Breast Cancer Smart Phone Application (BC SPA) study Part I: structure and contents of the BC SPA to promote women psychosocial adjustment

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Abstract

Young breast cancer patients (BCP) use online health services to know more about the diagnosis, treatment, and follow-up of breast cancer (BC). However, there is no research into the impact of these resources on the health outcomes of BCP. This is especially true for more recent ways of interaction, using smartphone applications (SPA), more personal and private devices that may prompt new ways of finding and using information, and of sharing it with others. We present the design of a study of the psychosocial impact of these technologies in BCP, based on the use of a BC SPA designed by a team of health and IT professionals.

Key Words: User Centered Design; Self Management of Breast Cancer; Psychosocial Adjustment; Patient-Centered Care.

1. Introduction

Breast cancer (BC) is the most frequent oncologic disease in the female Portuguese population, especially in young women, who use online health services to improve her knowledge about the diagnosis, treatment, and BC follow-up. These young breast cancer patients (BCP) have mobile internet access and can quickly find information and support, but there is no research into the impact of these resources on the health outcomes of BCP. Moreover, a recent research found that only 56% of applications with cancer-related facts offered valid

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scientific information [1]. Therefore, some studies point the need to evaluate the quality of BC information provided online [2]. Even if an adequate information source is chosen, it must be available in a timely fashion, according to the patients' needs, at particular moments of their disease. In this sense, smart-phone applications (SPAs) are singularly well suited. The number of users with smartphones (SP) has been increasing, and SPAs are often selected as the first resource to learn more about cancer related-issues. Furthermore, a SPA designed for BCP might enhance an autonomous and independent self-management of the disease, by becoming an available source of accurate information adapted to patient's needs. Also, SPAs can be a useful interface between patient and her physician to discuss and share clinical and psychosocial information [3].

It is important to compile and make understandable all the disperse BC related information. The two new SPAs on BC only have information about BCP medical needs [4,5]. In this sense, it is important to bridge the gap between what BCP currently have and what they need to have available, and provide an innovative service taking advantage of the expansion of SP and SPA users. The BC-SPA was prepared by a team of health and IT professionals with recognized skills in three areas (psychosocial impact of chronic disease; quantitative and qualitative methodology; and user centered design), to be applied to Portuguese population, since has been found the need to personalized health technologies, namely amongst BCP [6,7,8]. In this paper we present the first part of an original and innovative Portuguese study (which has, as final objective, the development of an application for BC and the assessment of its' psychosocial impact). This first phase of the research aims to understand which information related to BC is most needed in coping with illness, and to assess which clinical, psychological and social needs are presented by BCP. A final version of the SPA will be given to BCP, allowing us to compare their behavior with a control group, to investigate the psychosocial impact of the BC-SPA. We expect that the development of this tool will establish an empowering process to BCP, especially in their sense of control, self-monitoring, health-protective behaviors, social support perceptions and their quality of life and well-being [9]. SPA regarding BC could be an innovative way to gather information and provide support.

2. The Breast Cancer SPA Study

This research presents the first part of the study, which evaluates the clinical, psychological and social needs of BCP throughout the disease (diagnosis, treatments and survivorship). This study will use a qualitative method to analyze verbal reports, obtained through focus groups with BCP (Group 1) and health professionals (Group 2). In these groups it will be asked directly to the actors the information they would like to have available in each phase of the disease. The focus group will have eight people each. The audio-recorded interview will start by explaining the study's goals, the signing of informed consent forms and authorization for the audio-recording of the interview. Discussion will then ensue by following a simple script with one open question: "What are the most important and frequent areas that BCP need to know about...(phase of the disease)?". The information will be transcribed and subject to Content Analysis (the content analysis technique will yield a list of important categories which will represent the actual needs, concerns, and questions of BCP, and will serve as the basis for the development of a SPA, which intends to address their real needs). The SPA will be developed for the SP operating system, given both the ease of development (well-known technology, accessible development tools and documentation) and the fact there are many users of SP. We will follow a User Centered Design approach. After user and task analysis are performed, we will start by creating a Low Fidelity Paper Prototype. This is a non-functional prototype, based on pen and paper sketches of the interface that allows for the major design decisions (task flow, screen organization, location of information, etc.) to be explored and agreed upon. It is a well-known low-cost Human-Computer Interaction technique that can rapidly and easily iterate until a consensus forms (among team members and between the team and potential users). Once the main design guidelines have been decided, the first prototype will be crafted. That prototype will be evaluated by usability experts, who will perform a heuristic evaluation to find the most glaring usability

problems. The analysis of that evaluation will inform the creation of a second prototype. This prototype will be as close to final as possible, and will be subjected to a round of user evaluation. The users will be required to perform certain tasks (to be defined) in the interface. Metrics such as task completion time and number of errors will be measured and analyzed, as will the user's satisfaction, resorting to instruments such as the standard System Usability Scale. A final version of the SPA will be developed based on those results. This version will be instrumented as to record usage metrics and patterns, enabling us to understand how BCP really use it, what information they seek, and how they interact with each other.

3. Conclusions

The BC-SPA intends to be an interactive application for SP designed to supply the need of information and knowledge that these patients revealed about the diagnosis, treatment, survivorship, and the psychosocial impact of the disease in personal life. In this sense, the BC-SPA will be developed, entailing the main areas of BCP needs, such as: Clinical (e.g. accurate information about diagnosis, treatment and recovery, side effects of treatments, acquired physical limitations); Physical functioning (e.g. promotion of health behavior; nutritional advices to promote a healthy diet; suggestions about physical exercises); Health promotion (e.g. advises and reminders about exams and blood analysis; information about health protective behaviors); Assertive communication (e.g. between social network, family members, and health professionals); Psychological (e.g. information about emotional disclosure, stress management and coping strategies; information about body image, self-esteem, sexuality,); Family and social relationships (e.g. maintenance of social relations and social activities); Social (e.g. information about instrumental and functional issues; BC rights and needs). With this paper we intend to present the baseline content for the development of the new BC-SPA, which assists the BCP in disease self-management and will be a reliable resource for searching for further information regarding BC, from authorized sources and their peers. By evaluating the psychosocial impact of those technologies in BC psychosocial adjustment, we will be able to properly assess the advantages and disadvantages of their use.

Acknowledgements

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