Aspects of family-managed care at home

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Abstract. More and more care, for example of older adults, is performed at home. Municipality home-care workers and novel technologies support this translocation of care. At home, an important care provider is also the immediate family. A recent trend is to formalize this volunteer-, and family-based care. However, this formalization requires new support systems for collaboration and communication. Also, when informal care turns formal there is a risk that a caring family-member might have to give up professional goals such as a career, or suffer economically as one may not be able to work fulltime while caring for another family member, such as an older parent. Hence it is both in the society and the individual’s interests that future supportive care technologies consider already at design time how to support care while not impede the everyday lives and possibilities for the caring family.

Introduction

More and more care move into private homes. This trend is seen across all European countries regardless of their diverse welfare systems [1]. This ongoing trend is driven by a number of factors; hospitals discharge their patients earlier than only a few years ago, older adults prefer to stay at home as long as possible [2] and it is cheaper to treat people, also with severe illnesses, at home [3]. Indeed, many possibilities and positive outcomes emerge when transferring institutional-based care to patients’ private homes, but there are also challenges (see e.g. [4]).

In many situations, care at home requires different forms of support. A person may be subject to municipality referred home-care, technological aids may support the care receiver or caregiver and informal, family-based care is not
uncommon. The ratio between these support-types may change from situation to situation but also depend on cultural and societal differences among countries. For example is the role of referred care much less evident in south-European countries such as Italy (where more care is provided, or paid for by the family) compared with the north-European countries such as Denmark and Sweden [5, 6]. However, many care receivers and especially their families do not consider the referred care support (e.g. a person or technology provided by the society to assist with the day-to-day care) to be sufficient [7], and hence the family either pay for additional care support or take on some of the care burden by themselves. The mismatch between the care provided by the society and the required level of care (as perceived by the family) hence turns, to different degrees and at times, family-members into informal care providers.

A new aspect of home-based care is the interest in for example the Nordic countries to both 1) formalize and 2) increase the ‘volunteer’-based involvement of a care receiver’s family in the provision of care [8-10]. This shift occurs while reducing the amount of personal, professional care provided by the municipality or other care-responsible entities. The increased focus on family-based care and the will from society to formalize and increase such care may in the future challenge and reshape a family where at least one of its members requires assistance and care. Based on the diverse trends outlined above that indicates a continuous increase in family-based care at home, this paper will now do an early attempt to discuss aspects of family-based care that may challenge both families and society in future, mixed society-family provided care scenarios.

From love to amateur homecare worker

As stated in the introduction, family-based care at home is currently performed due to a number of reasons. And it is not uncommon that there is a rather clear division of labor between professional and family based care (when professional care is provided). For example do professional care workers normally handle medication, hygiene and other critical care activities while family members provide more social, home maintenance and shopping support [11].

Until now there has been a rather clear division how family-based care has been perceived in for example northern and southern Europe. A difference has for example been how society has perceived informal, family based care in respect to referred, society-provided care. Among professional care workers the relationship with next of kin can be both fruitful and challenging [11]. Different needs and perspectives are at stage and these must be mediated. While a professional care worker perform care as part of a paid profession, volunteer-based care is on many occasions provided out of love rather than as an enforced care [12]. However, due to demographic changes northern Europe now has to explore new ways to safeguard the care of older adults. Hence, in countries such as Denmark
municipalities have shown interest in how informal care may become a more explicit and larger part of the total care provided [10]. As a consequence, next of kin have to provide care for their older relatives to a larger extent than today, either by buying care services or providing care by themselves. This in turn may 1) turn care into a question of class or economical possibilities, 2) challenge especially women in their work life and careers and 3) challenge the privacy of our older adults and 4) create a market for unskilled care workers.

**Discussion**

If the current trend in northern Europe will continue, we will not completely move from a referred care situation to an informal care situation. Rather, we will move toward a hybrid care solution, where both professional and informal care will not only co-exist, but depend upon each other. This dependency that come from turning informal care formal, will increase the need for communication, coordination and collaboration between professional and amateur care providers, all with different roles and stances towards the care receiver and the role of being a care provider. Here technology can help. However, one should be aware that moving care technologies into private homes can be challenging from a socio-technical perspective that goes beyond the illness or needed care support [13].

More women than men work as professional care providers in many parts of Europe. Also, in Europe the informal care provider has traditionally been a woman [6] and much of the informal care is still provided by women, for example adult daughters or the wife of the care receiver [9]. While there has been a rather vivid debate on what effect childcare has on women, their careers, and their role within the family and in society, less attention have been given to the corresponding effects of eldercare [6]. However, it has been identified a direct relationship between starting (and increasing) informal caregiving and a decrease in work hours [6, 14]. It is therefore important that future technology is built to facilitate family-provided care and to sustain a family’s collaboration with formal care organizations while minimizing the economical and professional impact family-based care may have on both individual and family level. Also, if supportive care technologies should be used by, and support, amateur care workers the technology must be easily understood and managed. As no formal care training can be expected to be provided ‘a mass’ by for example a municipality to a large body of amateur care providers, novel training and learning strategies have to be investigated and implemented. One such strategy could be to design care and support technologies so it can provide ‘on-site’ and ‘in-activity’ training.
Conclusion

Family-based care, being volunteer-based, informal or a formal part of a referred care solution can prove beneficial for all involved actors. But there can be also challenges in collaboration. The family-municipality (or other care institution) collaboration must hence be supported and technology can be one strategy to provide such support. However, as we design and implement collaborative technologies to enable families to provide formal care we must understand who within the family are the main users of the technology and what effects (positive and negative) formal, family-based care may have on the involved actors (e.g. the family, municipality, the care receiver, family-members’ employers etc).

References