but the motivation for the behavior goals or change often come from the opportunity to reevaluate their health and health activities when faced with a life changing diagnosis an increased awareness of the value of good health [16]. Many practices that are positive in a self-management context are also common self-care goals shared by people with and without specific health complaints or chronic illness, such as weight management, proper nutrition and physical exercise [5]. This can be used as an opportunity to reshape their priorities and identity to a more healthy lifestyle, focusing on these common and less stigmatized activities shared with people outside the boundary of their diagnosis and finding additional motivation to the necessity of lifestyle changes [17].

Managing emotional and cognitive load
Lastly, a substantial component of self-management is finding ways to manage the potential emotional and cognitive load of learning to live with a chronic illness. Being diagnosed with a chronic illness and learning that it is indeed forever, or indeterminately, and that it might involve unwelcome symptoms, reduction in motor or cognitive abilities, and in some cases an early death, will naturally tend to cause emotions of loss, anger, hopelessness, frustration and more, that can be challenging to deal with. Additionally, the cognitive load of processing disease-related information, restructuring everyday life and building new behaviors can demand enormous amounts of energy and mental capacity, reducing the ability to perform in other areas such as work and further pressuring the efforts to maintain the wanted self-image [14].

2.3 Successful Self-Management

The critical factors in making the right choices for successful self-management are several, but their common denominator is that they all derive from a conscious decision to take control of the self-management of the disease, a point that could be important to consider in a design process. When the decision is made, success follows from both explicit components like goal-setting and action plans, but also the degree of confidence or self-efficacy, and the attitudes and beliefs of individuals as they bring different levels of capability, understanding, socio-emotional characteristics and different sets of values and beliefs into self-management that impact the achievability of successful administration of health and illness [2]. Based on the literature this summarization of the most critical factors of successful self-management has been constructed:

Self-efficacy
According to Mitzner et al. [2], Self-efficacy is experience of control over one’s environment and behavior and is a central influence on an individual’s subjective experience of their illness and guides the cognitive and behavioral responses involved in self-management, as well as being associated with positive self-management behaviors and better health status. Barlow et al. [3] gives a more action-oriented definition: “Efficacious self-
management encompasses ability to monitor one’s condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life.”[3] For the purpose of this paper I borrow from the definition outlined by Mitzner et al. and define self-efficacy in self-management as the belief an individual holds in his or her ability to control or impact their health through behavior.

Goal-setting
For goal-setting to be beneficial to the self-management process it is essential that the goals are set by the individual [18]. Although symptom management might seem like a priority in managing disease, an individual might have other priorities that also take into account the way the disease fits in with their everyday lives and the roles he or she needs to or wants to fill. Only the patient can truly be the expert of his or her own illness experience and what are the more important goals [19]. In this context it is to be remembered that successful self-management can only be assessed by the individual and their personal experience of control, accomplishment and fulfillment [18].

Action plans
Action plans are goals deconstructed into actionable and immediately obtainable target behaviors. Breaking behavior goals into smaller sub goals makes them more manageable and increases confidence and makes the loss less prominent in the case of failure and increasing the likelihood of trying anew [16]. When action plans are realistic and thus evoking a high degree of confidence in their likely accomplishment in the owner, they are a powerful element in successful self-management. Bodenheimer et al. [8] propose measuring confidence that a task is manageable on a scale from 0 to 10, where 7 is maintained as the threshold for whether an action plan is likely to be accomplished. In self-efficacy theory it is held that the successful achievement of an action plan is more important than the particular behavior because the ultimate goal is to build confidence that can fuel motivation [8]. They remove doubt and cognitive load by specifying as much as possible when, where, how and why an action towards healthier behavior is to happen and preferably also includes alternatives or specifications for times when fatigue, disease symptoms or lack of motivation challenges the likelihood of accomplishment [2].

Perspective
Many patients tend to view their health needs as secondary to other needs in their immediate social environment, such as caring for a debilitated loved one or dealing with the loss of a spouse, or simply maintaining the activities and social relations they are used to [8]. According to participants interviewed by Thorne et al. [4] assuming control of their self-management gave them a shift in philosophical perspective related to their disease and meant they experienced having the power to “mediate the effects of the disease” so as to adjust it to fit their lives. This also entailed redefining their roles and relationship, as well as the disease itself and balancing the demands of the disease against the activities and relationships that made their lives meaningful [2, 14].

Motivation
Motivation in some instances can derive from the realization that by taking control of the management of chronic illness can counter preventable complications or from an understanding of how disease outcomes can be directly dependent on decisions made in relation to self-care and secondary prevention. Taking control in itself is and effective motivator for learning about the disease and internal learning as to the body’s individual response to interventions and contexts [4].

Education
According to Mitzner et al. [2] there is mounting evidence that lack of proper understanding of disease relevant information is a barrier to successful self-management and that this implies that even if individuals successfully gather and organize the required information it is likely they are not able to make use of it in a way that supports successful self-management. In addition,
health information is seldom presented with the patient in mind or to bridge gaps in education, literacy or capabilities. In other words, a last factor of success is the availability and appropriateness of necessary disease specific information and general health knowledge. Appropriate in this context refers to which degree the presentation of the material takes into account the literacy, culture and existing level of understanding of the recipient.

3. DESIGN FOR BEHAVIOR CHANGE

Persuasive design is a subset of design for behavior change that focuses on facilitating human behavior change through employing behavioral and other branches of psychology in a technology context. Because persuasive technologies are usually intended to be used in an everyday context of people’s lives, Consolvo et al. [18] argue that it is necessary to incorporate social psychological theories as well as the more traditional behavioral theories in the design of persuasive products. On this foundation they construct and validate 8 theory-based strategies for persuasive design that intersect with the individual’s social world. For the purpose of this study the author has drawn on these eight strategies as well as research by Nakajima et al. [20] and Kim et al. [21] to explore design strategies for persuasive technology that might apply to support for self-management strategies. The support for the findings are highlighted in table 1.

Abstract & Reflective
Abstracted data can facilitate awareness of and reflection on behaviors by visualizing behavior patterns and improving understanding of the connection with behavior consequences [20, 21] while providing the user with the control of whether or not the data is shared with the environment and thus allowing the data to be available and visible at all times without causing embarrassment to the user [18]. Another benefit can be creating emotional engagement through use of iconic metaphors with pre-attached meanings [20], or modeling health behavior [22].

Unobtrusive
Data should be collected and presented in such a way as to not unnecessarily interrupting or disturbing the user or calling unwanted attention to him or her [18, 20, 21]. Determining the necessary level of obtrusiveness is the task of the designer and will depend on the targeted behavior. Consolvo et al. [18] further recommend that that persuasive technology support occasional ignorability, as when a user is particularly busy or incapacitated. The disruptive nature of new technology should be minimized by ensuring continuity in time, space and aesthetics for the user[7].

Public & Flexible
Persuasive technologies can in some instances be necessary or desired to be available for use or reading anywhere at any time, and therefore should then preferably be appropriate for public use without causing stigma or unwanted attention [18, 20, 21]. They should also consider the everyday life of the user and be flexible enough to adjust to the need of the individual [5, 7, 23]. In chronic illness this could means making it adjustable to the disease specific demands or allowing for the relative health status of the user.

Relevant & Aesthetic
To ensure user appeal the technology it should be designed to be appropriately visually engaging and aesthetic [21]. It is also necessary for devices or products that are used in a private sphere to reflect the personal style of the user, whether it forms a part of the home interior or their clothing. This also means designing for cultural relevancy [22]. An aesthetic appearance can also improve surface credibility [18]. In a self-management setting the area of use can be assumed to be closely connected to the user or their home, and their concern for their health might make it important that they feel they can rely on the technology to be helpful.

Balanced Positive
To encourage change it is recommended to use positive reinforcement and avoid punishing the user, even when they fail to complete their goals [18, 20, 24]. A system of
rewards for performing desired behaviors or reaching their goals coupled with a lack of rewards rather than punishment is recommended as users can react negatively to punishment, especially when the lack of compliance is due to external factors that are not recorded in the system, and can cause them to lose motivation or stop use altogether [20]. However it is necessary to sustain the users interest even as they are hindered from using the system, possibly for some time [18]. Naka et al. [20] suggest that using solely positive reinforcement can cause the system to become “boring” over time, and that a design goal should rather be to create an overall positive experience [23].

**Controllable**
The user should be able to edit and/or manipulate their data when appropriate, such as when forgetting an input sensory device at home or running out of battery, or in the occasion of other relevant activities that are not measurable in the usual context or to reflect what the user might experience as a more suitable representation [18, 20]. This approach might also lower the threshold for those that might be uncomfortable or unaccustomed to parts of the technology system by allowing users to adjust data input methods to their preferences and experience with technology [18]. This might be a facilitating mechanism to chronically ill users who feel their cognitive capacity is already stretched by trying to cope with copious amounts of new information, routines and emotional strain.

**Trending & Historical**
A persuasion system should reflect and visualize trends and accomplishments over time to aid in the understanding and evaluation of the behavior change process and reinforcement of the positive associations of progress and goal attainment, as well as immediate feedback [18, 21, 23]. The possibility to be reminded of either past good behavior adherence or the positive development can act as a motivator and build confidence in the users ability to change. For the chronically ill experiencing a period of more intense symptoms or fatigue this might work as a positive reminder that things are not always bad and that they are obtaining something. Exploiting this to aid in the conscious use of previous experience in the development of personal self-management practices is a possibility for design that should be explored.

**Comprehensive**
All relevant behaviors should be includable in some way or other. Users can feel cheated if their efforts to make positive changes are not appropriately accounted for which may make them demotivated [18, 21]. Especially in users that require huge efforts to manage even small steps in the right direction or that go through periods of great discomfort while working towards their goal, as can often be the case in the chronically ill and people suffering from multiple diagnosis, this puts continued use at a high risk.

**Learning & Evolving**
Design for learning and understandability with respect to the main elements of technology is important to ensure the product is usable and relevant also to those that are unfamiliar or uncomfortable with the chosen technology [7]. Further the designer needs to consider the user as the receiver and interpreter of information and one who can take action to empower them to help themselves and remove the limits of the patient role [7]. Any feedback-loop should take into the account the changing perspectives and experience of the user and develop with the user [23].
4. RESULTS

The opportunities in design for self-management lie in the ability of designers to facilitate the process and management of its components. Facilitating the process of self-management might mean aiding users gain control and confidence and take on the responsibility of caring for their own needs. To facilitate the management of the relevant components the designer’s task might be to ensure the technology fits the user’s needs and their everyday life as well as making the tasks easier, reducing negative associations and ensuring long term adherence to self-management.

4.1 Self-management design requirements

Designing for better understanding of the disease mechanisms and trajectory should include tools to gather and systemize relevant information whether from self-monitoring, medical advice or disease specific information [2]. Facilitating the individualization of the self-management process however means the technology needs to be adaptable to the individual’s needs and symptoms [4]. Similarly, allowing for the user’s preferred network of experts, treatment options and social support could be necessary to fulfill the individual’s preferences and independence in their process [3]. In general designers should aim for a holistic focus that encompasses all relevant goals and needs for health and wellbeing, including self-care practices and renegotiation of daily activities as well as social roles. This might include allowing for slip-ups or conscious choices to stray from the self-management practices at given times without punishing the user, while at the same time keeping them on track and reducing negative effects.

Another important focus for the designer should be to consider the success factors of self-management and include support for them in technology aiming to aid self-management. In practical terms this could include designing content that asks the user to define personal goals for their life and health and to guide them in breaking long-term or abstract goals into tangible and obtainable action plans suited to their individual capabilities and needs. At a more overarching level the success factors imply that designers should also take into account the need to build self-efficacy and belief in own abilities in

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Table 1: Literature support for persuasive design guidelines
the users [2, 3]. Further the literature points to the benefit and necessity of an evolving perspective and to find elements of motivation that can help the user initiate positive behavior change as well as keep up long-term adherence to the changes and the process. Finally, continuously developing their knowledge and understanding of their disease and how to make beneficial choices for themselves has been shown to be important to successful self-management and should be considered by the designer of technology aiming to support the management of chronic and long term illness, including ensuring that the information is presented in a way that is meaningful to the user and that reflects their current level of understanding [2, 4].

4.2 Relevance of persuasive technology guidelines

In the light of the considerations designers should take when designing for the chronically ill it is possible to extract the possible benefits of taking lessons from the experiences with persuasive technology. Data abstraction can aid users in reflecting on past and current behavior and create a better understanding of the effect single or series of behaviors have on their health, a primary concern for design for self-management [1]. An unobtrusive product means that the use of the technology does not cause unnecessary intrusions in the user’s life and that the application of the technology is a positive experience. Similarly a product that is public and flexible will be available to the user at all times without causing stigma or unwanted attention, as well as being adaptable to individual needs. On the same path, aiming for relevant aesthetics includes aiming for suitability to the individual’s taste, but also that it evokes trust by appearing credible and enthusiasm by engaging and appropriate visual presentation.

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*Table 2: Points of intersection between self-management design requirements and persuasive technology design guidelines*
Another approach used in persuasive technology that might benefit self-management products is using positive reinforcement balanced with reminders and incentives to keep up long-term use and interest. Another relevant balance act recommended is keeping the collection of data as simple and unobtrusive as possible while still leaving the user in control of their data and what is recorded [18]. Connected to this point and equally relevant is the need to allow for a comprehensive collection of data, meaning that the technology should include all associated behavior and information. Also, preserving data over time to illustrate the user’s development over time through a trending or historical function would help to increase understanding and keeping things in perspective. Finally, learning and evolving means the technology and the content should adjust to the users level of understanding and grow with the user as their skills and experience increase, supporting self-efficacy and motivation to continue. The points of intersection between the design requirements for self-management and the guidelines for design for persuasive technology have been highlighted in table 2.

5. THEORY-BASED DESIGN STRATEGIES FOR SELF-MANAGEMENT

The design guidelines for persuasive technology are meant to be universally applicable and should therefore be relevant in almost any behavior change technology setting, as is also the case with self-management technology. Because of this broad applicability however, they afflict themselves very little with how to design for the content of the technology with the exception of some design researchers that advocate more direct use of behavior change theory [22]. Self-management theory however has well developed structures of self-management behavior change requisites and recommendations that can help fill this gap. Based on my findings in self-management and persuasive design literature I have constructed 5 design strategies for self-management technology content that is intended as an extension to the established persuasive technology guidelines.

1. Design for self-management tools

*Self-management tools have been found to be a success factor in successful self-management and should be the cornerstone of the technology content.*

There are several tools for self-management that can help users reach their goals, such as education, goal-setting and action plans. Education and learning is a central component in persuasive technology guidelines, but self-management literature points out that including disease specific information can be beneficial. Goal-setting as a tool should be as explicit as possible to increase motivation and make the evaluation of progress easier. The technology should also allow for individual needs through use of both short-term and long-term goals. Action plans should be designed for in such a way that they are as comprehensive as possible in mapping the context in which a target behavior should happen. To ensure realistic plans that have a high probability of achievement the level of confidence could be used as a measure to evaluate action plan feasibility.

2. Design for self-management drivers

*Self-management drivers are the motors of self-management behavior change and work closely with the self-management tools.*

Drivers are what create the power to take responsibility and to change and should not be underestimated for potential effect on self-management results. From the literature we recognize knowledge, perspective, motivation and self-efficacy as important drivers. Knowledge should be recognized as a force in it’s own right and be actively rewarded through user driven application to assess the level of experience and understanding to adjust technology and behavior change demands on the user. When designing for motivation it should be considered that motivation is not only a driver but also important to the experience, as being
motivated necessitates a desire to change as opposed to only a need to change. In other words designers should be careful not to exhaust the potential of motivation as a driver, but rather aim to allow for a surplus. The most important driver is still self-efficacy, and it is essential that the technology can assist the user to demonstrate to his or her self that they possess the power to change their behavior.

3. Design for change

In illness, the abilities and capacity of the individual can change abruptly and this needs to be considered in the design of all technology for disease management.

Considering how to facilitate user interest is important, but equally vital is the development of appropriate strategies to overcome disruptions that challenge motivation, self-efficacy, capacity or ability. Unforeseen disruptions can also be or feel extremely unjust to the individual and special care should be taken to defuse any negative emotions or associations they create.

4. Design for the long-term

Chronic disease management is forever and requires a long-term perspective as well as strategies to overcome the inevitable disruptions and setbacks that will occur in the disease trajectory.

Designing for sustaining long-term use of the technology is a prerequisite if the technology is to hold real value to the self-management process. In self-management the technology should further consider the evolving expertise and capabilities of the individual as they gain experience, knowledge and understanding from managing their disease over time. As the know-how evolves, both scope of target behavior goals and the complexity of the technology should evolve with the user to maintain interest and reward the progress that happens outside the actual behavior change.

5. Design for the illness experience

The success of a self-management strategy depends on the positive contribution it makes to the quality of life and the illness experience of the individual.

Although explicit goals are better suited as marker for behavior change, the overarching goal is to ensure a holistic self-management process that allows for human personal needs such as growth and learning, human value, social connectedness, variety, safety and contribution. Several of these are integrated in the four strategies above, however needs of social belonging and personal value should receive particular focus as elements of the illness experience. This can include use of positive reinforcement, promoting self-efficacy and designing for normalization to avoid isolation and stigma.

6. DISCUSSION

A very real challenge in considering the applicability of persuasive technology design guidelines to the development of design strategies for self-management tools is of course the absence of existing tools, good or bad, to evaluate. The current literature that has been laid to ground in this review is predominantly based on research from workshops, interviews and self-management classes and not tools that individuals use in the actual self-management process [2].

Another limitations is that the case studies that were used as background for the persuasive technology design guidelines are mostly concerned with simple, singular behaviors rather than the complex variety of behaviors and components that are addressed in self-management practices. Actually gathering all relevant information could also mean users spend more time tracking their behavior than living, thus there is a need to find a balance between what is needed to get useful data and what is manageable and sensible in terms of effort. It should also be mentioned that while chronic illnesses often share many requirements and characteristics, they can also be widely different and no set of
guidelines will be able to encompass all varieties and at the same time be useful across the board.

Considering how much should be included is also a relevant question in terms of user control and values. None of the guidelines consider how values that designers bring to the technology might affect the use of them, or how much control should be left to the user. Exploring the boundary between what the user can successfully take responsibility for and what should be assumed and directed by the designer is a subject that is little explored in this article but that is a very important question in the development of all technology and in particular technology that aims to facilitate behavior change by exploiting knowledge on human psychology as in behavior change theory. This is also especially important when dealing with sick people that might be too tired and desperate to make well-considered decisions on their own personal boundaries and privacy.

Additionally, none of the persuasive technologies have been tested over more than 3 months, most only for a matter of weeks, which makes it difficult to evaluate their validity for the long-term use that is so important in self-management. There are no guidelines that specifically treat how to support long-term user involvement, although some references are made under Balanced Positive, however this is necessarily an important focus when dealing with chronic illness. It is also a challenge that self-management is not completely voluntary. Even when the process is the result of a conscious decision to take control, the user did not choose to become chronically ill and is likely to bear some resentment that can challenge motivation. Tired and sick people might require more slack and more motivation, without the technology becoming obtrusive or annoying, which also puts more stress on the designer to find the right balance. It should be noted that although increasing the likeliness of behavior change might appear to be the target of self-management, in fact it is with all likelihood possible to improve the experience, the sense of control, the understanding and reduce the psychological load without the absolutely unavoidable changes in behavior and could be an approach to explore for the very reduced individual.

Looking at the development of healthcare technology experience with the health condition in the equation and ways of coping in daily life is important, and only those living with the condition can provide that experience and determine their own standards of life quality [8]. However this need is seldom verbalized and can be unavailable outside of context [7]. Besides involving the future users in the development of a technology or product, designing for flexibility in the use of a product can help users personalize the support system to their needs. Co-design and other adjacent methods might have some potential in gaining understanding of the users needs and perceptions of what quality of life is to them. At the same time, as much as a pure technical perspective on healthcare technology fails to include important perspectives, so may also the perspective of the potential user be somewhat limited in perception of actual possibilities in innovation. It is of course the role of the designer to make these connections and to understand the underlying problems of the future users, but when resources are limited gaining enough understanding from interviews or workshops can be challenging. It is therefore necessary to explore fields such as self-management separately with regards to possibilities and implications for design, so as to create a better platform from which to develop new innovations.

The guidelines for persuasive technology do not approach the complexity of the illness experience and the holistic health behavior change that is often necessary in self-management, as they are developed predominantly to target specific areas of behavior change such as more physical activity, reducing electricity use or developing better tooth brushing routines. On the other hand it could be said that the self-management tools are in a way more specific
as they involve the actual process of behavior change, whereas the guidelines occupy themselves more with how to make behavior change technology in general be successful. Further, as self-management literature occupies itself predominantly with the conscious decisions of the user a more explicit use of behavior change theory could help highlight the subconscious aspects of this process

The successful use of these guidelines could possibly be easier if used together with specific examples from technology case studies that share some resemblance to the self-management design challenge that is approached. Some examples from persuasive technology case studies that might be relevant in the development of self-management technology, but that is not universal enough to be considered general guidelines exist. For instance, it has been found that numeric representation does not increase awareness or motivation, however they help set explicit goals and a combination of numeric and abstract representation can increase understanding [21]. This indicates that there might be some potential in exploring the possibility of combining numeric an abstracted data representation to gain maximum benefit in goal-setting strategies and self-education.

7. CONCLUSION

As persuasive technology and self-management share a goal of facilitating behavior change and to systematize data from the user’s everyday life to help them reach their goals the guidelines for the first have some relevancy for the last and should be considered in the design of technology to support the self-management of chronic disease. However, as no such technology exists today this applicability is purely theoretical and a primary concern for further study would be to develop testable prototypes. To do this it will be necessary to define what the goal of the design is, whether to support understanding, through data collection and analysis, to facilitate behavior change directly through goal-setting and action plans, to reduce cognitive load, by aiding in medication management, managing contact info for practitioners in the healthcare network, reminders of treatment or exercises, or to aid in changing the perspective for a more positive and self-efficient one. These are not mutually exclusive, or exhaustive, and can potentially be combined to gain a wider understanding and a more holistic approach to self-management. Technology for self-management is a highly relevant and interesting field of study that needs to be explored further.

8. REFERENCES