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Digital Support Requirements for the Care Community QuartierPflege

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ABSTRACT

The integration of informal caregiving into everyday life can lead to burdens that negatively affect health and psychological well-being of family caregivers. Care communities consisting of a dynamic network of informal and professional actors can offer a solution to reduce family caregiver burden. Close cooperation in such care communities gives rise to the immediate need for efficient coordination tools including digital support. Existing Apps for family caregivers do not always provide sufficient support to improve health and quality of life. Currently, there is no App holistically supporting daily work in care communities consisting of informal and professional actors. To fill this gap, specific App requirements for coordinating daily work in such care communities were identified in a user-centric approach. Therefore, structured personal interviews were conducted with $N = 16$ potential actors of care communities. Audio-recorded interviews were literally transcribed and analyzed in MaxQDA by structured qualitative content analysis. App requirements were divided into four major categories: operational planning (e.g., submission of care needs, handover books, calendar, synchronization of family caregivers' and care recipients' profiles), information (e.g., an information section per care recipient), communication (e.g., internal chat, speech-to-text-function) and human resources (e.g., administration of staff, working time and payment). In addition, privacy aspects (e.g., providing most important physical limitations of care recipients, but no medical diagnosis), usability and user experience (e.g., intuitive usage, logical structure, visually appealing design) as well as backend App requirements (e.g., implementation of different horizontal and vertical App permissions) were addressed. The target group of future App users could be wide with different roles in coordinating the daily work in care communities, which results in complex software requirements. Usability and user experience of a future App need to be evaluated with the target group. Furthermore, it should be evaluated whether digital support of care communities of informal and professional caregivers offers a holistic approach and a sustainable improvement of the quality of life and health of family caregivers.

Keywords: Care community, Informal caregiving, Digital support requirements, User-centered app development, Qualitative data, Interviews, QuartierPflege

INTRODUCTION

Due to demographic change, predicted shortage of professional caregivers is a challenge for societies as a whole (Spillman, Allen and Favreault, 2021). In Germany, family members provide care regularly and are even legally called upon to assist in home care. The integration of informal caregiving into everyday life can lead to burdens that negatively affect health and psychological well-being. More and more older people prefer to remain living in their own homes, even if they urgently need support in coping with activities of everyday life. In many cases, informal caregivers, such as family members and friends choose to take responsibility to fulfill their loved one's desire to age in place (Chattopadhyay, 2020). Coordinating various health care providers, managing medications, and even performing medical tasks for which few are trained often becomes a daily routine for the informal actors (Price *et al.*, 2020; Reinhard *et al.*, 2019). In order to balance caregiving and other responsibilities, some leave the workforce, and hobbies or social relationships are often neglected, leading to feelings of isolation and loneliness (Lee *et al.*, 2022; Price *et al.*, 2020). Additionally, the life-changing experience of needing to care for a loved one is often accompanied by increased emotional distress caused by symptoms of the care recipient (Jansen *et al.*, 2019; Queluz *et al.*, 2020). Many family caregivers themselves are older and with insufficient (sometimes missed) support from government agencies, they struggle from financial problems or helplessness in finding relevant information regarding support options (Chattopadhyay, 2020; Novais *et al.*, 2017). Digital technology is key to enable aging in place and enhance care (Kim, Gollamudi and Steinhubl, 2017). However, to relieve the burden on family caregivers, a reliable network is needed that provides active support and social assistance.

Care communities can offer a solution to reduce family caregiver burden. According to Kricheldorff (2018) a good coexistence of the generations and the involvement of a wide variety of local actors are essential for a successful good life when designing structures close to home. Proven approaches for a cultural change in the social area and neighborhood are moderated, professionally controlled on-site participation processes. The mixture of forms of action that are consistently approachable, participation-oriented, close to the living environment and anchored in the neighborhood has proven successful too (Kricheldorff, 2018). Different actors in care communities can involve relatives, professional caregivers, volunteering neighbors, part-time or full-time laypersons and, depending on the situation, even other care recipients. These informal and professional actors form a dynamic network and need to cooperate in close coordination.

The existing care community model "QuartierPflege" developed by a nonprofit organization (Gesellschaft für Gemeinsinn e.V.) in Leipzig, Germany envisions support in everyday assistance, housekeeping and basic care via a network of trusted neighbors. For this purpose, networks are to be developed, in which an average of three to six neighbors support one care recipient. To ensure a sense of familiarity, these networks are little clusters in neighborhoods with approx. 1000 to 1500 residential units. Supporting neighbors can do as much work as their time allows, from voluntary work to full-time employment. An appropriate payment can be funded by the German care insurance fund. Some tasks of everyday assistance, housekeeping and basic care require training by professionals, which is organized by QuartierPflege. Medical care activities continue to be carried out by professional caregivers. The local case management developed in QuartierPflege as a new coordinative role structure serves to coordinate all actors in the neighborhood centrally. For example, it manages the training sessions between neighbors and professional caregivers so that tasks can be taken over successively without any issues. It also organizes network care activities for care recipients. In addition, family caregivers have a similar role as caring neighbors. However, a different level of responsibility and sensitivity is required when dealing with family caregivers. Rewarding them appropriately for the work, they do anyway and partially relieving them through the network of caring neighbors is one of the aims of QuartierPflege. If family caregivers and their care recipients wish so, they can also be assigned a focal network position.

QuartierPflege does not intend to cover up all needs of care recipients with every type of care degrees. Rather, it intends to provide active basic support and social assistance that can actually be implemented by neighbors. Digital support tailored to the specific networks needs could open up the opportunity for all actors in QuartierPflege to interact more quickly and easily, to record their daily work, to organize themselves, to gain further qualifications, to commit themselves over a longer period of time, and to be relieved of workload. This gives rise to the immediate need for efficient coordination including digital support, which can enable active participation by all actors.

Currently, various Apps for family caregivers are available (Bidenko and Bohnet-Joschko, 2022; Grossman, Zak and Zelinski, 2018; Sala-González *et al.*, 2021). The most common features of these Apps provide different kinds of information, (professional) services for caregivers or support in organizational matters. These App features have a supportive character, but mainly relate to the care activities (Bidenko and Bohnet-Joschko, 2022). Recent findings indicates that available Apps poorly match the personal needs of family caregivers (Sala-González *et al.*, 2021). For example, Bidenko and Bohnet-Joschko (2022) could not find any App addressing the family caregivers' need for free time and leisure activities. Overall, Apps for family caregivers focus less on their health and quality of life by failing to offer sufficient specific features for this purposes (Bidenko and Bohnet-Joschko, 2022; Grossman, Zak and Zelinski, 2018). Beyond that, there is no App holistically supporting daily work in care communities consisting of informal and professional actors. Therefore, the aim of this research paper is to fill this gap identifying specific App requirements for coordinating daily work in such care communities using a user-centric approach. The future objective is to develop an App or App extension as a practically effective and transferable innovation to improve the quality of life and health of family caregivers.

METHOD

In total, $N = 16$ participants were interviewed in Germany during November and December 2022. One person did not answer the demographic questionnaire and was therefore excluded in the descriptive analysis. On average, the eight women and seven men were 57 years old (*SD* = 14.5). At the time of the interviews, two-thirds were involved in home care (66%), married (67%), and held a graduate degree (60%). Half of the interviewees were employed (53%) and worked a mean of 31.25 hours per week (*SD* = 7.91).

Interviewees provided informed consent and agreed to audio recording of the interview. In order to extend the existing care community model of QuartierPflege by means of an App in a user-centered way, structured personal interviews were conducted with involved actors (family caregivers, neighbors, volunteers, professional caregivers). The interviews covered three thematic blocks. The first section asked about the burdens of family caregivers and possible reliefs (example: "How has your everyday life changed as a result of caring for your relative? What changes do you perceive as particularly stressful?"). The concept of QuartierPflege and the processes within this network were discussed in the second section (example: "Please imagine that there is a person in your neighborhood who is responsible for organizing the support provided by the network described: What would be particularly important for you in this regard?"). The last section included questions about the use of digital technology, which App functions participants consider important in QuartierPflege, as well as questions about privacy issues (example: "Please imagine to have an App on your smartphone, in which you could see how the network is organized or how the tasks are planned. What features would you like to see in such an App?"). After the interview, participants answered a short demographic questionnaire.

On average, the interviews lasted 1.5 hours, for which participants received a remuneration of 10€ per hour. The interviews were audio-recorded and then literally transcribed using f4x automatic speech recognition software. These automatic transcripts were reviewed for accuracy and completeness. The software MaxQDA 2022 for qualitative data analysis was used to process all transcripts and analyze them by structured qualitative content analysis according to Kuckartz (2018). Results presented in this research paper only contain quotes by family caregivers and professional caregivers. The findings are illustrated with direct quotes with references to the coded segments in MaxQDA. A specific format was used, such as "B_01_PA, 126," where "B_01" denotes participant 01 and "PA" denotes the role as a family caregiver. Professional caregivers are represented with "PR". The following number ("126") indicates the paragraph number of the respective interview in MaxQDA.

RESULTS

The results presented in this paper focus on specific App requirements for coordinating daily work in care communities. Therefore, burdens of family caregivers are presented very briefly. Specific outcomes related to the care community QuartierPflege will be discussed in the conclusion.

Specific Burdens of Family Caregivers

Most family caregivers reported that time spent on care is a major cause of multiple stressors. Due to the time commitment, some participants emphasized that friendships were neglected and expressed feelings of loneliness.

The time spent on household maintenance and work activities had to be reduced as well. Others felt that their life is basically centered around the care recipient, *"So everyday life changes tremendously, because things that you used to like to do so much, they just fall away now. It really focuses now more or less on all these things that have to do with these people [care recipients]."* (B_10_PA, 5). Psychological impact of caregiving resulted from the responsibility one has for the well-being of the other. Some participants also highlighted the emotional burden and loss caused by symptoms of their family member, *"And so in the end there's basically nothing left of my husband. Nothing... So he doesn't get dressed by himself anymore, he doesn't eat by himself anymore."* (B_01_PA, 9). Besides hiring costly professional caregivers, participants emphasized the need for active local support as a possible way to reduce burden. In particular, household support or short-term accompaniment of the care recipient were frequently mentioned, *"What would help relieve the pressure would be someone who goes shopping, who runs certain errands. [...] So doing errands, just being there for the person, having a conversation, that kind of thing."* (B_01_PA, 87). Furthermore, participants wished for more information that is accessible on specific diseases and treatment concepts as well as local support opportunities in general.

Digital Support Requirements

Participants named a variety of App requirements in order to support the coordination in care communities digitally that consequently reduces burdens of family caregivers. These requirements were divided into four major categories: (1) operational planning, (2) information, (3) communication and (4) human resources. In addition, participants addressed aspects of privacy, usability and user experience as well as backend App requirements. Many of the interviewees' statements were a conglomerate of interdependent requirements, so that a one-to-one code assignment was rarely possible. The following sections illustrate the interdependencies of the required App functions.

Operational Planning

Most App requirements related to operational planning issues. Primarily, the submission of care needs was emphasized here, followed by the documentation of care activities, and a calendar function. To submit care needs it should be possible to specify which basic support in everyday assistance, housekeeping and basic care is needed on which day, time, and in which frequency. In addition, participants mentioned, *"There must be a daily calendar where people can see who is coming when, for what purpose, and there must be contact details so that people can get in touch with them."* (B_07_PR, 110). Participants frequently highlighted the importance of personal contact. It would be necessary to fulfill normal, human needs or special requests, such as, *"One is not allowed to eat certain things. [...] Does he go shopping in general, or how does the person who goes shopping for me get my bucket list? That* *should be part of the App."* (B_01_PA, 126). Such important basic information could be stored in an information section about the care recipient. Contact details should be accessible in a personal staff profile.

Another essential part of the App should be an effective and efficient documentation of care activities by the network of neighbors. For many participants some kind of a handover book is crucial for caring activities to be comprehensible for the network, *"Then it's called "accompaniment to the ophthalmologist". Now this can be a regular test, [...] or the person is blind or has something significant. [...] Then the neighbor can transmit the information or the diagnosis to the caring relative, something can be written in and the other person can read it. So, some things are critical."* (B_03_PA, 93). Family caregivers also highlighted their need for some kind of notifications as reassurance that their loved ones are doing well and that the assigned caring neighbors are doing their job, *"That I know this will be read on the other end in a certain time frame."* (B_03_PA, 113). For this purpose, it would also be conceivable to synchronize the profiles of family caregivers and care recipients. Documentation features should also support the administration of human resources, which could also enhance the quality of care activities and personal contact, *"She has additional needs, maybe today is her husband's day of death, maybe it would be nice to stay a little longer. So that this can also be documented. [...] and becomes a billable service. A working time recording within the App is not bad at all."* (B_08_PR, 143-145).

Depending on the role in the network, the calendar function should include relevant appointments, for example: the roster of caring neighbors or doctor appointments of the care recipient. Family caregivers emphasized that it is equally important for the network to know *"[...] when the family caregiver intends to take a vacation for his or her own recreation, so that I can organize a replacement."* (B_02_PA, 120).

Information and Communication

Participants imagined the App as an extensive information tool, adapted to the role each one has in the network (very complex for the local case management, but tailor made for neighbors, family caregivers, and care recipients). When referring to the information tool, participants often underlined a clear user interface, *"That you can find your own area in a graphically simple way with the information: 'What's important for me right now?"'* (B_01_PA, 113). Important basic information of the care recipient could be stored in a personal information section, already mentioned above. According to one family caregiver, this basic information may seem to be less relevant but could make a huge difference. For example, whether the care recipient wishes to be addressed by first or last name, *"Some people no longer hear their first name. [... but] it is also nice for some people if they can still hear their first name. These are all such subtleties."* (B_03_PA. 79).

Another major App requirement mentioned by participants was an App internal chat function to communicate within the network of caring neighbors or one to one. For the network being able to organize themselves and to be independent of the local case management to some extent, a general availability of the involved was essential for the participants, *"In the best case, you know who is doing it, if there are any problems. So that you can communicate with them in an uncomplicated way, specifically via this App, without having any phone numbers and without knowing whether they are on WhatsApp or not."* (B_01_PA, 113). One participant noted a speech-to-text-function would be a nice communication feature to reduce efforts for documentation but also enhance usability for older people (B_08_PR, 157).

Human Resources

Human resource management tools should be implemented in an App in order to digitally support the daily work in care communities. Some examples were already mentioned above (contact details, personal staff profile, handover book, record working time within the App, rosters). As outlined, these requirements were often closely related to operational issues, information, and communication features. In addition, participants frequently highlighted their desire to be independent of the local case management to some extent. To fulfill this need, a handover book and personal staff profiles were two major features that should be implemented in the App. Especially, personal staff profiles are expected to offer a great potential for guaranteeing the quality of caring activities. They could improve the fit between the caring neighbors and the care recipients, *"Well, for my sake, that you say: 'Well, I need someone who has a lot of patience' or [...] 'I don't really understand everything' [...] in other words, someone who is sensitive to such handicaps."* (B_03_PA, 79). Soft-skills like patience, empathy, sensitivity, or respectful communications skills should therefore be available in the personal staff profiles. However, participants emphasized, *"At the latest, after the first or second visit, they know anyway if it fits."* (B_01_PA, 126).

Additional Aspects

Digital support for daily work in care communities via an App requires special aspects of privacy, usability and user experience as well as backend App requirements, which were also mentioned by participants. Since sensitive data is sometimes used, participants explained which data should be stored digitally and which should rather remain private. Personal data such as name, age, gender, address, phone or e-mail-address could be stored for every person of the network. The (professional) experience or completed trainings of the caring neighbors should be provided. It would be all right to provide the most important physical limitations of the care recipients as well as their care degree. However, data like financial matters, mourning stories, or special medical diagnosis should not be digitally stored. Nevertheless, participants often considered that it depends on the role in the network, which data are available and which not, *"Specific patient data are needed by the professional care provider, but not by the neighborhood. It depends on the role."* (B_01_PA, 126). Therefore, it would be essential to implement different horizontal and vertical App permissions. Additionally, participants talked about requirements like encrypted data transmission, server location, an automatic logout, and consent forms of network members.

Participants' reflections on usability and user experience showed, that the App should *"be very coherent and quite simple and for old people"* (B_03_PA, 99). However, the App should not be developed just for older people. Instead, *"it has to be manageable for everyone."* (B_02_PA, 126). Moreover, an easy and intuitive usage, logical structure, and clear arrangement of the App functions were mentioned fundamental. Likewise, participants wished a visually appealing design with good adjusted contrasts. To submit caring needs and document caring activities in an effective and efficient way, various types of assisting functions were proposed. One example was the speech-to-text-function noted by one participant (B_08_PR, 157). Another example mentioned by a participant was to integrate a route description for caring neighbors visiting the care recipients for the first time (B_03_PA, 99). This could also be connected to a navigation App.

During the interviews, all participants recognized that the system to be developed might be very complex. Coordinating the daily work in care communities by means of an App entails a high level of planning complexity, which needs to be covered by the system. Different horizontal and vertical App permissions depending on the role within the network were only one part of this concern. Contact details, profiles, calendar functions, handover books (as examples mentioned above), and other operational and administrative tools have to be linked to one another. To make the system work, participants noted the importance of participatory development, *"[…] that's why you always have to look at it from the point of view of those who mainly work with it."* (B_08_PR, 197).

CONCLUSION

The burdens of family caregivers were largely consistent with those found in a previous literature review. Relief potential could be found in the care community QuartierPflege, particularly in the areas of housekeeping and everyday assistance, as these tasks could be taken over by caring neighbors of various age groups. In addition, this could provide some free time to family caregivers because their own time spent on these care activities would be reduced. This would also be in the spirit of QuartierPflege. As a new model of care communities, QuartierPflege offers a holistic, but consequently also complex approach to improve the quality of life and health of family caregivers. Mutual trust in the caring neighborhood, personal responsibility of all network actors as well as the ability to organize themselves independently are key factors to success. Thus, the resulting software requirements for digital support are complex. One example is the digital submission of care needs and matching them with the available network of caring neighbors: Imagine a caring neighbor has to cancel his or her appointment contrary to expectations. The care recipients' request is then returned to the network of caring neighbors. Another neighbor qualified for the activity can now accept the task. Thus, the requested care need remains guaranteed without any intervention of the local case management. If no neighbor can take over the task, the local case management is notified and organizes a professional caregiver or the family caregiver. At the end of the day, the required care needs remain assured.

The approach of digitally coordinating an entire care community is already a unique selling point. Nevertheless, far more App requirements besides submitting care needs have been identified to successfully coordinate a care community of informal and professional actors. However, the small, inconspicuous App functions would seemingly make the big difference compared to existing Apps (e.g., directions linked to the navigation App, profile synchronization of family caregivers and care recipients, personal profiles of caregiving neighbors and care recipients). To gain further insights in required App features and possible reliefs by the new care community QuartierPflege, the interviews are currently still ongoing (expected end: March 2023). Especially, the group of care recipients is focused in upcoming interviews.

Because there is a wide range of support and relief potential overall, the target group of future App users could be wide. Therefore, the App should be usable and appealing to all possible users. Accordingly, the usability and user experience of the future App need to be evaluated with the diverse target group. Furthermore, it should be evaluated whether the care community QuartierPflege offers a reliable network for caring activities and a sustainable improvement of the quality of life and health of family caregivers.

In addition, it is necessary to ensure data protection and privacy, because the App to be developed will work with highly sensitive personal data. Among other things, internal protection could be ensured by different horizontal and vertical App permissions. The complete list of requirements for a QuartierPflege-App can be received on request to the author.

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