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Support for Informal Caregivers: Use of Infrastructures

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Abstract. Informal health caring became a substantial part of our society. In Europe, official health care institutions cannot really cover the required care activities without the involvement of family members in caring activities. This role was taken by informal caregivers for a long time already. This paper tries to bring up this crucial setting into attention of health care community by identifying caregivers' needs and requirements, mapping infrastructural elements to caregivers' needs to achieve a satisfactory product, technology and service provision in this area, by suggesting an interconnected health care infrastructure as a possible solution. This analysis ends up in a more complex interconnected care infrastructure consisting of people and technology components, in the tradition of research on socio technology.

Introduction

Around 80% of all the care provided in European Union is carried out by family caregivers (Coon & Evans, 2009). Literature shows enough evidence that informal caregivers often express the need for help, not only in terms of financial assistance, as often proposed by social institutions, but also with respect to social and emotional support (Brownsell et al., 2012; Magnusson et al., 2004; Nies, 2004). Since a decade there have been a large number of European AAL (Ambient Assisted Living) research projects to obtain information and comfort for informal caregivers. Unfortunately, the results of these projects, like products, prototypes but also insights gained through the analysis of studies or user

evaluations, are still not enough disseminated. In our recent study[1] on the relevance and actual use of such results, we identified several products and services on the aspect of *staying healthy* (Hensely-Schinkinger et al., in preparation). In most cases, *sensor technologies* were used to capture data from homes of caregivers mainly to monitor the activities of care receivers or their situation in order to help them accordingly in case of need. Some other projects were addressing the *use of social network* to reach out and then connect the care receivers and in this course also partly the caregivers. The main target group of these projects are care receivers, so there is still room for research when it comes to offer support to informal caregivers (Levine et al., 2010).

In this paper we try to present systematically the needs and requirements of informal caregivers and to map them to infrastructural elements, based on our previous research (AAL project TOPIC[2]). Acknowledging the need for further investigation and technological development in this area, TOPIC, a European project by the AAL Joint Programme, aimed to advance the *understanding of informal caregivers' needs* and *design* information and communication technology (*ICT*) *solutions* to support them in their daily environments (Breskovic et al., 2013; Pinatti De Carvalho et al., 2013, 2014, 2016; Tellioğlu et al., 2014, 2015, 2016, 2017; Hensely-Schinkinger et al., 2015, 2018; Hensely-Schinkinger & Tellioğlu, 2017). The project addressed and solved the lack of an integrated social support platform and the lack of accessible ICT applications for elderly. The project congregated 10 partners located in Austria, Germany and France.

This paper introduces briefly the situation of informal caregivers before showing relevant elements of care infrastructures which are considered to be useful to support this target group. Afterwards needs and requirements of informal caregivers are described. It concludes with a suggestion how to map infrastructural elements to caregivers' needs to achieve caregivers' satisfaction in respect to products, technologies and services provided to them. We claim that an *interconnected health care infrastructure* based on the socio-technical approach can offer a possible solution to this not yet solved problem.

Informal caregivers

Informal caregivers are diverse in many senses, in age, gender, relation to the care receiver, location of living, additional support provided by others, etc. The sociodemographic data in Europe (Birtha & Holm, 2017; Nagl-Cupal et al., 2018; Hoffmann & Rodrigues, 2010) shows that the age range of informal caregivers spans from 35 to 65. 35% of informal caregivers are children, 28% are parents,

[1] https://cts.wien/projects/aal_best_practice/

[2] http://www.aal-europe.eu/projects/topic/

11% are spouses. Another fact is that 85% of informal caregivers are female. Higher the age of informal caregiver, the percentage of male informal caregivers increases. 72% of informal caregivers share their home with their care receiver. 62% of informal caregivers who live in another house are only in 15 min distance to their care receiver. 31% of informal caregivers are not supported in their health caring activities, without any support of their relatives or friends.

Health caring tasks defer based on the duration and type of the activities (Stokes, 2009). In Europe, around 30% of informal caregivers find their caring activities very intensive, with around 56 hours per week or more. More than 50% spend less than 10 caring hours per week. In Austria, there are 48% of informal caregivers who are in charge of health caring around the clock (Nagl-Cupal et al., 2018).

Being an informal caregiver is a temporary endeavor and while being the main proxy of the care receiver, the intensity of the care work depends on the health condition of the care receiver. The daily routine is mainly determined by the care receiver, all arrangements of caring ("need help and attention" or in case of professional help "late again") and of course also by spontaneous interruptions which might occur unexpectedly. Informal caregivers do not have any time to do something else than caring, they are socially excluded, so they cannot meet friends or spend time with others. This burdensome period gets worse when informal caregivers still have a job, are old or have a health condition.

Elements of care infrastructures

An "infrastructure is something that emerges for people in practice, connected to activities and structures" (Star & Ruhleder, 1996, p.114). It can be configured by adjusting different dimensions of it, like its embeddedness, transparency, reach or scope, links with conventions of practice, by considering the characteristics of the target group and their real environment. Seen from a health caring perspective, infrastructures become very central for informal caregivers. A combination of people and technologies can be the right infrastructural solution to help informal caregivers overcome the challenges they have.

Using the socio-technical approach (Mumford, 2001), we can say that *informal caregivers* are crucial actors addressing the social part of care infrastructures. Informal caregivers act and use several infrastructural elements to fulfill their goal of health caring. People around informal caregivers are usually their *relatives*, other *family members*, or their friends and neighbors. These people might have the most exchange with informal caregivers by visiting them or talking to them regularly, but they might be also locationally and relation-wise far away. Some of the relatives, especially the ones who are living in another city or having their own families and work, are usually in rare contact, only in particular cases, like taking care of legal issues, medical treatments, other organizational or financial activities. Some of them act only if they are asked for.

The most of the informal caregivers we were in contact with called at least one *friend* or *neighbor* who was on their side if they were in need of help. The case studies show that the geographic proximity of the people to the informal caregivers is a defining factor how much and how often their attention can be taken for aid. Sometimes it is only spending time with them by having a coffee or tea, sometimes just asking how they feel or whether they need help, but sometimes it is more than that, by taking even more responsibility of care processes to be carried out.

Certain care-related issues cannot be solved or answered by lay people. *Professionals* with different backgrounds are indispensable to help bear the burden of caring at home. Care professionals do not only provide their tangible services by coming home and providing health, physical therapy, housekeeping, cooking etc. services, but they are also available for ad-hoc questions or in unplanned occurrences. Furthermore, professionals are sometimes the only social contact that informal caregivers have from the outside world. So, it is important that professionals build a team with the informal caregivers and cooperate in respect to care activities that informal caregivers have to continue carrying out when professionals are gone and they are alone with the care receiver.

Besides single persons as professionals, some *organizations* are specialized in products and services for AAL and health care. Their offer is usually a trustful asset for informal caregivers, especially if these organizations are selected and recommended by professionals.

As all human beings, informal caregivers need a *social environment* in which they can exchange with others, usually with similar experiences. But also, they can get information about things directly from a care community they are interested in or want to be part of. The exchange with the peers does not need to be active always, some of the informal caregivers are good readers and commenters but not active posters.

Seen from *technology* perspective, two categories can be identified in the context of caring by informal caregivers: providing information and communication channels. *Information* provision can contain several data originated by professionals or the peers, by varying from being very specific to very general. This range can include medical, care or legal information, current services for particular care situations or changes in the society and official regulations. The information channel is normally one way, from several sources to the informal caregivers. But a search, filtering or configuration functionality of a platform can make the offers selectable and configurable and, this way, personalizable and interactive for consumers like informal caregivers.

On the other hand, the *communication channels* supported by the care infrastructures can be utilized in a larger flexibility in use, content and circle of people to reach out. Audio, video or textual communication have their strengths in specific situations and scenarios, and exactly there they should be applied. For

instance, combined with more innovative ways of stressing out oneself like storytelling or (video or audio) commenting, many to many communications can be a good countermeasure to fight against social isolation.

Needs of informal caregivers

Based on the related and own research work in the area of AAL (mainly studied by applying qualitative methods), we summarize the needs of informal caregivers as knowhow, tangible, social and psychological support, which will be described briefly in the following subsections.

Knowhow support

Health caring requires a certain degree of knowledge for day-to-day care arrangements in and outside the home, knowhow about care processes to ensure affordable care activities, especially by considering any possible health condition of the informal caregiver while providing domestic health care, including instructions of care or medical information covering diagnosis or treatment of the care receiver, etc. Informal caregivers need well-established trustful sources of information with an easy access that should offer a fast and useful reply even to an ad-hoc request.

Tangible support

Due to the health condition, emotional or physical restrictions, not everything can be done by informal caregivers while caring at home. Tangible goods and services provided can be a supporting help to avoid a certain work load which informal caregivers have to carry. Some examples are: shopping support; household support like cleaning, cooking, taking care of the care receiver, e.g., bathing, medical health support like organization and arrangement of doctor's appointments, buying medicine at the pharmacies; food delivery; support for activities at official institutions like banks, state authorities; services to hand over caring for a while for having a break temporarily, spanning from couple of hours during a day to a longer period of time due to a rehabilitation or treatment process. Flexibility of the service providers is here the main success factor: the service should be provided both on a regular base and on demand.

Additionally, a marketplace on a customer-to-customer exchange could be very useful to inquire necessary equipment or furniture for caring and vice versa to offer things which are not needed any more for the specific health caring situation at home, like walker rollator or other type of exercising tools, often due to the change of the health condition of the care receiver. Secure, trustworthy and

easy to use platforms with a sustainable maintenance are most suitable infrastructures for such a tangible support.

Social support

After having a hard change of the life situation, by becoming a caregiver and putting everything else behind this responsibility, social isolation and loneliness are the most common problems informal caregivers face. A well-accepted support to address these challenges is ideally characterized by offering services that are friendly, community-based, on- and off topic about health caring subjects, enabling active and passive participation or anonymized access.

There are several ways of providing a useful social support to informal caregivers: For a 24-7 ad-hoc support, a hotline could be established to reach out to professionals and their competent network to help informal caregivers in urgent situations. Health care related activities or other types of events, like gatherings to interesting subjects related, e.g., to active aging, health, culture, entertainment, making like cooking, hand crafted activities, etc., can be arranged and moderated by associations or by caregivers themselves within their peer community. Caregivers could be encouraged to initiate activities they think of.

Storytelling is one of the very useful approaches to express oneself. An easy-to-use interface of a care infrastructure can facilitate creating a common space in which caregivers find interesting stories of others, who they can connect to easily, and furthermore, they share their stories in a natural way by just telling and recording it in audio and video format and making it accessible to their peers. Commenting directly in the story could nudge the interaction between peers and through this help reduce or avoid loneliness of single individuals in a relatively natural way.

Due to their care situation, being positive can be sometimes very difficult for informal caregivers. Positive computing can be a helpful approach to address positivity in the designed platforms (Calvo & Peters, 2015). Photos, videos but also text of others expressing a pleasant or happy situation could be a positive impact to the mood and distract caregivers even from their rather depressed daily routines. In our studies in TOPIC, caregivers mentioned several times that they would like to have a (virtual) space in which they are not confronted with any care-related subject. They want to have a “care-off” time, individually but also together with others, and this on a regular base. They see this as a factor that helps normalize their burdensome life a little bit.

On the other hand, the already well-experienced support groups can be established also in virtual environments, by mimicking the elements of real settings to seem familiar to the caregivers. Furthermore, these support groups can be extended by a body system to offer an individual exchange with a trustworthy peer, no matter face-to-face or digitally.

Psychological support

The hard and troublesome life of informal caregivers might end up with psychological breakdown or depression and hopelessness. In such and other cases informal caregivers need counseling and supervision on a regular base (through arranged appointments) or irregularly (via a hotline). In this type of support, confidentiality, one-to-one interaction, timeliness of the support are crucial requirements. Psychological support can be provided directly by according professionals depending on the mental condition of the informal caregiver. The communication and therapy if needed must be dealt confidentially, with a secure exchange with professionals, especially when it is digital. A hotline for ad-hoc emergency needs can complement this support and brings a more human approach to it.

From needs to possible solutions

Table 1 summarizes the needs of informal caregivers described above by addressing some specific design-related requirements and by suggesting possible solutions and offers that are design inspirations for future work.

Table 1. Support needed for informal caregivers, requirements identified and suggested ideas for possible solutions

Needed support	Requirements	Ideas for solutions
Knowhow support	Usable, accessible, configurable, personalizeable, simple language	• Platform with small learning modules • Multimodal information provision, also combinations of audio, video and text • Up-to-date information dashboards with links to relevant institutions and sources • Not only pull access, but also a configurable push access to relevant and subscribed data • Possibility to pause and resume the consumption of the data available • Use of favorites, bookmarks for actions and instructions
Tangible support	Regularly or on demand, flexible in delivery, secure, trustworthy, configurable, quality assured, well-selected and -adapted for caring	• Bidirectional marketplace with relevant products and services • Configurable accounts for individual selection and subscription • Ad-hoc anonymized access to ongoing activities and events • A single point of access to rated and curated products and services • A single point of access to a comparison

		of products and services
Social support	Friendly, community-based, on- and off topic about health caring subjects, enabling active and passive participation or anonymized access	• 24-7 ad-hoc hotline support • Continuous offer on HC related activities, including arrangement and moderation • Continuous offer on off-HC-subjects related activities, including arrangement and moderation or only facilitation • Space for interactivity and support in initiating of organization of gatherings by caregivers • Virtual support groups • Body systems • Platforms for easy storytelling and multimedia commenting of others' stories • Platforms for sharing multimedia data (social network of caregivers) • Platforms implemented by applying positive computing[3]
Psychological support	Reliable professional help, regularly or on demand, confidential, one-to-one interaction	• Hotline support for ad-hoc emergent help • Appointment based communication with professionals • Counseling and supervision

Table 2 tries to map needs to infrastructural elements to build a coherent relation between the elements of care infrastructures and requirements of informal caregivers.

Table 2. Mapping the support needed by informal caregivers to infrastructural elements

	Informal Caregiver	NEEDED SUPPORT			
		Knowhow	Tangible	Social	Psychological
INFRASTRUCTURAL ELEMENTS	ICT–Information	X	X		
	ICT–Communication	X	X	X	X
	Friends & Family Members		X	X	X
	Individual Professionals	X		X	X
	Professional Organizations	X	X		
	Peers	X	X	X	

Social and psychological challenges are dealt with by involving the right people through the most suitable communication channels. The right part of the Table 2

[3] http://www.positivecomputing.org

is rather actor oriented and individual. Knowledge and tangible support for informal caregivers are more general. They can be offered to a larger group of caregivers the same way. Organizations connected and information provided solely through ICT are possible on this general part. The access to the support on the left side of the table can be arranged by configuration, selection, filtering or bookmarking, while on the right side one-to-one or one-to-many connections can be initiated by the informal caregivers for which they can use selection and configuration possibilities of an infrastructure.

Following the thought of a care infrastructure, a further step can be taken to connect different infrastructural elements to a unified infrastructural system, what we would call *interconnected health care infrastructures*. Besides consisting of involved actors, these infrastructures, which also host non-human elements, are interconnected via interfaces based on standards and regulations, support coordination of care to improve self-management of care, support awareness among home inhabitants, intimate socials, extended socials, are usable and adaptable, open and secure with flexible access control. Further work is needed to detail such interconnected care infrastructures, preferably by using scenarios and use cases created around informal caregivers.

Conclusions

In this paper, we identified needs and requirements of informal caregivers. The lessons learned presented are based on the related and own research work in the area of AAL. The main elements of a care infrastructure are systematically identified and put into relation with informal caregivers needs and requirements. This ended up in a more complex interconnected care infrastructure consisting of people and technology components, in the tradition of socio-technical approaches.

Additionally, ideas for possible solutions are presented by specifying concrete requirements of informal caregivers to address a possible solution space and possible implications for an infrastructural development in this direction. These should be seen as inspirations and initial ideas based on evidence-based case studies carried out so far in the area of informal health caring.

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