Web-Based Resources for Peer Support – Opportunities and Challenges

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Abstract. Social software and Web 2.0 provides new opportunities for participation and collaborative knowledge construction in peer support and self-care to live well despite transient or permanent health problems. Opportunities include many-to-many interactions to share and accumulate knowledge and experiences from several perspectives. We are conducting a study to create a collaborative environment for peer support and knowledge construction related to a rare condition. The study draws from participatory design and agile approach to development; extensively using design workshops and iterative prototyping. Several workshops led to systematize perspectives of different participant groups, and provided feedback about functionalities illustrated in different mock-ups and prototypes. Here we report experiences, and focus on feedback from participants leading to special considerations in design of the web-based environment.

Keywords. peer-support, social software, Web 2.0, collaborative knowledge construction, rare conditions

1. Introduction

As health care migrates from professional practices and organized care settings, e.g., hospitals, outpatient clinics, care-centers or doctor’s offices, to the home dwelling, new practices emerge and demand timely access to health-related knowledge and experiences of daily living. Traditionally, patients’ contributions to their health related activities are largely under-articulated, and considered invisible work [1]. Information about treatment options, care strategies, as well as learning material or access to personal health information can be available through health portals. These environments support ‘one to one interaction’ between one patient and one provider, or the institution provides information material that the patient can access and use. Tools and practices giving access to knowledge and information for group interaction, collaborative construction and collection of experiences will be increasingly important to assist patients, their family, and health care providers dealing with challenges of “living well” with a condition and support activities of self-care and coping [2].

Opportunities from social software and the web 2.0 technology trend offer ample opportunity to support interactions, discourse-types and knowledge production processes in increasingly novel ways [3]. Such processes would transcend time and space, and provide arenas for different voices and perspectives to co-evolve. The
collaborative elements and user-generated content in wikis, blogs, and vocabularies ("folksonomies") are of special interest. They offer affordances to shift from discussion forums to collective creation of resources with accumulating experiences, practical doing and a wide variety of knowledge and expertise.

In the project RareICT we are creating an environment to support challenges of "living well", and engage in activities for self-care and coping. Our purpose is to systematize available experiences, practical doing and knowledge related to a rare physical, congenital malformation, anorectal anomaly. "Living well" with a rare condition is largely experienced as a trial-error exercise for the individual and their family. The malformation can have different degree(s) of severity and present a variety of challenges to daily living. The individual with the condition and their family face lifelong challenges related to physical functioning, as well as psychosocial and emotional wellbeing [4]. This is an example of services moving beyond traditional 'one to one' interaction in the consultation and 'one to many' interactions found in commonplace health portals, where we can explore opportunities and challenges for creating and sharing knowledge in ‘many to many’ interactions among the participants.

2. Framing and Methodological Approach

The study aligns with a socio-cultural and activity-theoretical approach to explore change and development [5, 6]. We are interested in how activities of peer support evolve, and how participants share and mobilize knowledge and experience in an environment of wikis and blogs. In particular, what can constitute content, how can environments be designed for different participants’ continued knowledge construction, and how can such environments be supported and augmented by social software tools and functionalities. We recognize that beliefs, perspectives and goals of participants can be inscribed into infrastructure in various ways in a design process. The social media and its practices introduced here offer support for negotiations and collective achievements [3]. This opens for exploration of the evolving resource as a learning resource, specially focusing on experiences from the workshops and clarification of conditions for collaboration and contributions of knowledge and experiences.

We set up the study to be exploratory, design-based and production-oriented [7]. A starting assumption is that content contributed from all future use groups are of equal value since experiences and solutions in daily living is distributed and ill-systematized. We arranged two cycles of workshops; 4 workshops in the first cycle and 6 workshops in the second cycle. In these workshops different experiences, strategies, and knowledge was shared and discussed, and suggestions for design and areas of use for the environment were exploited. Altogether 50 persons contributed. Our data corpus consists of material from workshop interviews with participants to elicit different perspectives, our internal development blog with evolving aims, challenges and rationales for choices modelled in the mock-ups, and discussions about the mock-ups.

3. The Design and Research Process

The first cycle of workshops focused on articulation and accumulation of knowledge, experiences and practical doing. Participants in the workshops emphasized how they have to re-think and challenge the “taken-for-granted” in everyday situations and value
the sharing of knowledge, experiences, routines, and expertise and experiences. Issues related to treatment follow-up, e.g., leakage, eating, surgery (e.g., stoma), and meeting challenges in everyday life were reiterated as problematic. This can be seen as open-ended problems, where collaboration and access to knowledge and experiences across user-groups can be valuable for sound problem solving strategies.

Based on the clarifications in these workshops we created mock-ups to explore social software functionalities. We suggested a solution to support 1) instrumental and explorative use, 2) open and filtered reception of content, 3) support creation of activities in networks among and across user groups, and 4) multimodal reading and participation. Multimodal in this context is understood as combined text-types such as verbal and visual communication, but expanded to invite discourse-types such as formal/informal or narrative/instructive. This led to modeling two main types of user-participation 1) blog-related questions/responses and 2) wiki entries and collaborative content development, and generated relations between them by semantic linking. We also modeled a list of terms and support for searching the site. The mock-up’s interface conveyed affiliation; the site as an authentic, user-driven site, and group identity – user, parent, health worker, and possibilities for sorting information according to affiliation.

To model these design choices we illustrated a workflow from left to right. This suggests a certain direction and notions of process, exemplified as “overview” (first section), “questions and comments” (second section) and “share & comment on knowledge and experiences” (third section). Figure 1, a picture from one of the mock-ups illustrates the three sections and explanation of terms (yellow field).

Figure 1. The mock up: ‘overview’, ‘question and comments’, and ‘share & comment’

The second cycle of workshops was organized as discussions around the mock-ups or prototypes to illustrate features of wiki-, blog- and semantic linking that facilitate collective knowledge advancement and evolving practices. This focus was to illustrate 1) examples self-care and “living well”, 2) processes of contributing information and knowledge, and 3) examples of use of ICT-resources as environment to share experiences and create knowledge. The workshop discussions opened for new
requirements and allowed exploring different participants’ perspectives. This process informed decisions about future features added to the web-based resource.

4. Findings and Discussion

The first mock-ups suggested that all knowledge, experiences and practicalities were negotiable and of equal value, since most experiences and knowledge about daily living are distributed, personal, situational and often ill systematized. This led to illumination of interesting tensions. The current patterns of collaboration and structures of participation often exhibit an asymmetric relationship between health providers and patients and their families. Patients and family members emphasized relevant information they could trust. They felt intimidated about editing others’ contributions, but more at ease to adding experiences or advise. Health providers suggested to direct participation or restrict participants’ opportunities to change or edit the content.

There was consensus that a sufficiently secure and protected environment for privacy and confidentiality about sensitive, personal health matters were a prerequisite, if a shared, evolving resource should be used, and become valuable. The health providers and the patients/families’ concerns about accountability, position/role and questions like how to know that available information is accurate and trustworthy, led us to further explore, challenge and comment the use of wikis and blogs in the progress of design. Considerations in some areas, for example health care, may require special or transitional modifications in prevailing approaches to collaboration, collaborative knowledge advancement and sharing of experience. Hence, we identified three major areas of consideration for design:

1. The knowledge, practices, and technology support for web 2.0.
2. The health care providers’ information and communication practices.
3. The patients’ and relatives’ request for trustworthy information.

These areas present challenges and opportunities for discussions, sorting out concerns and different requirements related to access, openness, trust, accountability, privacy and confidentiality, and opportunities for exchange of different voices. To design an environment where participants choose to share experiences, practical doing and accumulated knowledge and experiences, requires careful consideration of the concerns of the users and the opportunities in the tools. We will start by elaborating on three types of concerns.

Accountability and trust. Web 2.0 technologies, like ‘wiki’ and ‘blog’, build on openness and trust. Community members themselves ensure accuracy and quality of content, and opportunism, vandalism and misuse are handled through community monitoring. There is a set of functions to restore content if damaged. This contrasts health care providers’ practice where experts in the field review and approve content before it is shared with the patient and family. For RareICT and other web-based resources opportunities to divide content into different domains and create relations across them using semantic links can address challenges of accountability and trust.

Privacy and confidentiality. A social medium is an environment that by default is open for all members to read and sometimes write. This challenges how health information and patient teaching usually commence. In order to achieve a balance, we can design spaces to support different types of conversations, between peers as well as between health providers and patients in the web-based resource. It is important to
explore how access to spaces can be regulated and at the same time be meaningful for contributions of experiences, knowledge and practicalities to advance peer-support.

Voices and exchange. In wiki-environments content can easily be generated and published. As such, this is an environment where patients, families and health providers can exchange knowledge, experiences or practicalities. Here are opportunities for different voices to elaborate open-ended problems that transcend time and space. They can build a resource and a social network that support construction, sharing and learning from each other in the web-based resource. In many aspects this challenges the current structures of participation, realizing democratic ideals of equality, patient empowerment and consumer control about health matters.

5. Concluding Remarks

Functionalities and affordances available by the social software and web 2.0 technology trends activate opportunities and challenges to advance peer-support. RareICT demonstrates opportunities for knowledge creation in the interplays of subject matter and content, design, and use of functionalities in the chosen tools. Participatory and open web-based environments can encourage sharing of experiences, practicalities, and personal expertise to enhance peer-support. At the same time, qualities of the relationships and patterns of collaboration in health care should be accounted for and augmented. To do so, web-based resources need to address challenges about integrity, accountability and trust, confidentiality and privacy.

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References