Perspectives for digitally-enabled engagement tools within prospective surveillance model for breast cancer survivors

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Abstract

Medicine has evolved substantially since Hippocrates. This change may be largely perceived throughout the availability of technical advances, but it also expresses a paradigm shift triggered not only by better comprehension of the diseases but also the perception we have of its impact.

A case in point is breast cancer, the most common cancer both in developed and developing regions, which treatment techniques result in several impairments, and, consequently, contribute to a decreased quality of life. While the assessment of the oncological outcome of the treatment can be easily objectively quantified, the same does not withstand for functional aspects closely related to quality of life. Though some methods for monitoring and assessing do exist, an integrated approach able to achieve early detection, promote risk-reduction and self-management, while engaging the patient in an appropriate follow-up strategy, is still missing.

The objective of this work is to identify potential contributions in need for the development of future breast cancer survivors (BCS) surveillance programs, trying to expound on the aspect of digitally enabled healthcare resources as engagement tools while seeking to contribute to the development of an effective personalized, prospective medicine program.

1 Introduction

Surgical treatment of breast cancer has been evolving. Obligatory mastectomy has been replaced by a well-established trend towards the adoption of breast-conserving approaches. The aim of breast cancer conservative treatment (BCCT) is to be as effective as mastectomy in terms of oncological outcome while promoting better cosmesis, better self-esteem and less psychological morbidity. This change is largely due to the availability of technical advances in terms of therapeutic methodologies, but it also expresses a paradigm shift triggered by better comprehension of both the disease and the perception we have of its impact [20].

As BCS are living longer, the adverse effects resulting from the cancer treatment are more frequent. Upper body morbidity (UBM) (e.g. decreased range of motion, muscle strength, pain and lymphedema) are among the most prevalent side effects [14, 17]. While the assessment of the oncological outcome of the breast cancer treatment (BCT) can be easily objectively quantified by disease-free and overall survival rates, the same does not withstand for functional aspects closely related to quality of life (QOL). Assessment of BCS symptoms and health-related quality of life (HRQOL) outcomes are usually made using patient-reported outcome (PRO) questionnaires, that quantify significant outcome variables from the patient’s perspective [14, 16]. However, there are no uniform standardized objective assessment criteria for assessing the upper body function (UBF) in BCS [14]. Furthermore, it has yet to be determined which clinicians (breast cancer specialists, family practitioners, rehabilitative clinicians) are formally responsible for the diagnosis, treatment and management of survivors’ UBM related care needs [17], thus enhancing the need of a proper UBF assessment tool that enables a more active role of the patient.

Hereupon, this work presents a brief contextualization of a framework outline for the future development of digitally-enabled engagement tools within prospective surveillance model for BCS.

2 Background and Related Work

2.1 Lymphedema and UBF Impairments

Regarding lymphedema alone, it has been estimated that over 1 million BCS in the United States [14] and 10 million women worldwide [17] may meet the criteria for breast cancer-related lymphedema (BCRL). Lymphedema is a swelling condition, resulting from lymphatic ablation commonly associated with BCT. Women who have undergone BCT are at risk of developing BCRL during their lifetimes, which impacts on different dimensions of a woman’s QOL, including her physical, psychological, and emotional well-being [9]. Clinical assessment of the condition is usually performed by evaluation of the difference in volume between the operated side and the other, or, against a pre-operative measurement. Although there is a lack of consensus for standardized protocols in regard to measurement techniques [14], objective methods include bioimpedance spectroscopy, arm circumference, water displacement or lymphoscintigraphy. More recently a Kinect-based system was proposed and evaluated for the purpose of estimating upper-limb volume [3].

It is, however, possible to identify other aspects of interest to further evaluate function that may not be necessary related with BCRL, that result in limitations in activities of daily living. Arm/shoulder mobility, usually assessed by goniometer-based measurements of flexion, is an objective measure of UBF that has been used in the breast cancer rehabilitation. More recently, several studies proposed the use of Kinect for UBF assessment, trough estimation of reachable workspace based on hand and shoulder trajectories point clouds [7], [12].

2.2 Serious games as digitally-enabled engagement tools

Besides UBF assessment itself, recently proposed prospective surveillance model for BCS [19] highlight the importance of monitoring for functional and physical impairment commonly associated with BCT. Such concern has been recurrently reiterated [14], [17]. It can also be noted that since adverse effects can occur years after BCT, long-term follow-up strategies and objective widely available assessment methods are presented to be in need to materialization of such surveillance.

In this sense, growing trends of the quantified-self movement, personal health records tools dissemination and interactive video games that combine physical exercise with game-play and have a primary purpose other than entertainment [1] present themselves as currently active research lines with great potential [5]. While there are several games that include serious topics (e.g. [13]), the inclusion of serious game elements is not yet enough to induce learning or real-world action [18]. Recently proposed cognitive behavioural game design (CBGD) framework suggests that such real-world behaviour change in the player should be accomplished trough incorporated into game design the use of elements in social cognitive theory (SCT) and multiple intelligences (Mis) theory in an enjoyable way via the use of in-game libraries.

More broadly, engaging patients in their healthcare can be recognized as a growing trend that also reflects the increasing world population with chronic disease [15]). However, although the concept of patient engagement being increasingly presented as yielding great potential to improve healthcare, many gaps can be identified for the latter to be achieved, starting by defining the concept of patient engagement itself [6]. This term may not only be used to refer to different types of interactions between patients and health care systems but also it is possible to find different terms with overlapping definition (i.e. patient activation, patient involvement, patient participation, patient adherence, patient empowerment and patient compliance). As presented in [6] a systemic conceptualization of the patients’ role in healthcare is presented. In the aforementioned work of Graffigna et al. [6] it is also described the Patient Health Engagement Scale (PHE-scale), a measure of patient engagement grounded in psychometric methods. Patient Activation Measure (PAM) [8] should also be mentioned as a concurrent measure, although the concept of activation is more limited to the situation of a doctor-patient consultation.
3 Serious Games for Breast Cancer Survivors

Regarding lymphedema and UBF impairments, besides no uniform standardized objective assessment criteria has found, it was shown that some patients develop symptoms of BCRL without objective changes in arm circumference, indicating that clinical measurements may underestimate its incidence and impact [16]. Other than that, the correlation of such limitations with HRQOL has not been systematically evaluated [4]. Furthermore, current models of the shoulder and upper limb still present limitations as tools for robust UBF analysis with clinical relevance [2].

Although engaging patients in their healthcare can be recognized as a current trend, methods for clinical and at home use to eliminate biases and recall inaccuracies from self-report data, as well as achieve early detection, promote risk-reduction and self-management procedures are still missing [11]. Although multiple works have been recently published, examination of the efficacy of intervention to the individual patient needs is still missing. Overall, despite engagement being considered a valuable resource, research on patient engagement technologies regarding impact on health outcomes has been limited [15].

In line with the aforementioned discussion, this work proposes that an integrated approach for BCS physical impairments early detection, integrated evaluation of surgical outcome and self-management promotion should be comprised of two following main elements:

3.1 Objective evaluation of functional outcome after BCT

Within this first part, the purpose is at providing measures of the outcome after particular treatment options to the clinicians, in order to them not only to perform a better informed decision in future treatments, but also enable improved BCS follow-up. This is to be accomplished through the over time assessment of such quantities as circumferential arm measures, range of motion but mainly the apprehension of the prescribed exercise performance. Highlight here the challenges related with quantification of current rehabilitation procedures and identification of functional impairments that precede more advanced states of UBM.

In that manner, recent computer vision and machine learning methods present great potential, given the availability of off-the-shelf markerless sensors that full-fill requirements of low cost, easy and widespread use [10]. Nonetheless, given the necessity of high precision of measurements of not only upper body joints position and orientation but also objects with changing appearance in cluttered and occluded scenes, the tasks of model and assess the upper extremity functional capability in respect to BCS in an unconstrained manner, should be regarded as an open challenge.

3.2 Serious games tailored for BCS

In order to promote early detection of UBM, education on risk-reduction and self-management habits through the application of serious games, as it was previously introduced, it can be presented as in need the study and comparison of current approaches on interface and game design, such us the use of communicating and/or reinforcing knowledge, use of recommender systems given user in game assessment and the exploration of interface embodiment alternatives. This should allow future BDS surveillance programs to be comprehensive, as games should besides deduce from the participants’ behaviour objective UBF measures with interest to physicians, enable BCS independent and playful use of engaging and exercise promoting activities. Ultimately, the evaluation of the alternative game solutions should be performed with recourse to a patient health engagement scale (i.e. PHE-scale, PAM, ...), as well as further demographic and clinical variables, in order to describe socio-demographic and clinical characteristics of the patients.

4 Conclusion

Common breast cancer treatment techniques result in several impairments in women’s upper-body function, and, consequently, contribute to a decreasened quality of life. Methods for monitoring and assess are not only missing as it possible to recognize the potential of interdisciplinary collaboration to the materialization of an effective personalized medicine program in breast cancer-related upper body morbidity assessment and prevention.

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