Psycho-emotional tools for better treatment adherence and therapeutic outcomes for cancer patients

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Abstract. Personalized medicine should target not only the genetic and clinical aspects of the individual patients but also the different cognitive, psychological, family and social factors involved in various clinical choices. To this direction, in this paper, we present instruments to assess the psycho-emotional status of cancer patients and to evaluate the resilience in their family constructing in such a way an augmented patient profile. Using this profile, 1) information provision can be tailored according to patients characteristics; 2) areas of functioning can be monitored both by the patient and by the clinicians, providing suggestions and alerts; 3) personalized decision aids can be develop to increase patient's participation in the consultation process with their physicians and improve their satisfaction and involvement in the decision-making process. Our preliminary evaluation shows promising results and the potential benefits of the tools.

1. Introduction

Cancer research has led to more cancer patients being cured, and many more enabled to live with their cancer. Due to new screening practices, early diagnosis and new therapies, an increasing number of patients become chronic cancer survivors or have been successfully treated [1]. As cancer is now considered a chronic disease, patients and their families face the need to take an active role in their own care and in some cases in their treatment. It is a fact that a proportion of chronic patients consider that their opinion is ignored and they are not able to make decisions about their health care. In general, patients want more information from health professionals than they are given and more involvement in therapeutic procedures [2].

These new requirements pave the way for the elimination of the paternalistic model of doctor-patient relationship that prevailed until now and the establishment of a new partnership model that empowers patients and their caregivers to set and achieve their own health goals [4]. Educating patients for the self-management of their disease strengthens health behaviors by promoting health literacy and collaborative decision-making skills, problem solving and action planning related to their condition [4]. Empowering patients implies that patients feel that they have control on their disease

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which in turn improves the therapeutic outcomes [3]. Family education and enhancement of resilience is another important factor since the diagnosis of cancer affects the wellbeing of the whole family adding overwhelming stresses and uncertainties [5].

Nowadays, advances in information and communication technology (ICT), together with the resent spread of portable devices such as smartphones and tablets, offer a great opportunity to re-design the concept of self-management. Patients from different age groups with different therapeutic protocols, with varying clinical and psychological characteristics and side-effects may exhibit different needs for support [7].

This paper focuses on the research activities within the iManageCancer[2] H2020 EU project for psycho-emotional-based patient empowerment. The project, has the objective to provide a cancer specific self-management platform designed according to the needs of patient groups while in parallel focusing on the wellbeing of the cancer patient with special emphasis on avoiding, early detecting and managing adverse events of cancer therapy but also, importantly, on the psycho-emotional evaluation and self-motivated goals. This papers focuses on the psycho-emotional tools that will be provided by the project and more specifically on the following:

- A tool to *assess and monitor the psycho-emotional status* of the patients.
- A tool to *evaluate the resilience* of the family.
- A *decision aid* to enable decision support and guidance, through an emotional and cognitive perspective.
- Finally a tool to *collect and visualize the entire patient psycho-emotional profile* for the doctors enhancing engagement and patient-doctor communication.

Two of the aforementioned tools (the psycho-emotional tool and the profiler) have already been implemented and initial evaluation shows promising results. The remaining tools are currently under development. All tools will be provided as components of an intelligent Personal Health Record system enabling the patient active involvement in the decision process and enhancing patient-doctor communication.

The rest of this paper is structured as follows: In section 2 the methods are presented and then in section 3 we present our initial results on the psycho-emotional monitoring of the patient and his family and on building decision aids for empowering patients. Finally, section 3 concludes this paper and discusses our future plans.

2. Methods

To identify the requirements for the psycho-emotional tools we relied on a systematic review on patient empowerment [6], psycho-emotional constructs relevant in cancer treatments, and decision aids, as well as on a requirement analysis based on interviews of the patients and the specification of use cases. Our review showed that although there are to some extent already available decision aids on existing controlled studies on cancer, only a few of them take into consideration individual variables such as cultural level, individual risk attitudes, personal beliefs and emotional state that are

[2] http://imanagecancer.eu/

critical to determine people's reactions and choices for their health. For more information on the review the interested reader is forwarded to the relevant paper [8].

In addition, in order to take into account the opinion of the patients, an online survey was created and promoted to the cancer community via ecancer.org[3]. The survey was translated in English, Italian, German and Greek and 226 people from all Europe submitted their opinion [9]. Among others, we identified that around 90% of the responders possess a PC or a laptop and a smart phone with up to 95% in Italy and they would be willing to use them for health related issues. In addition most of the patients want to discuss more details of their disease with their physician whereas 70% of the patients would like tools to enable better interaction with the doctors.

Based on the results of the survey, an intensive review of existing scenarios and use cases and during a two days' workshop, the consortium concluded to fifteen total scenarios with three of them dedicated for creating psycho-emotional tools: a) decision aid to support patients' participation in consultation, b) psycho-emotional status and management and c) family resilience evaluation. According to those scenarios, four individual tools will be finally built, shown in Figure 1. The psycho-emotional evaluation tool is already available to construct patient individual profile, the family resilience tool will be used to enhance patient profile with family resilience information and finally the decision aid will be used to monitor patient health choices, make him organize his questions and propose to him choices to be further discussed with this doctor. Finally the Profile tool is a tool enabling doctors to quickly visualize patient profiling information providing useful insights and psycho-emotional recommendations. Bellow we will describe in detail our recent results and our future planning.

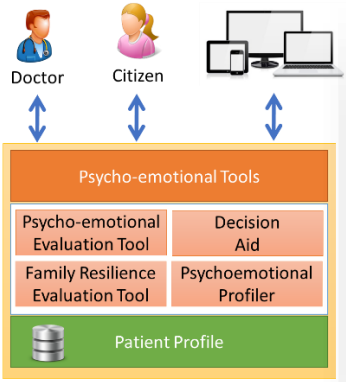

Figure 1. The psycho-emotional tools

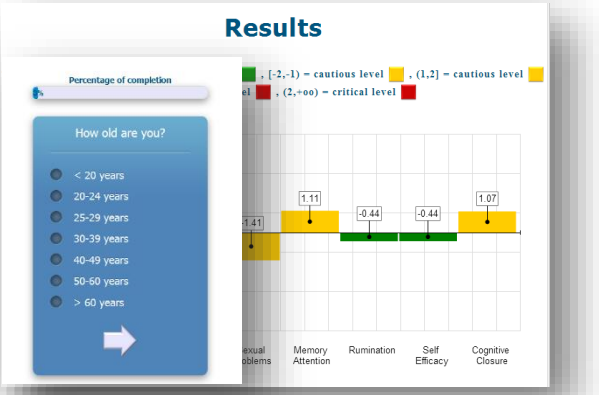

Figure 2. The psycho-emotional questionnaire (front) and the psycho-emotional profiler tool (back)

3. Results - Psycho-emotional Tools

3.1. Psycho-emotional status and management

iManageCancer platform will use a standardized, validated [2], psycho-behavioral questionnaire in order to monitor psycho-emotional status of cancer patients and their individual resources in coping with cancer. This tool is already implemented and is

[3] http://ecancer.org

shown in Figure 2 (ftont). The ALGA questionnaire measures psychological aspects (e.g. anxiety, depressive symptoms and self-efficacy), psychosocial aspects (e.g. social abilities, financial problems, sexual problems and body image), cognitive aspects (e.g. memory and attention, rumination and cognitive closure), and finally the perceived health state (general self-rated health, pain, fatigue, physical abilities and appetite). Additional aspects will be included in an extension of the psycho-emotional monitoring tool that is currently under development and will take into account aspects such as patient engagement, decisional role and preferences and mood states.

The web-based version of the questionnaire is available in 4 languages (Italian, English, German and Greek) and it has been developed to be compatible with all web browsers and mobile devices. In addition it can either be visualized either individually or as an app of the iManageCancer PHR Avatar (available through https://iphr.ics.forth.gr username:jsmith password:password.example).

The whole assessment or part of it will be compiled periodically and prior to consultation and visits and automatically the doctor will have access to patient latest status using the profiler tool that will be described in the sequel.

3.2. Family resilience tool

From a psychological perspective, individual resilience can be defined as the ability to utilize resources to cope with adversity. Different studies have come up with different ways of categorizing such resources [10][11][12], such as resilience in 1) external support (family, friends, etc.), 2) internal strength (feelings, attitudes, values) and 3) interpersonal skills (communication, problem solving, social relationships etc).

In our case, when a family member is faced with a terminal illness, the potential death presents a crisis and a challenge to the entire family as a system. As a parent, the fact that the child has cancer, is one of the worst situations to face. According to the family systems theory [13], individuals cannot be understood in isolation from one another, but rather as a part of their family, as the family is an emotional unit [14]. Families are systems of interconnected and interdependent individuals: what happens to one family member affects the other members.

The main goal of this family's tool is to measure the family resilience in order to individuate the critical areas that can deplete the patient's resources and to foster interventions that empower the whole family system. The family resilience tool will investigate areas concerning crucial psychological factors within family such as low esteem/self-efficacy, negative thinking, emotional reactions, personal sense of competence, self-reliance, health beliefs and other factors related to family's interpersonal relationship such as communication and problem solving skills, family disharmony instability or breakout and family's attitudes and values.

The tool is currently under development and will be used both by the patient and the family. Periodically, patient and family will receive a reminder from the application to perform the family resilience evaluation. All data will be computed and scored by the tool and afterwards a feedback on family resilience profile in lay language will be provided, in the case these scores are significantly elevated, an alert will be sent to clinicians. The family resilience tool will provide personalized recommendations to patient and family depending on their scores as well.

3.3. Decision aid to support patients' participation in consultation

Patient's decision aids are tools that translate evidence into a patient-friendly form by providing, at a minimum, information on the options, benefits and risks, and implicit methods to clarify personal values. In addition, many decision aids also include information on the condition, probabilities of the outcomes of options (benefits/harms), exercises to help patients explicitly clarify their values, and guidance in the steps of decision making. A variety of decision aids have been developed and proved successful in increasing knowledge, enhance active involvement in decision making by patients, and decrease patients' decisional anxiety [8]. These tools have the potential to facilitate patient empowerment in the decision-making process. However, there is the need to provide decision aids according the patient personal characteristics, such as the patient's thinking and decision styles [8].

iManageCancer will take these aspects into account to optimize patients behaviour in gathering the useful information and recognize that a decision needs to be made, understanding the current scientific evidence, clarifying their values associated with outcomes of options, and achieving a quality decision. A consultation planning tool for patients is currently under development to increase their participation in the consultation process with their physicians and improve their satisfaction with the decision-making process. The tool will help to increase patient's knowledge on the disease, on treatment options and potential side effects, from which the patient can choose to create his own list of questions he wishes to discuss with his doctor. The list can be shared with the doctor in advance of the consultation.

3.4. The psycho-emotional profiler tool

The Profiler is a web application that analyzes the patients' answers to the psycho-emotional and family resilience questionnaires and his choices and input from the decision aid and creates their personal profile in real-time. Through the Profiler the doctor can easily search for a specific patient and visualize her/his results. Currently the visualization part with respect to the psycho-emotional status has been implemented and is shown in Figure 2 whereas the integration and visualization of the family resilience and the decision aid tool is under development. Currently, the scores for each factor included in the questionnaire ('global self-rated health', 'perceived physical health', 'anxiety', 'self-efficacy', 'cognitive closure', 'memory', 'body image', and 'sexual life') are automatically calculated and presented in a graphic mode [15]. Scores that deviate more than 2 standard deviations from the average population are represented using red columns (or red buttons). The average population can be a sample of breast cancer patients or a sample of healthy subjects, depending from the need and the interest of the physician. When one or more of the patient's scores deviate from average, one or more recommendations are provided to the physician together with a short explanation of the corresponding factor(s). As more of the tools become available new visualization methods will be implemented to help clinician quickly identify the patient profile and optimize his communication with the patient.

4. Discussion and Conclusions

The iManageCancer platform collects multidisciplinary data covering areas from the medical, the psychological, the environmental and the lifestyle domains thus collected information and recommendations to patients are remarkable personalized [16]. In this paper we focus on the psycho-emotional tools that take into account patients' and their environment psychological state, preferences and emotional reactions the platform and provide to the patients the opportunity to reach the optimal decision making for them.

Currently both the psycho-emotional questionnaire and the profiler have been evaluated by administering the questionnaire to 778 healthy control subjects and 45 women operated for newly diagnosed primary breast cancer. The questionnaire was administered before their normal visit to the doctor while waiting in the lobby. The users were very positive toward the developed interface and the visualization in order to summarize the results. In addition the comments provided (visualization methods, pre-fill some questionnaire fields with past answers etc.) were used to optimize the information delivery to both patients and clinicians. In the context of the iManageCancer project two pilots will be conducted and assessed, one for adult cancer patients and one for children, to evaluate among others the aforementioned tools. Multiple parameters will be measured such as feasibility, acceptance, usability, performance, costs, and outcome on quality of life of cancer patients. Pilots will start on August 2016 and December 2016 for the children and the adults respectively and are planned to last 18 months. Common usability criteria like satisfaction, believes, acceptability, comfort-opinions on usability and frequency of usage of the system will be used to assess the usability and functionality of the overall system and the individual psycho-emotional tools. A more thorough evaluation will be published in a follow-up paper when the clinical trials finish.

To the best of our knowledge our approach is the only one combining psycho-emotional monitoring of the individual patient and his family, and decision aid to enable patient empowerment end strengthen patient-doctor communication.

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