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Fostering Psychosocial Development and Well-being for Teenagers with Cancer through Playful Experiences

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Abstract

In this paper we propose a preliminary design framework on how to enhance the development and wellbeing of teenagers with cancer through playful experiences. We aim to make a contribution on how to foster psychological and social development through play and how ambiguity and connectedness can be applied as a design strategy. The paper concludes with a discussion on how ambiguity and connectedness can generate playful experiences in a design and which research questions we need to tackle to develop the framework further.

Author Keywords

Developmental Oriented Care, Childhood cancer, Interaction Design, Technology, Social media

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

In this paper, play will be discussed as a way of fostering the wellbeing of teenagers with cancer. Particularly we will focus on how *ambiguity* and

connectedness can be applied as a strategy to design playful experiences. Ambiguity and connectedness (two established fields of research in HCI) will be used to provide a perspective on play and offer a fresh point of view on which qualities are required in designing for psychosocial development and well-being.

The work presented in this paper is part of a design research project that focuses on designing interactive products and environments that help foster the age-related development of children with cancer, an approach called development-oriented care (DOC). These interactive environments will be developed together with the Princess Máxima Center for Pediatric Oncology in the Netherlands.

Teenagers, cancer and psychosocial development

Based on our first visits to a Dutch pediatric hospital, we observed how difficult it is for children and their families to cope with the increased level of stress that results from treatment and frequent hospital visits. This is particularly difficult for teenagers because of their life stage that involves the transition from childhood to adulthood.

Psychosocial development relates to the cognitive development within social processes [3]. According to the theory of Erikson, there are eight stages of psychosocial development that describe the impact of social experience (on the self) across the whole lifespan. Specifically for the adolescence period, Erikson talks about the *conscious sense of self developed through social interaction* (stage 5). Successfully completing this stage promotes, what Erikson refers to as, a “healthy personality” [5].

Cancer can threaten this stage of psychosocial development for teenagers in several ways. Extreme body changes such as gaining weight and losing hair can lower their self-confidence and thus may hinder teenagers to socially engage. Also the common side effects of treatment like exhaustion make it difficult to participate in daily activities, again reducing opportunities for social contact. On top of that, chemical imbalances resulting from chemotherapy result in mood swings, which may complicate social relationships.

Playful experiences for wellbeing

Teenagers’ wellbeing can be addressed by taking into account their momentary experiences, their sense of identity and their connections with others [8]. Research suggests that enjoyable social experiences are critical to help teenagers overcome the disruption in their lives and psychosocial development caused by cancer and hospitalization [5, 11]. According to Apter’s reversal theory [1], play can stimulate their resilience to the new situation and their ability to regulate emotions as well as re-establish meaning. We argue that play forms that balance sensory and social stimuli [4] are promising towards promoting enjoyable social experiences for teenaged cancer patients. Because teenagers can easily become bored, or experience common side effects from their treatment such as fatigue and mood swings, teenagers also need to be able to switch between free play and more structured formats. In order to give shape to these playful experiences we consider *ambiguity* and *connectedness* as the central principles guiding design.

Ambiguity

Designing with *ambiguity* opens up the designed artifact for interpretation and appropriation in the context of one's personal life [10]. According to Gaver [11], using ambiguity as a resource for design can in fact make user product interaction more engaging. Ambiguity provides new perspectives on a life situation that changed dramatically after cancer diagnosis. This can motivate teenagers with cancer, and their social network, to interpret their new situation differently and establish more constructive relationships.

Connectedness

Designing for *connectedness* can trigger social engagement and reflection for the patient in their social network. Findings by Wildevuur et al. [12] show that people who remain actively engaged in life and are connected to those around them are generally happier, in better physical and mental health, and are more empowered to cope effectively with change and life transitions. Connectedness can therefore facilitate designs that help maintain and grow valued social relationships and providing a sense of continuity in everyday life [2].

Framework for designing playful experiences for well-being

We have developed a preliminary design framework for supporting the development and wellbeing of teenagers with cancer through playful experiences in which ambiguity and connectedness are the central principles guiding design (Fig. 1).

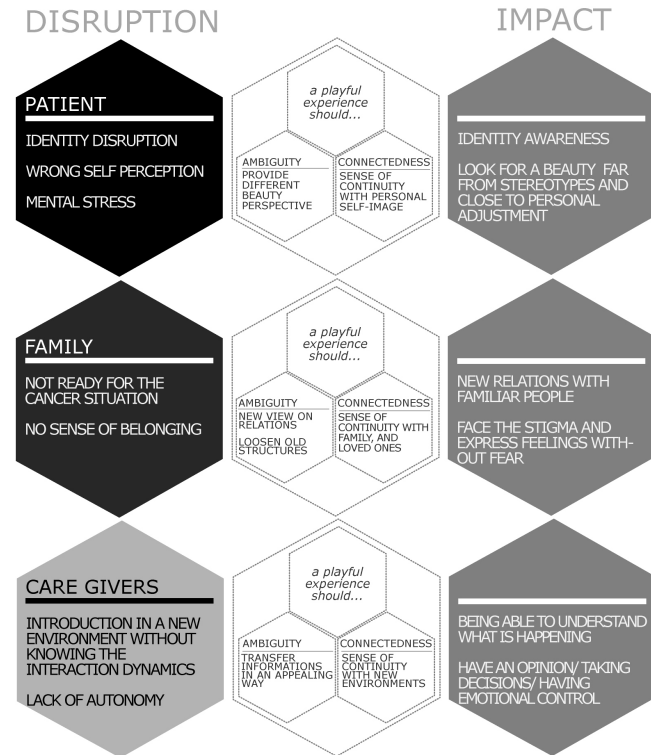


Figure 1. Playful experiences framework

These principles can provide teenage patients with a new perspective [7]. This new perspective can help to establish healthy relationships with themselves and others through the reformulation of identities and social links [9]. We propose that opportunities for playfulness should address three levels of social functioning: (a) teenagers as individuals, (b) teenagers and their family

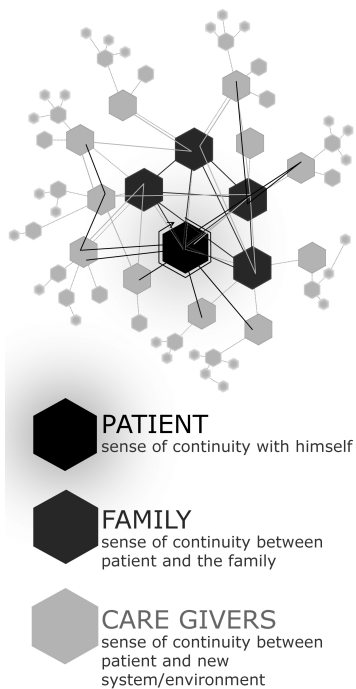


Figure 2. Three levels of social functioning for the framework implementation

and (c) teenagers and their care network (fig.2). These three levels and their impact are described below.

Teenagers as individuals

The aim of playful experiences on the individual level is to aid the teenager in *reconnecting with their body and mind*. Self-acceptance is necessary before patients can seek and benefit from the acceptance from others. For example, teenagers need to deal with body changes that can occur during cancer treatment such as gaining weight and losing hair. Playful experiences can help them cope with these changes by aiding them to obtain an optimistic attitude, for example: *“now that I am bald, my hair will grow again stronger than before”*.

Teenagers and their family

The aim of playful experiences on the familial level is to *rebuild and strengthen family relationships* in light of disruption. The fears and uncertainties related to cancer can disrupt the emotional relationships between teenagers and their family members (a relationship that already often tends to be troublesome in the teenage years). Playful experiences can engage family members in new daily life circumstances and roles. For example, the optimistic son that cheered up the family may feel depressed after his cancer diagnoses, and now he is the person requiring the optimism and support from others.

Teenagers and their care network

The aim of playful experiences on the care network level is to *empower teenagers to socially engage within*

their community of care. For example, to help them speak out to physicians about what kind of treatment they prefer or which nurse should care for them during hospitalization. Playful experiences on this level can help patients overcome social barriers to professional staff and feel empowered within the healthcare system.

Conclusions

In this paper we have presented a preliminary framework outlining how playful experiences built upon ambiguity and connectedness can promote the psychosocial development and wellbeing of teenagers with cancer. To further advance this framework we need to understand more deeply how teenagers with cancer can relate to themselves and to others more constructively after their diagnosis, by looking at best practices in psychotherapy and social work. Future work will identify the *real-world challenges* that teenagers, their family, and their broader social network face when being confronted with cancer and how playful experiences can allow for reflection and transformation. Design explorations will be conducted to investigate how ambiguity and connectedness can be meaningfully embodied into systems and artifacts. The long-term ambition of this project is to create general design solutions for social rehabilitation after disruptive life events.

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