Current trends in Electronic Family Resilience Tools: Implementing a tool for the cancer domain

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Abstract— **It is well documented that the diagnosis of cancer affects the wellbeing of the whole family adding overwhelming stresses and uncertainties. As such, family education and enhancement of resilience is an important factor that should be promoted and facilitated in a holistic manner for addressing a severe and chronic condition such as cancer. In this paper, we review the notion of resilience in the literature identifying three tools that try to support it. Then we focus in the cancer domain and we describe a tool implemented to this direction. To our knowledge, this is the first time such a tool is used to complete patient profile with family resilience information, eventually leading to patient and family engagement and empowerment.**

I. INTRODUCTION

A chronic and life threatening disease, such as cancer, is maybe one of the most significant challenges that a family can face. The impact of cancer diagnosis upon family is tremendous and no one remains untouched. When a family member is facing a serious illness, the whole family's quality of life deteriorates dramatically. Nevertheless, it is not a rare phenomenon some families manage to exhibit resilience and recover [1]. Research that has been conducted among cancer survivors indicated the adverse impact of both the disease and the therapeutic procedures on patient's lives. Patient's families are also affected in psychological and social way, and as such, patients face much more difficulties than overcoming the disease itself. In this "fight" in most of the cases, cancer patients are not alone. In fact, the diagnosis and the consequent procedures of cancer treatment is "a family issue" requiring adaption and functional changing of the whole family [2]. When a family member is struggling with a serious illness, the potential mortality presents a crisis and a challenge to the entire family as an ecosystem [3]. Given the fact that some people may be naturally more resilient than others in dealing difficult situations, comes to the fore the issue how to reinforce individuals and families facing severe conditions to be more resilient and stronger in order to face the stressors that they meet, especially at the situation that a child is chronically ill. As a parent, the fact that a child has cancer is one of the worst situations to face. When a child is diagnosed with

cancer, it has a profound effect on the entire family [4], which has special issues to overcome. In order to empower children with cancer, it is crucial to start from the family. Family's adaptive response to adversities is vital and determines the subsequent child's response and functioning [5]. To this direction, it is of paramount importance to promote empowerment and resilient frameworks through families that face great adversities.

Advances in information and communication technology (ICT), together with the recent spread of portable devices, such as smartphones and tablets, offer great opportunities to families and provide the manners to transform their role from passive to active. To this direction, our contributions in this paper are the following: We initially review the concept of resilience in the literature in Section 2. Then we identify three ICT tools, namely FOCUS, ChiRP and RPMonline that try to support the family resilience in Section 3. Finally, we present our implementation for cancer patients demonstrating its uniqueness in Section 4. Finally, Section 5 concludes this paper and presents directions for future work.

II. THE CONCEPT OF RESILIENCE

Resilience is the ability of an individual, a family or a specific group of people to overcome adversities, misfortunes or suffering situations. This recovery is achieved through processes that enforce individual or collective strengthening, empowerment, and rehabilitation [6]. These positive changes and adaptive processes, are referred to by Rutter as steeling effects, and that is one of the defining characteristics in the field of resilience [7]. Dealing with a difficult and unexpected situation sometimes make people stronger and more resistant to a potential future stressor. The last two decades, a great proportion of research on the one hand and clinicians, and policy makers on the other hand has shown significant attention on issues "from risk to resilience" [8]. Specifically, resilience is conceived as the ability to be less vulnerable to environmental experiences, to overcome the consequent stress due to an adversity and to gain an as good as possible outcome despite adversities [9]. It is worth mentioning that

resilience starts with the recognition that there are huge individual differences and variations. It is a matter of fact that people's response to the same experience may differ as well as the upcoming results of this response. The understanding of how these variations arise will possible pave the way on implications for intervention strategies with ultimate goals both prevention and treatment [9]. By the 1970's, researchers had discovered that sufferers from schizophrenia who exhibited a milder form of the disease, were people that before the onset of the disease had a life that was characterized by achievements at work, sufficient social relations, happy marriage and the ability to carry out their daily responsibilities [10]. In the same concept, surveys of children with mothers suffering from schizophrenia revealed that many of them had a normal development despite their high-risk status. These findings had a tremendous impact on constantly rising empirical efforts to understand the different ways that individual's response when they experience an adversity [11]. Werner's longitudinal studies of resilient youth provide important evidence that concerns a complex interactional view of resilience that involves multiple internal and external influences over time [12]. Complementary, different studies have come up with different ways of categorizing such resources, 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) [13]. In fact, resilience was first introduced and flourished in the field of developmental psychopathology research, which revealed that children from dysfunctional families were normally functional. In the decade of 90s, the concept of resilience became popular among researchers who studied the way that families address and cope against adverse events. These observations established resilience as a family-level construct [14].

In the past few years, there have been many attempts to define the term of family resilience. The majority of them seem to have arisen from definitions related to individual resilience, however the study in a family concept may be more complicated. Traditionally, family resilience is considered as the sum of individual's family member's resilience [15]. A recent view of family resilience concludes the relational properties of families as a unit or the processes among the family that amplify family survival under difficult circumstances [14]. Briefly, family resilience is defined as the families capacity, as a functional system, to resist and recuperate from adversity [16]. Nevertheless, family resilience concludes more than overcome an adverse event, take upon a burden, or survive from a family disaster. This approach requires personal and relational transformation. By empowering essential actions for resilience, families would become vigorous and more capable to cope with suffering through their collective efforts. An unexpected change to a family can be an opportunity to reconsider their priorities encouraging the re-establishment of stronger foundations between family's relations. Adversities can be a productive way to reinforce family members to find out resources and skills that they had not discover before [17]. According to the family systems theory, individuals cannot be understood in isolation from one another, but rather as a part of their family, as the family is an emotional unit [18]. Families are structures of interrelated and interdependent members: what affects one family member influences the other members and vice versa. Under these detrimental situations, the resilience at the family level represents the trajectory that a family follows as it adapts in a positive and meaningful way in order to bounce back from adverse circumstances. According to this, resilience should not be considered as a rigid set of strengths and traits but as a developmental process unique to each family system which results to adaptive outcomes [19]. Despite all these adversities, many individuals who struggle with cancer demonstrate significant resilience that boosts their coping abilities and helps them face the illness in a more adaptive way [1]. Although hard to believe, many individuals that live with difficult conditions, such as cancer or other life-threatening diseases, are able to experience not only negative but also positive emotions and in some cases they claim increased quality of life, better interpersonal relationships, and improvement in attitudes and priorities (e.g., the feeling of gratefulness and respect of each day) [20].

III. FAMILY RESILIENCE TOOLS

Even though the family resilience concept exists more than half a century electronic applications and tools supporting the family resilience are limited. To the best of our knowledge only the following methodologies/tools have been digitalized:

FOCUS: FOCUS (Families OverComing Under Stress) was originally created as a protective and adaptive intervention process that focused on the need of military families to overcome many stressors. FOCUS aimed to promote positive adaptation among families, to reinforce family resilience against adversity. FOCUS, among others, has embedded an eight-session resilience-training program for parents and children called Individual Family Resiliency Training (IFRT). IFRT includes a family assessment that users complete online and get real-time feedback immediately. IFRT programme focuses on many shared family-level aspects such as: communication, goal setting, problem solving, emotion regulation and managing deployment reminders [21].

CHiRP: Child illness and Resilience Program aims to improve the resilience and well-being of families and caregivers of children and young people who experience a long-lasting medical problem in Australia. In fact, children who suffer

from a chronic disease and even their family members are more vulnerable to develop subsequent mental health conditions. These difficulties may appear due to the lack of services and substantial support and due to the daily struggling in the face of a serious illness especially when they are experienced by a child. This intervention uses a stepped care design that supports as well as possible families under distress. The intervention consist of three discrete steps while the third step "*active dissemination: parent information support group intervention*" is the point of our interest. It is a matter of fact that parents and care givers of a child suffering from a chronic illness have decreased opportunities to participate in a time-demanding face-to-face program. Under these circumstances the information support group of CHiRP intervention tool post once a week onto an online forum material pertaining to family resilience. Participants can read the material and be encouraged to participate with the whole family. Caregivers could also post comments for an online group discussion and get feedback [22].

RPMonline: P.I.P.P.I (Intervention Program for Prevention of Institutionalization) is a research-training intervention program that created as an in-depth care program for at-risk families and aims to promote child wellness. RPMonline is an online tool, which developed in order to be used by practitioners and families and help them organize the care plan for each child. The main purpose of this tool is to integrate all the process of the care plan (assessing risk and promoting protective factors, planning and evaluating interventions) and focuses on empowering all members that are implicated in the intervention, primarily children and their parents and secondarily their doctors, teachers, relatives and so on. This web-based application includes online instruments to promote cooperation where different individuals could be connected. RPM-Android is a tablet application dedicated to provide integrated support for social practitioners who work with parents and children that are four to eleven years old. The RPMonline and the RPM-Android assess the same key functionalities such as assessment, micro-planning, evaluation and a log of meetings with families. The interface and all the dimensions of the application are written in an easy understandable way in order to promote dedication to the planned activities and participation of the whole family. The child is able to express his/her mood and also to draw via Eco-map the quality of the relationships between him/her and caregivers [23]. To the best of our knowledge there is no family resilience tool dedicated for the cancer domain.

IV. IMANAGECANCER FAMILY RESILIENCE TOOL

The iManageCancer project supports chronic cancer treatment and care via a cancer disease self-management platform which designed contemplating to the specific needs of this patients' group and focusing on the wellbeing of cancer patients with special emphasis on psycho-emotional evaluation [24] and patient empowerment [25], [26], [27].

The project has already developed an instrument in order to evaluate critical areas within the family. The family resilience tool aims to evaluate and recognize the risk factors that will impede patient's empowerment and consequent health positive outcomes. While clinical factors are patient's intrinsic factors, psychological and emotional reactions to the disease will heavily affect also parents and siblings of the child with cancer, or the partner and children in the case of cancer in adults. While this influence is nowadays accepted, there isn't an efficient instrument to highlight this critical area; In particular, the psychosocial dynamics among the family members and the overall family cohesion, communication, and coping styles will be investigated and analyzed. Collecting these variables will allow the platform to foster the protective characteristics of the entire family. The outcome of such an evaluation will provide additional profiling information and is integrated directly within the iManageCancer platform.
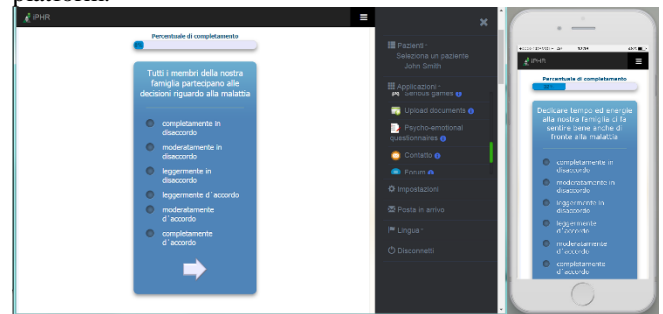

Fig. 1 Screenshots of the family resilience tool using a computer (left) and a mobile device (right)

The main goal of this family's tool is to measure the family resilience using ICT technology and 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 investigates areas concerning crucial psychological factors within the 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 has been developed as an individual app within a Personal Health Record system (named iPHR) [3], is accessible though desktop computers and mobile devices and is translated into four languages English, German, Italian and Greek. A screenshot of the aforementioned tool is shown in Figure 1. The tool will be used both by the patient and the

family. The iPHR will inform periodically the patient and the family 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. In a following phase, the family resilience tool will provide personalized recommendations to patient and family depending on their scores well.

V. CONCLUSION

In this paper we focus on the notion of resilience and we identify tools for monitoring and supporting it. In addition, we present our implementation for the cancer domain. Our tool promotes family engagement, monitors several dimensions of the family resilience and eventually will provide alerts and recommendations augmenting power empowerment. Pilots will start on 2017 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 family resilience tool. To the best of our knowledge our tool is the only tool existing for monitoring the family resilience supporting the whole family's engagement and empowerment.

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