

Designing for Human Well-Being: A Case Study with Informal Caregivers of Individuals with Cancer

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Abstract. Informal Caregivers such as a spouse, other close relatives or friends of cancer patients can play an essential role in home-based treatment and care. However, the informal caregivers might not be prepared for this responsibility, and they might have several unmet requirements for taking care of patients in the home environment. The informal caregivers' physical, social and psychological health is also profoundly affected due to the health conditions of their relatives. We propose a User-centred Positive Design as a hybrid framework by merging the traditional User-centered design and positive design frameworks to enhance the informal caregivers' subjective well-being. Our ongoing project (Carer-eSupport) will be used as a case study, and its main objective is to co-create and evaluate a web-based support system for informal caregivers of people with cancer. The proposed framework can be used for the design and development of health information systems with a special focus on users' wellbeing and positive emotions.

Keywords. Informal caregiving, Subjective well-being, Positive design, User-centered design, HCI, UCPD, Web-based support systems

1. Introduction

Cancer affects both the patients and their Informal Caregivers (ICs) [1]. ICs are usually the close relatives or friends of the patient who are responsible for caregiving without any payment. Caregiving to patients with cancer is a challenging and stressful task. The ICs usually are not well prepared for this responsibility and they lack the necessary information about receiving advice and help for home-based healthcare [1,2].

ICs' own physical and psychological health is also affected due to these life-changing circumstances. Many suffer from psychological problems such as depression, anxiety, and post-traumatic stress. ICs' burden of caring for cancer patients becomes intensive when the available resources and information are insufficient for caregiving in the home environment [3].

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In recent years, eHealth applications have emerged as efficient, cost-effective and easily accessible alternatives in healthcare [4]. Applications such as artificial intelligence-enabled and web-based support systems might be helpful for ICs' for caregiving individuals with cancer as well as to enhance their own subjective well-being. However, acceptance and adoption of these applications are still uncertain and further research is needed to investigate the proper design strategies that enable user participation and user well-being [5].

A user-centred design approach is widely used in human-computer interaction (HCI) research and beyond to design usable systems/tools that fulfil the users' needs[6]. The positive design framework (PDF) highlights the key elements of a person's subjective well-being [7]. In this paper, we propose the User-centred Positive Design (UCPD) by merging UCD and PDF. The merge between UCD and user's well-being has previously been explored by Gulliksen et. al. [8]. However, their work has focused on a professional work setting. The difference between those studies and this one is the context of informal caregiving and non-professional work setting.

Our proposed framework is expected to provide some clear guidelines for designing the eHealth systems that may support the users' subjective wellbeing and their positive emotions. We use our ongoing project (Carer-eSupport) as a case study; the project aimed to co-create and evaluate a web-based support system for informal caregivers of people with cancer.

2. Theoretical framework

2.1. User-centred Design

User-centered design (UCD) (also used as human-centered design) is an iterative process in which the users and their needs are considered in all steps of design and development. Norman and W. Draper stressed that addressing users' needs should be the main focus of the interface design of the system [9]. The primary purpose of UCD is to improve the usability and usefulness of the systems by using different techniques to involve the users in the design and development process of that system [10]. The circle in Figure 1 illustrates the four basic steps of the UCD process identified by the International standard organization (ISO).

2.2. Positive Design Framework

One of the primary reasons that motivate individuals to use a given technology is to improve their well-being by supporting their different needs[11]. The positive design approach describes how design can enhance the subjective well-being of the users. Desmet and Pohlmeier suggested a three-dimensional framework for positive design (the triangle in Figure 1); the framework highlights three critical elements of subjective well-being: virtue, pleasure, and personal significance [7]. Desmet and Pohlmeier argue that the suggested elements enable and stimulate human flourishing and positive emotions.

2.3. The Proposed User-centred Positive Design (UCPD) Framework

We propose a User-centred Positive Design (UCPD) framework, as shown in Figure 1, by combining the two frameworks PDF and UCD. UCD is important for a positive design, and the users’ subjective well-being is a key element in it [7]. The users of a given design are the true evaluators of their subjective well-being. Desmet and Pohlmeier stress that the system designer and the design process need to deliberately focus on human flourishing rather than just optimizing by finetuning the product/system and eliminating its flows [7]. In other words, a design should not only solve a given user’s problem but should also make a long-lasting and positive, holistic impact on the user’s well-being. Peters et. al also concluded in their study on designing for motivation, engagement and well-being that the impact of technology on human well-being can be and should be understood, designed and evaluated by focusing on the basic human psychological needs [12].

UCD gives us a systematic approach to fulfil the user’s need, however, it does not provide the theoretical guidelines to understand the users and their needs. Due to an unclear understanding of human needs and different ways to apply UCD, the process leads to poor quality and usability of the system [8]. Therefore, we propose to use the UCD [10] as an implementation process and the PDF [7] as a theoretical framework. Figure 1 illustrates the proposed UCPD framework, in which we argued that the positive design elements should be focused in the UCD process, and the main purpose of UCD should be the subjective well-being of the users.

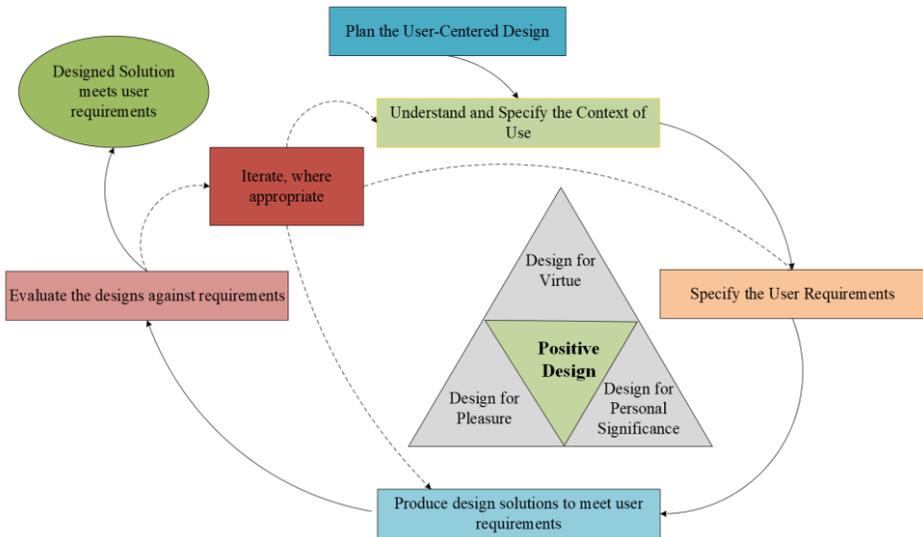


Figure 1. Proposed User-centered Positive Design Framework

3. The case study: Carer-eSupport project

We will use our ongoing project Carer-eSupport as a case study. We will test and adopt the proposed user-centered Positive Design (UCPD) framework in the project Carer-eSupport. The project aims to design, develop and evaluate a web-based support system

for the caregiving of cancer patients in the home environment. The intended system is also supposed to enhance the ICs' well-being and quality of life. We address the following research questions in this research project.

RQ1: What are the needs of informal caregivers of patients with cancer to support the patients in the home environment?

RQ2: How to design an Internet-based Support for Informal Caregivers to enhance their well-being and positive emotions?

RQ3: What are the critical factors influencing technology acceptance of Carer-eSupport?

3.1. Study Design

To ensure user participation, the UCD process will be used as research design in this project; and to enhance ICs' subject well-being, three elements of PDF: pleasure, virtue and personal significance will be used as theoretical guidance. Following UCD, interviews with the focus groups will be conducted to explore the users, their situation context and their perceived needs. Based on the interviews, an internet-based support system will be designed. The support system will be designed and developed in collaboration with U-CARE. The U-CARE provides an overall platform to deploy different eHealth services and it is used in several web-based interventions. The effects of the proposed support system on the ICs' well-being will be evaluated by a randomized controlled trial.

4. Discussion and Conclusion

In this paper, we shed light on the importance of users (ICs in the case study) well-being in the design and development of IT systems. UCD emphasize the user's involvement, and PDF advocates a holistic approach where human flourishing and subjective well-being should be the centre of any design approach. To support user's well-being and flourishing, we proposed the UCPD framework that merges PDF and UCD frameworks. In this study, we do not claim that the UCPD is a novel framework; after all, this is a merge between two already existing frameworks. However, the implementation of UCPD in our case study may lead to some substantial changes in the proposed framework, hence making it a novel framework in our future studies. The significance of this study is the context of the user as ICs.

Several studies attempted positive design strategies to support users' well-being [13–15]. To design eHealth solutions for the mental wellbeing of patients, Thieme et al. suggested a holistic approach where the key elements for mental wellbeing should be the user's psychological and social health, and positive emotions [14]. Cathy & Aidan used PDF to develop a design process called compassionate design; they suggest the design researchers should actively participate to develop the strategies that make a positive impact in the daily life of people who are suffering from different emotional and psychological issues [15].

To support users' well-being it is of utmost importance to involve the users in the design process of eHealth services [4]. However, the adoption of a systemic process to ensure the involvement of actual users seems scarce in previous research. Our proposed framework gives clear guidelines to involve the users in the design and development of eHealth interventions with a special focus on users' wellbeing and positive emotions.

We are excited to adopt the proposed UCPD framework in Figure 1 for the Carer-eSupport project. Even though ICs physical and mental health and well-being is also deeply affected, the current interventions are focused on patients' caregiving and the ICs subjective well-being is seldom considered [3,16]. ICs need support for caregiving to the patients as well as for their own well-being and daily life activities. In the Carer-eSupport project, we strive to provide that support to ICs. Therefore, the aim of this project and the critical situation of ICs makes the project a perfect test case for the UCPD approach. We hope our proposed UCPD framework will become a potential solution for HCI and user experience design researchers to deliberately emphasize more on human flourishing in their design strategies rather than just solving a problem by fulfilling the user requirements.

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