CareConnection – A Digital Caring Community Platform to Overcome Barriers of Asking for, Accepting and Giving Help

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ABSTRACT

Many people would like to remain in their familiar surroundings in old age, even if they need certain forms of assistance. But what exactly does everyday life look like, where are the hurdles and where can community-based support options start? The results of a citizen-based participatory interview study of community members of a rural Living Lab near Zurich, Switzerland and full-time researchers from two universities in Switzerland and Germany explore these questions. Results of the study relate to physical limitations and potentials in old age, aspects of well-being and mental health, social engagement, relationships and networks, as well as the theme of 'asking for help, accepting help and giving help'. Against the background of a key category, the barriers of 'asking for, accepting and giving help', an overarching reflection by the co-researchers and full-time researchers took place. This focus provided the basis for the participatory development of CareConnection, a digital community platform design that fosters social exchange and helps to overcome identified barriers, which can be physical, mental or social and within these categories temporal, spatial, structural and/or individual and thus enable or promote social encounters and interaction to establish a higher level of well-being and health.

CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); Empirical studies in HCI; Human computer interaction (HCI); HCI design and evaluation methods; Field studies; Human computer interaction (HCI); HCI theory, concepts and models.

KEYWORDS

Caring Community, Community Platform, Older Adults, Overcoming Barriers, Participatory Action Research, Community-based Participatory Research, Participatory Design, Citizen Science

1 INTRODUCTION

Citizen-centred approaches, such as Caring Communities [21, 27] and Living Labs [26], are increasingly being used to generate new local and sustainable solutions for supporting, caring and nurturing people at home and in their everyday environment. Such solutions are, as Otto et al. [29] underline, of great importance for the Swiss society due to various reasons regarding 1) the lack of support and 2) the fact of not accepting available help. Thus, their final report of a population survey shows that primarily inadequate search strategies are responsible, i.e., need and service do not meet each other. A lack of understanding of one's own need for help or the refusal to accept help or a specific support person are also frequent causes. Cost, language barriers and time are downstream reasons, although they should not be ignored. Furthermore, individualized services that can be easily integrated into everyday life are still a challenge, according to the authors. In addition to the necessary change in government support structures against this background, attention is increasingly focused on bottom-up approaches as being formulated in the Caring Community concept. This, like all other approaches used in the field of care, is based on the Digital Care and Nursing Modernization Act (DVPMG)[1], which also includes "digital care applications (DiPA) in outpatient care" (Ibid., translation by the authors). The project at hand accordingly aimed at creating a button-up citizen research-based initiative, funded by the Swiss National Science Foundation (SNSF) and German Research Foundation (CRC 1187). We are committed to supporting people in need of help by showing them new ways of solving problems based on social exchange, which in principle, but especially for older adults, is essential for personal well-being and thus for mental health [23, 24]. In this context, Caring Communities contribute to sharing the daily (domestic) care work among several shoulders in order to reduce the workload of family caregivers, e.g., through neighborhood networks, new support services and good networking with professional service providers and existing services [12, 18].

The supply and demand of community platforms for use by older people has been increasing in the European market for several years. Their focus is on networking and fostering social connection, providing care for persons with increased need for assistance, and strengthening autonomy and self-empowerment. Platforms of this kind are intended to help overcome invisible barriers to establishing and maintaining encounters and relationships between older persons [28] digital and in real life [35]. Against the background of the corresponding research landscape, we want to make a meaningful contribution based on an empirical study that pursues the (digital) development of a Caring Community in order to encourage older people to remain in their own homes in the long term in the event of a need for support and to relieve private caregivers.

CareConnection is the idea of a community platform to foster social exchange and support overcoming the barriers 'asking for, accepting and giving help'. These different types of barriers are core categories that emerged from the joint analysis of the study results. The design idea for CareConnection was then developed through discussion of these core categories and against the background of the research gap derived from the current research landscape. An

underlying barrier as described in the literature by Tronto [36], namely 'recognizing one's own needs', was taken into account in this design. The platform is to be understood as an umbrella, informing and offering different care possibilities – informal and formal – in one place. The first design goal has been reached by the principles of Participatory Action Research (PAR) [20] and Community-Based Participatory Research (CBPR) [14].

In the following, the most important outcome of the study will be briefly mapped after a short summary of the research background and description of the methods used. It will be followed by the platform design and its practice-based implications which will be explained in more detail.

2 RESEARCH BACKGROUND

The following chapters address relevant literature related to community platforms, overcoming barriers, and volunteer work.

2.1 Community platforms

Community platforms are designed to facilitate communication and collaboration among a larger group of people with shared interests. These platforms can take many forms, including social media platforms, online forums, and marketplaces. Community platforms are typically open, meaning that anyone can access them. One of the main advantages of community platforms is that they can foster a sense of community and belonging [7–9, 42]. They usually address broader social issues. Especially for older adults this means: "Current technologies provide opportunities to make ageing-in-place and civic participation more achievable, as they can support older adults to access resources that their community has to offer" [42]. Here, these platforms might possible contribute to a more sustainable healthcare system [40, 41], nonetheless, this research area is still underrepresented [42].

2.2 Overcoming barriers

Despite facing health problems that may require additional care, older adults often do not seek help. It is important to distinguish between informal and formal support. With regard to formal support, barriers arise from mistrust and previous negative encounters with health care providers, all of which discourage older adults from seeking help [6, 11, 37–39].

With regard to informal support, the presence and accessibility of such resources often reduces the need or inclination to seek formal support, as older people's concerns are addressed by people in their immediate environment [3, 13]. However, informal care can become a burden for the informal carer [4]. Caring Communities are suitable for relieving this burden, but they hold their own challenges and barriers. Thus, they must first be established, which requires a lot of information and communication work. Also the needs and interests of the various potential users – private individuals as well as other stakeholders – must also be met, which requires a multiple focus in terms of content [35]. Other important factors that can become a challenge or barrier if not considered from user perspective are "data storage, funding and costs for users, clear name function, registration options, categories and structure, and visibility" [35]. It also is necessary to find a committed team that builds and runs the platform [42].

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[1]https://www.bfarm.de/SharedDocs/Downloads/DE/Medizinprodukte/DiPA_Leitfaden.pdf (accessed 19.07.2023)

Another important factor in seeking help from a user perspective is the perceived impact on the independence of older adults. They strive to avoid being perceived as a burden and instead seek recognition in a positive way. To overcome this challenge, older adults need to redefine help-seeking as a means of enhancing their personal independence [2, 3, 15, 17].

Concerning the accessibility and awareness of formal services, older adults voiced various issues that hindered help-seeking, including concerns about costs, extended waiting times, brief consultation durations, and conflicting schedules, all of which served as barriers [6]. Furthermore, a lack of available information and awareness of services was evident [2], which also correlates with the limited knowledge of older adults' understanding of the severity of their issue. To overcome this barrier, the need for greater understanding of available resources and services, greater convenience in accessing these services, and improved health literacy were identified [31].

2.3 Volunteer work

Voluntarism is of great importance, especially for organizations with limited resources [34]. The motivation for giving one's skills and time for the benefit of others ranges from altruism, to belonging, to ego and social recognition, to development and learning [10]. Also, for older adults, volunteering provides great opportunities. According to a study conducted by Cheung and Kwan [5], the engagement of older adults in volunteer work through the assistance of social workers was found to enhance their overall well-being. In their findings, Lima and Mariano [22] assert that volunteering can serve as a reliable means of promoting individual well-being and contributing to societal well-being.

3 METHODS

In the overall research study whose interview results led, among other technically-based ideas, to the development of the idea and design of CareConnection, we followed the approaches of Participatory Action Research (PAR) [20] and Community-Based Participatory Research (CBPR) [14, 16, 30], i.e. a needs-based and sustainable collaboration between full-time researchers and "co-researchers" [1, 12, 19, 25]. The study ran over a period of three years in a rural community near Zurich.

A total of 29 people, 18 women and 11 men, participated in individual interviews, two-person interviews and a group interview (focus group). The analysis of the interview results has been carried out iteratively [32]. The evaluation took place on a two-week basis in digital Participatory Design (PD) workshops with 7 co-researchers. The results showed that above all physical and mental aspects, social engagement, relationships and networks, as well as the topic of asking for, accepting and giving help are of concern to older people and that there are many barriers within these categories that need to be overcome in order to fulfil one's own needs.

CareConnection shall, besides a meaningful focus on older community members, also address younger people to meet the claim of intergenerationality of the Caring Community. In this regard, a collaborative design of the platform has been developed by one full-time researcher, three university students and two out of seven co-researchers, within two focus group meetings.

4 CARECONNECTION – A SOCIO-TECHNICAL CARING COMMUNITY PLATFORM FOR OLDER ADULTS ADDRESSING BARRIERS OF 'ASKING FOR, ACCEPTING AND GIVING HELP'

The interview study identified diverse barriers to 'asking for, accepting, and giving help'. These barriers can be physical, mental, or social, and can vary in time, space, structure, and individuality. We will briefly overview the platform's functions (see chapter 5) and focus on one barrier, shame (chapter 4, 5), for detailed examination in the context of the community platform design.

Barrier 'Shame'

Collaborative care work is an enriching approach, for which the socio-technical community platform creates a new space of encounter, which makes it possible to overcome the barrier of 'shame'. An example for this emotion:

"I have something that I have difficulty describing. Maybe I think too much and have the feeling that I as a person, as my life is now, am too complicated, I can't impose this on anyone. On top of that, I can't get away from smoking, which inhibits me even more. It is really an aggravation. (. . .) I [also] have difficulties in dealing with people. I have a lot of inhibitions about asking something or talking about something. But I'm also afraid of being contacted. Maybe at a time when I don't want to because it could get me into trouble." (Hanna)

Hanna is ashamed of her bad habit "smoking" which has become socially frowned upon. She also seems to be very self-critical. Her fear of being too complicated for others is indicative of low self-esteem.

There are further facets of shame identified in our interview study. 1: Shame, which makes it difficult to 'ask for and accept help', often has a lot to do with 'physical aspects' - e.g., a disability, age-related physical limitations, or illnesses with changes in walking or appearance can become a burden. 2: You can also feel ashamed towards oneself and others if you can no longer participate in community life as you can no longer do something. 3: A person's declining strength may no longer allow them to 'keep up' the household as usual or to take on the preparation/post-preparation for invitations. Consequently, this person no longer makes invitations because he/she/they is worried about being judged for the carelessly run household. This is one reason why contacts become fewer and fewer. 4: If one is aware that one is not extroverted and is/can be open, this can also hinder one. Likewise, when you see others being open and talkative, but you can't do it yourself, even though you might like to. 5: If giving and taking are not balanced, this can lead to guilt and shame. 8: Loss of quality of life, e.g., due to illness and/or disability can also lead to shame. 9: There are also people who are alone and feel ashamed of it.

5 CARECONNECTION – DESIGN IMPLICATIONS

Barriers to 'asking for help, accepting help and giving help' are of different nature and can be addressed in different ways through a socio-technical framework. The collaborative design of the community platform (see Figures 1 - 3) was carried out iteratively by the design team (3 students, 2 co-researchers), with one of the full-time researchers taking a hands-on supporting role.

CareConnection is a community platform that gives virtual as well as real space to both informal and formal exchange and support measures, creating a place of belonging [42]. Virtual through the encounters that are initially created in the digital space. Real for those moments of support that manifest in actual everyday life in the form of joint meetings, e.g., when shopping is done and handed over or when people meet for a walk in the park.

5.1 CareConnection – basic functions

As an umbrella platform, CareConnection operates informatively on a broad level by presenting and linking already existing offers, e.g., neighborhood help or home care services, which makes it easier to get in touch (Figure 1 focus area right). This convenience counteracts the barriers of poor accessibility, lack of information of recourses and services of care while seeking help as well as one of understanding the severity of the personal condition [2, 29, 31, 36] in terms of well-presented information and easy registration [35].

As a Caring Community interacting via the platform, new offers can be created at any time, adapted to the needs, requirements and demands of the users (caretaker & caregiver) (Figure 1 Focus area center – Help each other). These offers help to overcome financial barriers, as no payment is expected for mutual assistance within a community setting [6, 29, 35].
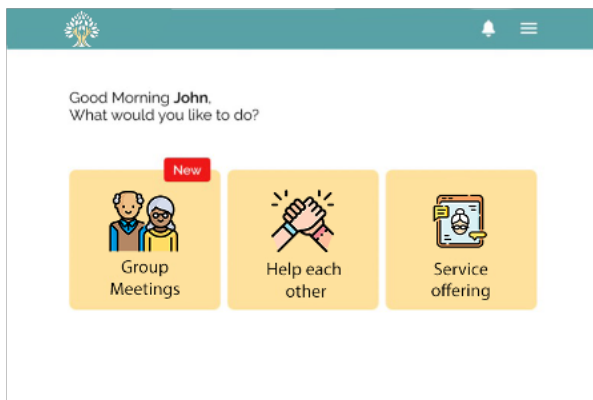

Figure 1: (left) Homepage of CareConnect with its focus on 1: group-based support function (left), individual support function (center), as well as 3: information option on existing offers from external stakeholders (right).

The platform enables a flexible role reversal and thus holds the potential of redefining the help-seeker [2, 3, 15, 17], increasing their personal well-being [5, 22] and potentially the well-being of the overall society [22]. This is not only in terms of fostering one's own independence instead of seeking help for reasons of need [2, 3, 15, 17], but additionally due to the reorientation of one's own use of the platform. People with support needs can find help here but can also become caregivers. The same applies to those who initially act as supporters. Both can take place on an individual or group basis (Figure 1 Focus area left – Group Meetings and center – Help each other).

Against this background, the community platform, in addition to its focus on social exchange and mutual support, also has an empowering and destigmatizing function, which becomes visible more quickly due to the socially networked structure.

5.2 Addressing the barrier 'shame'

Physical, mental or social limitations that prevent people from leaving their own home due to shame are adequately addressed by means of the technical interface (Figure 2). Those seeking help can expand their network via the meeting function and choose between private domesticity (Figure 2 My House) or public spaces (Figure 2 Others). Examples meet the needs of different age groups and thus consider the demand for intergenerationality. The design is subordinated to the focus on 'group meetings'.

Through the firmly integrated offers of help (Figure 3), people seeking help can easily find others who offer such in these areas and make contact indirectly. If seeking help the 'Ask for help' button can be used to ask for specific support (see preset) or make an individual request under 'Other'. Shame is reduced because the distance created by technology means that one does not have to ask for help directly and verbally, which would be the case when meeting in person or making a telephone call, or has to leave the house, if not willing to. The design is subordinate to the focus 'Help each other'. Furthermore, help providers can offer their support (see 'Help your friend', top right).

Another aspect that helps to reduce shame is the new temporality that is given through the technical approach, which, due to the new flexibility of being able to offer and receive help, cancels out perceived imbalances between giving and receiving. Due to the preset offer here, it is conveyed that these tasks are frequently requested support offers, which potentially lowers the barrier 'shame' and thus the superordinate barriers 'asking for and accepting help', as it becomes recognizable that one is not alone with this use.
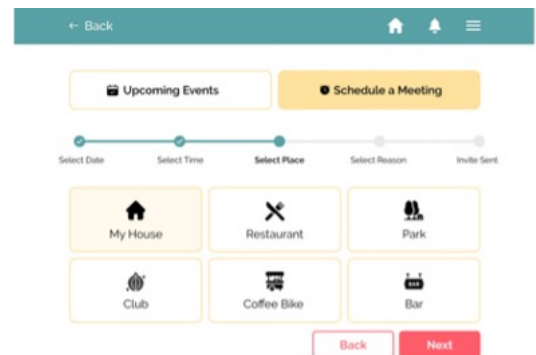

Figure 2: Scheduling a meeting with different offers for different target-groups against the backdrop of intergenerationality.
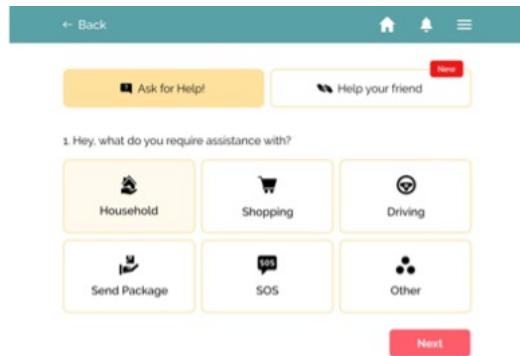
Figure 3: Asking for help with different contexts related to everyday life and an open category ('Other').

6 LIMITATIONS OF THE PLATFORM

Despite its needs-oriented design, CareConnection, like any digital platform on the web, comes with its own challenges. On the one hand, online platforms on the internet have the advantage that they are potentially open to all interested parties. However, they also bring challenges, especially when it comes to vulnerable groups of people or people who are not familiar with the Internet. In the following, we reflect on aspects and strategies of how we deal with these challenges.

Challenge of 'mistrust'

Mistrust can occur towards helpers you don't know/strangers. This challenge could thwart the use of the community platform. It could be met by its analogue counterpart, a mobile coffee bike developed in the local lab. On the one hand, the coffee bike is integrated into the CareConnection offer, where its dates and locations can be accessed (Figure 2); on the other hand, all non-users of the platform can find out about them locally in public places. The aim of the coffee bike is, just as with CareConnection, to bring together the needs of older adults or people with support needs with the existing services within the community. Through the presence in the immediate neighbourhoods every 2 weeks for 3 to 4 hours, the direct interaction with citizens is intended to overcome the same barriers of 'asking for help, accepting help and giving help' while enabling social exchange. In addition, further needs and requirements are to be discovered in order to be able to address them with suitable offers or to develop such. The coffee bike, which also offers coffee and cake, creates a local space for encounters, whereby its mobility brings it closer to the people in their neighbourhoods, thus bringing social exchange directly to them and trying to bridge the distance. With this format and its socially oriented focus, we also hope to address the underlying barrier of 'recognizing one's own needs'. Operated by the members of the Caring Community, trust can be built up with the citizens in this way and networking among each other can be promoted. In relation to CareConnection and the above-mentioned challenge of 'mistrust', members could take on a bridging function and in particular get to know private help providers better in order to make an initial assessment of their personality and motivation. However, two challenging circumstances remain, firstly the coffee bike is dependent on the commitment of the Caring Community members in order to really take into account its functions and an establishment of this activity, secondly the legal protection with regard to a protection of the help seekers against the helpers is a limiting factor.

Mistrust can also exist towards technology, especially the Internet. This could be countered not only by data protection, but also by appropriate assistance, which is explained when we look at a second challenge, namely that of 'technology ownership and corresponding media literacy'.

Challenge 'Technology ownership and media literacy'.

With regard to the lack of media or access to media and the corresponding competence in using it, a 10-year study by Seifert, Ackermann and Schelling (2020) shows that the percentage of older users is constantly increasing and that the digital divide between old and old is shifting in such a way that primarily over 80-year-olds are affected by a lack of access and digital literacy [33]. In this respect, the coffee bike, equipped with a central tablet, could be a contact point for those affected. In this way, they could be helped directly on site and with the support of the Caring Community members in setting up digital networking. This could also reduce mistrust through information and education. However, a remaining limiting factor is the technical competence of the Caring Community members themselves, which is not always given. As shown for example by the group of co-researchers in this study, four of whom consider themselves to be not technically competent.

7 CONCLUSION

On the basis of the results of a participatory interview study the design of a community platform named CareConnection has been developed collaboratively with co-researchers. CareConnection creates a new virtual space where a shared culture of care can be created and nurtured, overcoming certain barriers that are subordinate to the overarching barriers of 'asking for help, accepting help and giving help'. In doing so, we have introduced the barrier of shame in this contribution. The platform offers the target group of older people opportunities to organize their individual everyday life on an informal basis with the help of Caring Community members or other volunteers, or to obtain professional support, at no cost. This commitment empowers (older) persons with support needs to live independently in their own homes for the long term, strengthening community ties, promoting a sense of belonging and ultimately improving their quality of life.

CareConnection should help to make the Caring Community more present as a new intergenerational model of care, contributing to the health care system in a sustainable way [40], to establish it and to cultivate it within the community. At its core is a data-driven, community-focused approach that aligns with the values and needs of all stakeholders. For a final implementation of CareConnection, its design is currently being evaluated with further user groups.

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