

Management of Weight-Loss: Patients' and Healthcare Professionals' Requirements for an E-health System for Patients

Anita Das¹, Arild Faxvaag¹, and Dag Svanæs²

¹ Norwegian University of Science and Technology (NTNU),
Department of Neuromedicine, Medisinsk Teknisk Forskningscenter,
NO-7491 Trondheim, Norway

² Department of Computer and Information Science, Sem Sælandsvei 7-9,
NO-7491 Trondheim, Norway

{Anita.Das,Arild.Faxvaag}@ntnu.no, Dag.Svanæs@idi.ntnu.no

Abstract. An increasing number of patients with overweight undergo weight-reduction treatment. However, many people experience challenges with long-term maintenance and are in risk of weight-regain. Currently there is no unique solution that ensures long-term maintenance of lost weight. Several studies have explored the effectiveness of web-based and e-health interventions, on improving the outcomes of weight-management. The results are unclear. This paper describes requirements for e-health solutions for weight-loss patients. Our findings suggest that such solutions need to be developed in collaboration with both patients and healthcare professionals to ensure that they are in line with medical treatment in addition to taking consideration to the behavioral aspects of using such systems.

Keywords: Design, E-health, Healthcare, Obesity, User involvement.

1 Introduction

Involving multiple stakeholders in the design process is challenging due to the required time and investment. Within the healthcare domain, e-health systems typically have multiple end-user groups with widespread backgrounds and interests [1]. Patient-centered e-health solutions are patient focused, but are not always in conjunction with disease-management programs, in which healthcare professionals have a central role. For such systems it is therefore important to include the perspective of all stakeholders, both different patient groups and the relevant healthcare professionals.

Until lately, obesity have been managed within the primary care, but due to the increased prevalence of severe obesity, the demand for interventions such as surgical interventions and lifestyle programs offered by the specialist care is rising. People that undergo such treatment require lifelong lifestyle modification with focus on dietary habits and physical activity. With the treatments taking place within the specialist care, patients increasingly need to conduct self-monitoring activities in their home environment with little follow-up by healthcare professionals. E-health solutions hold

the potential to support patients after initial weight-loss, to help establish, support and maintain lifestyle changes. Successful long-term maintenance is associated with self-care management and self-monitoring [2]. However, conducting such activities are labor intensive, and compliance is often difficult [2]. Hence, we need a better understanding of the experienced challenges after treatment, about aspects influencing upon non-compliance, and how self-management can be promoted by the use of e-health systems in weight-loss patients. To be able to design a clinical e-health solution for this patient group, a first step is to gain knowledge and understanding of the challenges they experience, and further investigate how the behavior change process can be promoted by the use of e-health solutions. In this study we have involved patients and healthcare professionals in a participatory design process of a clinical e-health system, to elicit the multiple user groups' requirements and perspectives towards such a system.

2 Background

The prevalence of obesity in the western countries has increased the last decades [3]. Obesity is associated with increased morbidity and mortality, and is a risk factor for diabetes, cardiovascular problems, hypertension, cancer illnesses, osteoarthritis as well as other health problems of psychosocial characters [3]. Increasingly, obesity is being recognized as a chronic disease itself, requiring health interventions. Weight-loss has beneficial effects in co-morbidities and long-term survival, and can be achieved through lifestyle intervention, bariatric surgery or pharmacotherapy [4]. However, long-term maintenance of lost weight is difficult, and studies show that conventional treatment (incl. lifestyle modification programs and pharmaceutical agents) is relatively ineffective in a long-term perspective [5]. As for today, surgical interventions are shown to be the most effective, and produces substantial initial weight-loss in the great majority of patients [5]. However, studies imply that weight-loss of bariatric surgery is temporary, and that many patients regain weight after a while [5,6]. Long-term weight maintenance is therefore a challenge regardless of initial weight-reduction treatment, as many experience weight regain after a period of time.

Weight-reduction programs are resource demanding for the individual patient as well as for the healthcare services considering the time, economical costs and emotional investment it requires. Currently there is no unique solution that ensures long-term maintenance of lost weight [7]. Several studies has explored the effectiveness of web-based and e-health interventions, on improving the outcomes in the area of weight-management, physical activity and dietary intake with unclear results [7].

Since its infancy in the 1980s [8], the perspectives and techniques of Participatory Design (PD) have become part of the state-of-the-art in systems development. As exemplified by Druin's work with children [9], certain user groups require modification and adaptations to the existing PD methodologies. We will here report from a Participatory Design project with another non-standard user group: Obesity Patients.

3 Methods

During 2009 we conducted a qualitative study involving a series of four participatory design workshops including patients and healthcare professionals. The inclusion criteria for the patients were that they (a) had completed a weight-reduction program offered at the local hospital, (b) were age 18 or above, and (c) had basic proficiency in Norwegian language. The study got approval from the regional Ethics Committee (Central Norway, Trondheim), and all participants provided written consent when enrolling to the study.

3.1 Workshops

We conducted separate workshops with the multiple groups, and two facilitators from the research team had the roles as moderators during each workshop. Healthcare professionals were included in the first workshop, followed by two workshops that included patients that had undergone weight loss treatment either through conventional treatment (lifestyle therapy) or bariatric surgery.

The workshops consisted of design tasks, semi-structured interviews and group discussion. In advance, we had clarified the topics that were to be discussed, and we used open-ended questions that were followed by probing questions that clarified the participant's responses. The objectives of the workshops were to systematically gather information, ideas and perspectives from the multiple user groups.

Finally, we conducted a last workshop where we included selected participants from the previous three workshops. The purpose of the last workshop was to present our results, and to validate the findings. Each workshop lasted for 3.5 hours, and the whole session was video-and audio recorded.

3.2 Analysis

The recordings from the four workshops were transcribed verbatim. The data was analyzed qualitatively using a grounded theory approach [10]. The transcripts were coded before these were grouped together, and themes were identified.

4 Results

The aim of this study was to describe patients and healthcare professionals requirements of an e-health system to promote self-care management after weight-loss, to explore differences between these perspectives, and to assess the implications this may have for further e-health system development.

4.1 Participants

In total 20 people participated in the workshops, 12 people that had undergone weight-loss treatment at the local hospital, whereas six people had gone through bariatric surgery, and six had attended conventional treatment. Eight healthcare professionals attended the workshops, and their professional background was from nursing, medicine and clinical nutrition. Demographics are presented in table 1. To validate our findings from the first three workshops, we invited all the participants to

Table 1. Demographics

Participants	Female	Male	Total
Professionals	6	2	8
Lifestyle group	5	1	6
Surgery group	4	2	6
Total	15	5	20

a final workshop. Not all were able to attend this workshop due to personal practicalities, and the last workshop consisted of 10 participants. Five were from the healthcare personnel group, two from the conventional therapy group, and three from the bariatric surgery group.

4.2 User Requirements

All the groups suggested a secure-web-portal solution that would be accessible through the Internet. The benefit of gathering several features in one portal was the main reason. The possibility to send news feed and reminders from the web-portal to the users mobile telephone was proposed as an extra feature to motivate use of such a system. Ethical and privacy issues were discussed, and secure access that requires username and password for all users was pointed out to be important, as access to the system would only be give to patients treated at the hospital. Patients that had undergone weight reduction treatment would be the primary user, and healthcare professionals would have the role as moderators and facilitators.

The findings from the workshops identified that the multiple user groups have rather similar requirements when it comes to the features that they emphasize as important in a clinical e-health system for weight-loss patients. Table 2 gives an overview of the suggested features to be included in the system. However, the multiple groups have differing perspectives and rationales towards such a system.

Table 2. Required features in a clinical e-health system after weight-reduction treatment

Requirement	Healthcare Professionals	Patients
Information	X	X
Articles		X
Links	X	X
Discussion Forum	X	X
Private Communication	X	X
Buddy System		X
Self-management tools:	X	X
- Diary	X	X
- Notes		X
- Calendar	X	
- Diet plan	X	X
- Exercise plan	X	X
- Clinical Measures	X	
- Reminders on sms	X	X

Several broad themes were identified, and the participants emphasized patient education, communication and disease management as the most crucial ones. These issues will be further elaborated from the multiple perspectives.

4.3 The Healthcare Professionals Perspective

Healthcare professionals have the responsibility to provide patient education. According to the healthcare personnel group they use much time on providing and repeating the same information to the same patients several times, but they experience that the patients claim not have received this information, and that they are non-compliant. As a result, the healthcare professionals had started documentation of provided information, and experienced that this was the reality. As one of the professionals expressed:

“Not all, but let us say that 70% (of the patients) asks questions about things they already have received information about.”

The professionals were particularly worried about the patients that undergo bariatric surgery, due to the nutritional and metabolic problems that these patients may experience if non-compliant to recommended post-surgery regime. Such surgery is an intervention to help patients loose weight and involves a decrease of the size of the stomach. The necessity of preventing undesirable repercussions of the treatment is crucial. The patients need to undergo major changes considering eating habits, and they are dependent on taking lifelong vitamin supplements daily to prevent developing nutritional deficiencies over time [5]. The surgery alone is not the solution to weight-loss, and they need to follow guidelines for diet, exercise and lifestyle changes to prevent long-term weight-regain.

The healthcare professional group suggested to provide more elaborate patient information in the e-health system, and had hopes that this could support patient education. Insecurity among the patients was another issue that was discussed in relation to patient education. Particularly this was observed among the bariatric surgery patients, where lack of information regarding food, diet and nutrition was a recurring topic. Positive patient outcomes, confidence and prevention of future malnutrition were the rationales that the professionals emphasized.

Enhanced communication between healthcare professionals and patients, but also among patients was highlighted as important issues that could be promoted in a future e-health system. To serve different communication purposes, an online discussion forum where the patients could discuss and share experiences was suggested, as well as private communication for one-to-one dialogues. The healthcare professionals experienced that patients seek contact with others in the same situation, and are positive towards that patients can learn from each other. However, they had experienced patients that had been misled due to wrong information they had found online and in chat-forums. If possible, they would like to be there for their patients, as one of the healthcare professionals put it:

“The first thing is how important it can be if some of use are moderators (for the forum). There are enough online forums for these people, but these are not forums where experts (professionals) are present. That is where we can contribute - as a source to knowledge, as a source to correction.”

The healthcare professionals were aware of the fact that some patients would like more frequent consultations, and professional guidance and advice in some periods after treatment. Particularly they experienced that during the first phase after treatment, the number of telephones to the clinic increased, and sometimes a simple question could turn out to become a long lasting telephone consultation. With the time pressure-and workload, some emphasized the potential of using electronic medias for information, and one-to-one communication channels, that could provide efficacy benefits for the clinic. As of today, electronic communication with the use of e-mail and chat rooms are established ways of communication. However, within the specialist healthcare in Norway this is not an established reality. The reasons are complex, and may be explained by the legal issues that limit healthcare professionals to use electronic communication channels due to the security aspects. Another factor is the economical model behind the financing of the healthcare system in Norway, where face-to-face consultations and telephone calls gives benefits, rather than electronic communication that still does not exist as an option within the billing system.

Patients self-care management and disease management was emphasized as crucial by the healthcare professionals. An e-health system that could promote self-care management activities, and where the patient can organize and structure their day were heavy arguments for implementing such a system closely connected to the clinic. The professionals experienced that several patients lacked structure regarding eating and exercise. They suggested that reminders about eating could be of help, and that the patients could receive these reminders on their mobile telephone, as most people carry their phone wherever they go. Such reminders were also proposed to apply to vitamin pills and doctors appointments. Another self-management activity they currently recommended for their patients was to write diaries. They observed that when patients wrote a diet record or diary, this raised awareness about diet and diet pattern. However, according to the healthcare professionals, many patients were non-complaint towards diary writing, but they would advocate implementing a diary feature in the system anyway. The possibility of for instance sharing the diet record with the dietitian (for feedback) could be a motivational factor for starting to use such a tool.

4.4 The Patients Perspective

The patient groups expressed that in contrast to the healthcare professionals, they experienced that their information needs were not addressed sufficiently in the current clinical practice. An e-health system could promote information access, providing patient information retrieval whenever they needed it. Tailored information according to the treatment was underlined as important. Patients that were operated emphasized the need for elaborated information regarding the postoperative phase, about expected side effects of the operation, and about food and nutrition, as many experience food intolerance due to the surgery. Some could tell that the information they had received on paper had been misplaced, and after that the information was gone. In lack of information from the hospital, some had searched for information online, with the result of becoming even more confused. The Internet provides amounts of information, and the overload makes it difficult for patients to filter what to trust, and what to ignore. A place with validated information that they knew was correct would make the information retrieval process easier. One of the patients that had undergone surgery searched online, and ended up in a obesity forum with the following experience:

“That page... if you write something there, then you get an answer that belongs nowhere. Then you get a sensible answer, and then you have three others that criticize the sensible answer. And then you are back where you started, what is correct?”

The patients in the conventional therapy group did not express the same need for information regarding food and nutrition as the other patient group. These participants had gone through a lifestyle therapy program involving a residential intermittent program at a Rehabilitation Centre. The basis for this treatment is dynamic group based psychotherapy, but in addition the patients take part in a structured Physical Activity (PA) program daily (2 sessions of group PA+ one individual/day), and in a nutritional education program (about estimation of energy-balance, food, healthy cooking and eating etc). The ultimate aim of the treatment is to empower the patients so they can be in charge of their own lifestyle change. However, these patients emphasized that they needed information that clearly stated guidelines for diet and physical activity according to their physical health. Several of these participants had knowledge about healthy food, but had difficulties estimating the amount of food to eat, and to establish healthy lifestyle habits. Further they emphasized communication with healthcare professionals and other patients, for both evidence-based information that professionals holds, in addition to the experiential knowledge that patients have. Several of the participants in the conventional therapy group had reduced significant amount of weight, but had regained weight after a while. Using food as coping mechanisms, and lack of structure in daily life were issues that were mentioned as the causative factors. A woman in this group put it as follows:

“I eat because I like it, not because I necessarily am hungry. Food is, I probably eat in response to emotions – many people do that...So if I am happy - I eat, if I am bored - I eat, if I am exited - I eat.”

Regarding Disease Management, suggested tools to support self-care management were reminders on sms, diary writing, meal plans, PA-plans and commitment to others. One of the patients experienced that commitment was a motivational factor to exercise:

“For me, it helps with commitments, and for instance such as workout partners. And then it can be the fact that the exercise group has limited number of places. So when you get place, then you just have to show up.”

Lack of structure was mentioned as a challenge in both patient groups. The majority of the patients described their daily life before treatment as unstructured regarding food, diet and exercise, and many described poor and inconsistent eating patterns. Changing their lifestyle was a challenge for many. As one woman said:

“I am structured when I am at work, then everything goes according to the clock in my mind. It is during the weekends (the challenges come), because then I am free.”

The patients believed that the disease management process could be facilitated by the use of a clinical e-health system. A system with several features gathered in one

portal was the main argument for wanting to use such a system. Validated information by professionals, and that professionals can act as moderators and correct invalid statements or misinformation, were highly rated requirements. In contrast to commercial web-portals and websites, the expertise that professionals hold about the treatment of severe obesity is invaluable for the patients going through such treatment. Several patients could tell about little understanding about their condition from their surroundings, and underlined that professionals’ with knowledge about their particular condition was extremely important. General information about weight-loss and dieting becomes irrelevant, as these people experience their situation as more complex than only reducing weight.

4.5 The Perspectives Compared

The main differences between the rationales of the patients and the healthcare professionals can be summed up as show in table 3.

Table 3. Multiple rationales

The Professionals’ Rationales	Requirements	The Patients’ Rationales
Patient education	Information	Self-care
Efficacy	Communication	Support, guidance
Prevent side-effects	Self-management tools	Social network
Patient self-care		Health outcomes

Our findings imply that a clinical e-health system can promote validated information delivery and retrieval, enhanced communication, and self-care management tools for the patients. Even though the multiple groups’ requirements were similar, the rationales differ.

5 Discussion and Conclusion

Traditionally healthcare treatment has taken place in hospitals and healthcare institutions. Lately there has been a paradigm shift, where treatment also takes place in the home environment of the individual, particularly within chronic care. An understanding of this environment is crucial when implementing new technology. Patients hold on unique experiential knowledge, and they provide insight to their daily life, and about what their challenges and needs are.

Patients that have undergone weight-reduction treatment due to severe obesity need to implement lifelong lifestyle modification, and are dependent on implementing self-care and disease management. Our findings indicate that a clinical e-health system for this patients group would benefit from active involvement of healthcare professionals, even though the patients would be the primary users. Commercial e-health systems are probably more economical, but provide less professional contact [11]. The patients emphasize access to validated health information and communication with healthcare professionals. They require a social network with patients for social

support and experiential knowledge, and their main rationales are improved health outcomes and weight-management. The healthcare professionals emphasize patient education, prevention of side-effects of the treatment (bariatric surgery patients), and enhanced patient self-care management. Their rationales are efficiency of clinical practice, patient health outcomes, and improved quality of care.

In this project we also determined that we were dealing with two distinct user groups: Those undergoing surgery and those going through conventional lifestyle therapy. The difference was not mainly concerning medical or social characteristic, but simply the fact they had different needs. Having undergone weight-loss surgery leads to specific needs that are irrelevant for the other group. Mixing the two would only lead to confusion, and underlines the importance of involving multiple user groups during the development process. Professional knowledge and the experience that clinicians have gained over years are irreplaceable, as they have evidence-based knowledge about a whole group, and not only about one individual patient. That a clinical e-health system contain information that is in line with medical treatment is crucial. Our findings imply that when designing such a system, the perspectives of both healthcare professionals and patients need to be addressed, particularly when the system is to act in the continuation of the medical treatment offered by the specialist care.

Multiple stakeholders have different backgrounds, interests and expectations towards a system. In this study we found that the multiple groups' required features for a clinical e-health system for weight-loss patients are quite similar, but the multiple groups had different perspectives and rationales. These are important in a system development process, and imply that inclusion of multiple user groups may provide an added value when it comes to input about what to prioritize for implementation. The multiple user perspectives and requirements complement each other, and provide valuable input for system design. Our findings imply that development from only one perspective may contribute to a system that lacks important content and functionality.

Acknowledgments. We thank the participants for sharing their time, valuable experience and great ideas.

References

1. Årsand, E., Demiris, G.: User-centered methods for designing patient-centric self-help tools. *Informatics for Health and Social Care* 9 33(3), 158–169 (2008)
2. Tsai, C.C., Lee, G., Raab, F., Norman, G.J., Sohn, T., Griswold, G.G., Patrick, K.: Usability and Feasibility of PmEB: A mobile Phone Application for Monitoring Real Time Caloric Balance. *Mobile Networks and Applications* 12, 173–184 (2007)
3. World Health Organization, <http://www.who.int/en/>
4. Fujioka, K.: Management of Obesity as a Chronic Disease: Nonpharmacologic, Pharmacologic, and Surgical Options. *Obesity Research* 10, 116–123 (2002)
5. Karlsson, J., Taft, C., Rydén, A., Sjöström, L., Sullivan, M.: Ten-Year trends in health-related quality of life after surgical and conventional treatment for severe obesity: the SOS intervention study. *International Journal of Obesity* 31, 1248–1261 (2005)
6. Fujioka, K.: Follow-up of Nutritional and Metabolic problems After Bariatric Surgery. *Diabetes Care* 28(2), 481–484 (2005)

7. Neve, M., Morgan, P.J., Jones, P.R., Collins, C.E.: Effectiveness of a web-based interventions in achieving weight loss and weight-loss maintenance in overweight and obese adults: a systematic review with meta-analysis. *Obesity* 11, 306–321 (2009)
8. Ehn, P.: *Work-Oriented Design of Computer Artifacts*. Lawrence Erlbaum Associates, Inc., Mahwah (1991)
9. Guha, M.L., Druin, A., Chipman, G., Fails, J.A., Simms, S., Farber, A.: Working with young children as technology design partners. *Communications of the ACM* 48(1), 39–42 (2005)
10. Glaser, B.G., Strauss, A.L.: *The discovery of grounded theory: strategies for qualitative research*. Aldine, Chicago (1967)
11. Gold, B.C., Burke, S., Pintauro, S., Buzzell, P., Harvey-Berino, J.: *Weight Loss on the Web: A Pilot study Comparing a Structured Behavioral Intervention to a Commercial Program*