

Technology for Work-Life Balance in Terms of Informal Care Work

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Abstract. This paper draws attention to the issue of work-life balance in regard to informal care work and the impacts it has upon informal carers' lives. Through this paper, we bring this discussion to the fore and address how computer technologies can potentially support achieving some balance in this regard. This discussion is made in the context of TOPIC¹, a European project aiming at the development of an on-line platform to support informal carers at different dimensions of their lives.

Introduction

Informal care, although not properly paid, should be seen as work, because it has high economic value (Arno *et al.* 1999; van den Berg *et al.* 2005). Informal carers must engage in many care activities, which are demanding and often result in a heavy physical, emotional, and psychological burden. Although extensive research has addressed issues concerning informal carers as professionals and the implications of informal care in paid work (Boaz and Muller 1992; Arksey 2002; Henz 2006), little has been said about the balance between the informal work conducted by informal carers and their lives. Our paper draws attention to this issue and argues that further research in this area is necessary to provide technologies that can potentially support informal carers to cope. We argue that

¹ TOPIC – The Online Platform for Informal Caregivers – www.topic-aal.eu

paying attention to the boundaries between informal carers' work and lives can support the development of technologies to reduce their burden and help them to manage their caring activities. In so doing, some time can be made for them to take care of themselves.

Our research is embedded in a European AAL (Ambient Assisted Living)² project called TOPIC. It aims to support informal carers in their daily needs through a *CarePortfolio*, which is an integrated set of shared spaces and services to support the physical and mental care ability of informal carers by enabling learning and orientation about care. This support will be offered to carers by means of a set of accessible online services, which will be available at all times via a portal, available on the Internet, via tablets, smartphones, and smart TVs.

In the next section we describe informal care as a work activity – an important one in households and in our society. Then we discuss findings from the literature pointing towards the lack of a balance between the informal care work and informal carers' lives, highlighting the relevance of thinking of technologies to support informal carers to intensively care for someone and still have a life of their own. Following this discussion, we present our project by stressing out how we plan to deal with these issues and what our approach is, before concluding the paper.

Informal Care as a Type of Work

Informal care is often accounted for as an extension of housework (Strang 2001). The fact that this work is unpaid also contributes to make the demands stemming from it blend with informal carers' lives. However, informal carers commit themselves to many different types of activities to support the person(s) they are caring for, such as activities regarding (Given *et al.* 2001; Cranswick and Dosman 2008): *direct care* (e.g. administration of medications, wound care and dressings, assistance with mobility, etc.); *indirect care* (e.g. obtaining medications, scheduling appointments and coordinating care, looking after medication side effects, etc.); *symptom and comfort management* (e.g. keeping records of symptoms and medications, reporting effects and effectiveness of treatments); and so forth. As a result they are actively working to provide proper care for the person(s) they are looking after and are often submitted to heavy physical, psychological, or emotional burden (Chwalisz and Kisler 1995; Brouwer *et al.* 2004; Coon and Evans 2009).

From economic point of view, informal care can be defined as: “A quasi-market composite commodity consisting of heterogeneous parts produced (paid or unpaid) by one or more members of the social environment of the care recipient

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as a result of the care demands of the care recipient” (van den Berg *et al.* 2004 cited in van den Berg *et al.* 2005, 169-170). Indeed, past studies have shown that the economic value associated with informal care is massive (Arno *et al.* 1999; van den Berg *et al.* 2005). Arno *et al.* (1999), for instance, estimated that the economic value associated with informal care in the USA in 1997 was around \$196 billion. The authors conclude that informal care should be considered the bedrock for USA chronic care system and that proper support should be provided to informal carers.

Aiming at estimating the monetary value of informal care, van den Berg *et al.* (2005) applied a contingent valuation method by means of a survey with 153 caregivers of rheumatoid arthritis (van den Berg *et al.*, 2005). The authors gathered data about costs of informal care by asking informal carers whether they would accept to provide an additional hour of informal care per week and how much money they would expect to receive for it. From the analysis done through the application of the contingent valuation, the authors were able to estimate how much the hour of informal care for patients with rheumatoid arthritis would cost, putting forth an argument that informal care should be valued in economic terms of health care, corroborating the views from Arno *et al.* (1999) and Berg *et al.* (2005).

Informal Care and Informal Carers’ Lives: Any Balance?

For the past few years, increasing attention has been paid to the impacts that engaging in informal care have upon the lives of those providing it and different technological solutions have been proposed to support informal carers with their duties (Chwalisz and Kisler 1995; Hanson *et al.* 1999; Chambers and Connor 2002; Mahoney *et al.* 2003; Brouwer *et al.* 2004). These studies recurrently point out that the care work is usually very demanding and informal carers constantly feel overwhelmed and in need of help. The results of these demands are different types of burdens (e.g. psychological, physical, and emotional), which can be higher or lower depending on variables like the age, gender, and type of illness of the care receiver (Pochobradsky *et al.* 2005).

Savage and Bailey (2004), for instance, present findings suggesting that informal carers are at a higher risk of getting psychological ill in comparison with the average population. They have less life satisfaction, often feel worried and depressed, and have a high risk of suffering from a burnout syndrome. Acknowledging the matter, Snyder (2007) conducted two studies in two different human service organisations to find out how to extend Katherine Miller’s empathic communication model of burnout (Miller *et al.* 1988) “in an effort to

increase carer communicative responsiveness, reduce the negative consequences of contagion of negative affect, and help prevent caregiver burnout” (p.1).

Similar to human service work, care work requires “emotional labour” (Morris and Feldman 1996), which is “the effort, planning, and control needed to express organisationally desired emotion during personal transactions” (p.987). No matter whether emotional labour is performed through surface or deep acting (Hochschild 1983), it can be a source of stress for carers. It is a “double-edged sword” (Mann 2004): it has negative consequences for the carer, but it is needed to meet client needs and if it is properly provided, it can have positive impact on both. Emotional labour is only one aspect of the work informal carers carry out: understanding the person they care of through listening, interpreting, and reflecting; providing support and crisis intervention; assisting in problem solving, decision making, and behaviour change (Snyder, 2007, p.8).

From the studies above, it is clear that informal carers are exposed to a huge responsibility and long-term multi-layered hard work, though not acknowledged as professional work. Many informal carers have more to do next to caring for a person with special needs; they often have husband/wife, children, and work. As a result, informal care causes lots of stress, leading to a restriction of leisure time or time with the family (Strang 2001). But loss of leisure is related again to stress and most of all to health problems. It is an on going and maybe never ending and diminishing process (Bedini 2002).

Therefore, it is evident that carers usually do not experience a balance between the informal care activities they perform and their personal lives. Knowing that computer technologies can offer support to several activities involved in care giving, we see a huge potential to develop services and technologies for carers. TOPIC is a project that aims to address this issue and plans to design and implement a series of services and artefacts that might support informal carers to reach a balance between their care work and personal dimensions of their lives. We introduce some preliminary ideas of them in the next section.

TOPIC for Reducing the Informal Carers’ Burden

TOPIC is a project that has been employing a User-Centred Design approach supported by ethnographically informed studies for coming up with innovative solutions to support informal carers with their duties. It seeks to address the informal care work and life balance issue previously discussed by offering a platform for cooperation with formal carers and improving, integrating, and making (mobile) multimodal communication easier and accessible for informal carers to connect with other informal carers, friends, and family members. The main goal of the platform is to help informal carers alleviate stress and increase independency and efficiency of daily informal care giving tasks. We defend that this can be achieved by the provision of social support in three dimensions:

informational (flow of information, advices and opinions to help carers understand their problems), *tangible* (support in terms of goods or services for achieving daily tasks), and *emotional* (providing with the feelings of sympathy, empathy, friendship, and/or love).

On one hand, supporting informal carers on informational and tangible dimensions may facilitate their daily care activities. On the other hand, providing carers with emotional support helps them cope with their inner burden, but also facilitates organisation and management of their free time, aiming at a balance between their informal care duties and personal lives. Several *CarePortfolio* services allow carers to escape from their care work and focus on themselves. For example, *CarePortfolio* provides carers with the option of creating personal profiles similar to the online social network such as Facebook and Pinterest, and enables various communication between the users that includes but is not limited to: sharing (multimedia) files, recommending interesting Internet sources, and establishing audio, video, and text communication channels with friends and family.

Furthermore, *CarePortfolio* provides a *Fun Corner* – an online space for browsing through humorous videos and images, exchanging personal stories, and discovering new interests with the goal of having fun and relaxing. Finally, *CarePortfolio* implements a *Learning Corner*, which is an online space for providing carers with knowledge and information to facilitate their daily activities. Although the task of this service is primarily focused on providing information about caregiving, it also offers carers the possibility of acquiring new skills and widening their knowledge about personal interests.

Final Remarks

Aware of the burden and circumstances that informal carers face, we set out to investigate how we can meet the requirements emerging from them and facilitate a balance between informal care work and informal carers' life with services and technologies. Mostly important, our approach is user centred. We acknowledge here the high relevance of understanding the carers, their environment, and their situation. Our methodology integrates working with users, getting feedback from them, whatever we plan to develop for them, because we defend that in order for technologies to offer really useful support for carers (also for any type of users), participatory and user-centred approaches should be applied.

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