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Informatics-based Learning Resources for Patients and their Relatives in recovery

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Abstract

In this paper we describe experiences from design of an informatics-based learning resource for patients and relatives. The prototype, REPARERE (learning REsource for PATients and RELatives during REcovery), aims to support patients and their family recovering from heart surgery in meeting challenges in to daily living post discharge.

Using recovery experiences and patient teaching material, REPARERE includes examples of textual information, video-clips, images and illustrations relevant to the recovery trajectory and a user's digitally represented profile. The development of the prototype focuses on flexibility and usability, tailoring and sequencing resources, and inclusion of recommendations for universal access.

Development of web-based learning resources allows for exploration of 'just-in-case' and 'just-in-time' strategies to information retrieval and knowledge construction in health and learning trajectories. Findings from the literature, discussions with patients as well as health care providers indicate that unfulfilled information needs in the recovery period are common. Resources like REPARERE would be valuable supplement to facilitate patient learning about symptom management, self-care and coping while recovering.

Keywords; Patient learning; trajectory; consumer health informatics; tailoring; 'just-in-time'; 'just-in-case'; Open Source; universal access

Introduction

In new or unfamiliar situations access to "common" or "normal" experiences or suggested strategies can promote self-care, enhance coping and independence [1, 2, 3]. Appropriate information resources to handle personal health and illness situations are in increasing demand. The general public as well as recovering patient and their families request valid information and useful strategies appropriate to handle specific health issues [4]. Dealing with health and illness can be understood as trajectories [5, 6]. Although an individual's

trajectory is most often seen in retrospect, insight from common paths in a specific condition's trajectory are important to understand developing and changing nature of information and communication needs in a period of recovery.

Carefully developed and deployed technology mediated information- and communication interventions carry potential to effectively support trajectories of recovery following acute illness, or in learning to live with chronic conditions. Previously reported experiences of information and communication resources like HeartCare [2], Baby-Care Link [3] and CHESS [7] have pointed to increased consumer proficiency and coping, improved symptom management, enhanced self care, and increasingly empowered users. However, web-based learning resources seem few in number, and may therefore be regarded as an underused resource for self-care, symptom management and coping.

This paper shares some experiences from design of the prototype REPARERE (learning REsource for PATients and RELatives during REcovery), a learning resource supporting patients and relatives in recovery from Coronary Artery Bypass Graft (CABG) surgery. These experiences are used to illustrate potential uses for web-based learning resources that strengthen current approaches to patient education.

Materials and Methods

Information content for the prototype REPARERE came from analyses of collected information from four different sources. These included 1) semi-structured interviews with convalescents and one of their family member, 2) participatory observation of information meetings for patients and relatives when they were still in the collaborating heart clinic, 3) focus group interviews with health care providers about their patient information program, and 4) recovery experiences and information needs published in the literature.

Using a purposeful sampling technique, a group of convalescents in different periods of their recovery (10 male, 7 female) consented to semi-structured interview. They were asked about their recovery experiences and information and communication needs post hospital discharge. Only the male participants pointed out a family member, therefore 10 female

family members also provided information about their role as family member, and their information and communication needs during the family member's CABG recovery. The health care providers (physicians, nurses, physical therapists and social worker in the heart clinic's surgical or rehabilitation unit) provided information about their patient teaching program to prepare for the recovery period. The literature was identified by combining keywords; 'recovery', 'CABG', 'rehabilitation', 'trajectory', 'quality of life', 'spouse'.

This collected material was subject to content analysis [8, 9]. The themes identified in the analysis gave a picture of information and communication needs according to the perspective of the convalescent, family member and health care provider. This informed selection of content, sequencing of material according to the recovery trajectory, and choice of presentation modality, i.e. text, picture, video, illustration, in the REPARERE-prototype.

We used a horizontal prototype approach to development [10]. REPARERE is developed in an Open Source Environment, using the Apache Lenya Content Management System¹. The health information is represented in XML style sheets (XSL) and Cascade Style Sheets (CSS)² for flexible presentation of the content. To match the content to the trajectory of recovery, a digital user profile allows for customized retrieval or system tailoring based on pieces of information retrieved from defined elements in XML-document and XSL style sheets for presentation [11]. In addition, inclusion of Web Accessibility Initiative (WAI) requirements for universal access [12], e.g. making the resource useable for the vision or cognitively impaired **too**, and support user who may request special accessibility features or alternative use.

The prototype has been tried in a small design experiment to learn from and with two volunteer patients about the potential uses of REPARERE. The volunteers participated in the heart clinic's rehabilitation program, and approximately 12 weeks into their recovery period. They used REPARERE for 3 weeks, and took notes about their experiences. At the end of the period, a walk trough of a typical use situation and a group interview was carried out.

Results

Creating web-based learning resources, like REPARERE, involve an interdependent mix of health, learning and technologically related challenges. Our example incorporates examples of 1) relevant, sequenced information according to common experiences in the trajectory of CABG recovery; 2) communication arena for peer and/or professional interaction and support; and 3) universal access and alternative presentation and interaction.

Findings from our interviews with CABG-convalescents and their family member as well as health care providers, reiterated published literature about CABG recovery experiences, content of patient information and suggested secondary prevention of

cardiovascular disease. This information informed selection of content in our design. In a web-based resource, using information about changing focus of attention in a recovery opens for sequencing and tailoring to match information to anticipated user needs.

In the immediate period post CABG surgery, monitoring physical recovery, e.g. pain and wound management, rest, exercise and nutrition, is most important and receives most attention. In addition to such physically oriented recovery activities, unexpected experiences of memory problems, mood changes, problems to focus attention, and fatigue created some insecurity and uneasiness to the convalescent and/or family member. Later in the recovery trajectory, the object of activities shifted to regaining functional levels, secure psychosocial well-being and initiate life style changes. Likewise, examples of gender differences shaped recovery trajectories, e.g. men's expressions pointing to emotional suffering when realizing the "drama" of CABG, and women's expressions pointing to felt lack of social support and less exercise or physical activity.

Therefore, in REPARERE, information and communication resources for symptom management and self care during the recovery trajectory relates especially to

- physical healing and immediate recovery from surgery,
- increase physical activity and social functioning,
- psycho-social well-being and return to work and/or usual activities
- long-term changes for secondary prevention and healthy life style

Information relevant to such challenges in the recovery trajectory is presented in text, pictures, video and illustrations, to capitalize on the web's strength to communicate information in suitable form to the user.

The prototype REPARERE currently supports system tailored 'just-in-time' interactions; i.e. filtering information according to "this is most likely relevant for you now", and 'just-in-case' presentation, i.e. information that "is important about CABG-recovery". Generally, such an information and interaction design is reflected in the following diagram:

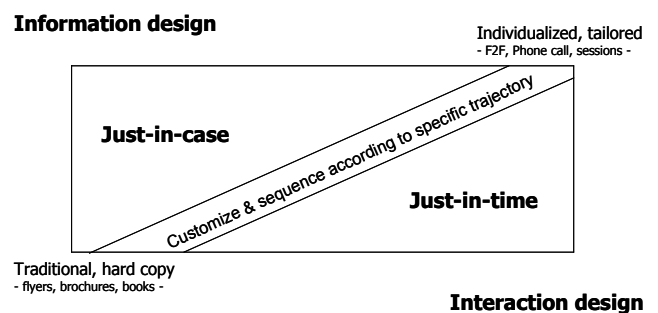


Figure 1 - Model for informatics-based learning resources

For tailoring information in a learning resource, information about health outcomes at different points during the recovery, may provide relevant information to the user, individualized and aligned to a particular situation. An individual's recovery trajectory; embedded information and communication needs seems more important than *time elapsed* since surgery.

¹<http://lenya.apache.org/>

²<http://www.w3.org/Style/CSS/>

Therefore, in addition to time since surgery, age, gender, co-morbidities, and/or special interest, we suggest that information about role as convalescent or family member, and perceived health related quality of life (HRQoL) can enable more dynamic customization and tailoring in the trajectory. We suggest to use an instrument like SF-36, that is in use as a quality of life measure in our country [13, 14] and in groups of CABG convalescents [15, 16] to individualize information to the user.

The health and learning related considerations point to technical challenges in design of REPARERE. To facilitate interaction, and to design simple and consistent user-interface, knowledge about the user's capacities is important. Separation of the actual content, the 'just-in-time' functionality, and presentation of content allows for more flexible presentation. The chosen Open Source platform, Apache-Lenya Content Management System (CMS) provides such flexibilities. This platform is used and extended to meet specific challenges in the design. XSL stylesheets manage and arrange presentation of information according to information about the user. This way REPARERE accommodate a 'just-in-time' composition, with tailored or customized retrieval and presentation of relevant information according to anticipation of needs in the trajectory of recovery. In addition, incorporation of principles for Universal Design improved accessibility regardless of transient impairment or disabilities [17].

The volunteers participating in the design experiment showed much interest in the content available in the prototype. They browsed REPARERE web-site like a booklet, i.e. according to a 'just-in-case' presentation, and did not use REPARERE as a tailored resource, i.e. the 'just-in-time' interaction. They perceived the available information as relevant for their own or family member's trajectory of recovery. However, to them all the information was important. They asked for more in-depth information about challenges or problems they had experienced as especially stressful, and emphasized peer to peer communication and exchange that REPARERE could facilitate in the future.

Discussion

Patient education and consumer health issues pose many challenges to design, such as affordability, adaptability and localizations, as well as personalization, customization and appropriation [18]. Therefore, the REPARERE prototype includes 1) examples derived from the analyzed material, presented as relevant, sequenced information according to common experiences in a trajectory of recovery. This information can be presented as such or customized mindful of age, gender, co-morbidities, role as convalescent or family member, and perceived health related quality of life; 2) communication arena for peer and/or professional support; and 3) universal design requirements to support alternative interaction and presentation.

As knowledge, expertise and experiences are re-combined or re-distributed by web-based learning resources; the division of labor expressed in traditional roles, existing norms and power balance are challenged. Herein dilemmas, gaps and tensions

may be illuminated. Multiple perspectives and different forms of knowledge (experiential knowledge, expert knowledge, and everyday practical knowledge) are integrated in the emergence of new social practices [19, 20]. Taking the convalescent's and/or family members' experiences actively into account shifts attention from "episodes of care", and point to complexities and challenges of living with a health condition, either recovering from acute illness, facing permanent change in health or a chronic illness. Conceptualizing *recovery* as a social practice opens for exploration of the interplay of trajectories of convalescent and/or family members, where they may utilize, contribute and continuously develop their expertise.

The future users of services like REPARERE share in common challenge to handle a set of new issues and challenges. At the same time they constitute a heterogeneous group regarding age, gender, socio-economic status, co-morbidities and role as patient or family member. Conceptualizing and modeling the recovery as intertwining trajectories [6, 20, 21], and eliciting information about "common" experiences in a specific condition's trajectory helps understand developing and changing nature of information and communication needs over time. The recovering patient and their families' trajectories seems shaped by efforts to understand expected, "normal" progress, return to usual life, work and leisure activities as well as initiate risk modification to delay recurrence of cardio-vascular symptoms [22]. Concurrently, focusing on normality may detract from necessary and beneficial life style changes to address chronic aspects of cardio-vascular disease [23].

REPARERE is an example of a web-based learning resource bringing together patients' recovery experiences, clinical expertise and practices, and requirements for universal access. Unfamiliar or un-chosen situations coupled with limited access to information about common experiences or suggested strategies can lead to disappointment and ill-use of valuable energy during recovery. In the case for REPARERE, the focus of attention shifts or develops during the recovery trajectory. Examples of relevant content are presented according to common experiences and changing focus of attention over time. Including and attending to multiple perspectives, e.g. convalescent, family members, health care providers, provide a broader basis to facilitate symptom management, self-care and coping. This opens for inclusion of collective experiences and collaborative coping and learning in peer groups related to health-illness recovery patterns.

Selection of objects and use of ICT to convey content, and tailoring presentation should be mindful of variation in users' qualifications, knowledge and previous experiences. Knowing more specifics about health-illness experiences, interest, capacity, as well as experience with technology mediated learning objects are important to select appropriate information and facilitate interaction [24]. REPARERE is designed with respect to diversity amongst lay people; patients and their families. Information and communication interventions with the specific goal of supporting and empowering patients and/or their families during periods of recovery or in managing chronic conditions offer complementary services to this on-going work. Web-based learning resources may support complex health-illness experiences and recovery trajectories expressed by multi-facetted experiences and changes for the individual and his or her family. Equally important, these resources can be a useful

communication arena for peer and professional support, sharing everyday experiences of living with a condition.

Applying ‘Just-in-Time’ strategies to individualize, tailor and contextualize information to patients and their families recovery can offer information and communication in a more timely fashion, and support symptom management and self-care to enhance well-being. The REPARERE prototype exemplifies a shift from a “one-size-fits-all” approach to patient learning. Tailored, individualized and contextualized information can support users who share a common challenge to handle a specific set of new issues and challenges. ‘Just-in-time’ (JIT) access to knowledge and clinical information may be a strategy to provide the most relevant, updated information matching the particularities of an individual’s trajectory. At the same time, the multiple social networks of people using such a tool constitute a heterogeneous collective.

Providing web-based resources to accommodate interwoven trajectories of recovery, learning and design require understanding changing needs and capacities of the convalescent and their families, to tailor resources according to development, change and requirements in health – illness experiences. Using an Open Source Content Management System like Apache Lenya, allows for flexibility and customization locally, and for sharing to larger development communities. Interactive, web-based learning resources may support new patterns in learning and knowledge construction through alternative modes of interaction. Integrated in the design of this learning resource are possibilities for alternative presentation and interaction. Universal access recommendations, in terms of selection of content (simplified or rich), media formats (text, pictures or video), device in use (interactive TV, computer or mobile phone) and vision disabilities (text size, contrasts and color variations) are among the possibilities.

From a self-care and symptom management perspective, information about common experiences gives a picture of what often constitutes normal and what to expect [1, 25]. REPARERE constitute a complex, shared resource that may point towards new possibilities when coping with a new life condition. It also points to how informatics-based resources may augment current approaches to patient education. The design experiment showed a large interest and need for internet based resources. In particular the volunteers emphasized peer to peer communication and exchange that REPARERE could facilitate. The use of internet communication services, such as chats was brought into the discussion, and encouraged integrations between chats and information resources. Also, the way the ‘just-in-time’ mechanism was discussed pointed to information highlighting rather than current information filtering.

Interactive, web-based learning resources allow for new patterns in learning and knowledge construction through new modes of interaction between multiple stakeholders [26]. Developed into a full-scale information and communication resources, informatics-based learning resources can provide dynamically tailored information according to intertwined trajectories of recovery and learning for the convalescent and their families. Information and communication interventions with the specific goal of supporting and empowering patients and/or their families are complementary services. Equally important, these

resources can be a useful communication arena for peer and professional support, sharing everyday experiences of living with a condition and managing a trajectory.

REPARERE takes into account diversity amongst future users, and acknowledges that health-illness experiences and recovery trajectories are complex, multi-faceted experiences manifested by many changes. Providing comprehensive and relevant content tailored to individual health information needs or care responsibilities, raise security concerns needing more careful attention before REPARERE is tried out in field experiments. At the same time, using the current prototype as a tool in discussions about development of infrastructures and applications may accommodate processes to explore potential for support to handle situations encountered by the convalescent and/or family during recovery.

Concluding remarks

Informatics-based learning resources can be valuable supplements for purposes of primary prevention or management of health-illness trajectories in periods of recovery or “living with” any chronic health condition. Patient education and consumer health issues pose many challenges to design, such as affordances adaptability and localizations – for personalization, customization and appropriation [18]. As discussed in this paper, REPARERE is an example of a web-based resource bringing together patients’ recovery experiences, clinical expertise and practices, and requirements for universal access in the design process. Further, REPARERE can become a communication arena for peer support or interaction with health care providers. These experiences are valuable to design resources for primary illness prevention, as well as resources for symptom management, coping, self-care and independence following acute illness episodes or chronic condition.

Resources like REPARERE providing support to a convalescent and their families is an example of a shift from a ‘Just-in-Case’ approach aimed to fit all, to tailored and contextualized information enabled by a ‘Just-in-time’ approach to information retrieval and knowledge construction. In REPARERE, the ‘Just-in-time’ approach in the information and interaction design is demonstrated by the path of a CABG recovery trajectory, and combining the Open Source Content Management System and XSL stylesheets.

In future research, it is also important to explore changing patterns of interactions, and how these may challenge and change traditional division of labor in the health care activities for illness prevention, as well as during period of recovery or in living well with a chronic condition.

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