
Understanding Informal Caregiver Needs for Coordinating Care to Support Aging in Place

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Abstract

In this poster, we present findings from a study focused on understanding the needs of informal family caregivers and gathering stakeholder perspectives on early concepts for an application designed to help family members coordinate the day-to-day care of their loved ones. The results of our formative study point to the need for solutions that can not only enhance the collaborative nature of caregiving but also support the family as the care recipient's journey and/or needs change.

Author Keywords

care coordination; informal caregivers; family caregivers; family calendar; caregiver needs; informal caregiver network; care circle; caregiver portal

ACM Classification Keywords

K.4.3. Organizational Impacts: Computer-supported collaborative work

Introduction

An informal caregiver (ICG) is someone who provides unpaid care to a care recipient (CR), typically a family member or close friend. Estimates from the American Association for Retired Persons state that 34.2 million adults in the United States acted as a caregiver for an adult over the age of 50 within the 12 months prior to their 2015 study [1].

Study Design

Semi-structured interviews with ICGs (n=18) were organized as follows:

- Introduction
- Scenario discussion and recording of caregiving situation
- Needs discussion and card sorting
- Review of coordination early concepts

Each interview lasted approximately 120 minutes.

All ICGs provided support to an adult with limitations in IADLs or managing a diagnosed chronic condition(s)

All ICGs used a computer, tablet, or smartphone daily

All ICGs provided feedback on perceived usefulness of concepts.

Responses were audio recorded and a second researcher took notes.

Informal caregivers often collaborate with their peers to provide support with instrumental activities of daily living (IADLs), like housework and meal preparation necessary for a person to live independently, to the CR. Nearly one hundred percent of the 1,087 ICGs interviewed in [1] reported helping their CR with at least one IADL with an average of 4.2 IADLs. The most common included transportation assistance, shopping (grocery and other) and household activities.

Coordination has been identified as a challenge that ICGs have when there is more than one involved with providing care to a CR. In [5], interviews were conducted in Germany to provide deeper insights into the needs and experiences of informal caregivers caring for chronically ill CRs. The researchers recognize the need for coordination support; however, also state the large effort it would take to bring together all stakeholders (e.g. caregivers, other family, and professionals).

Prior work in ICG care coordination has centered heavily on the concept of shared calendars. Bødker et al. studied time coordination of families and provided an example where CareCoor, a calendar-based system to connect home care aides and ICGs to provide the best care [2]. Plaisant et al. used shared family calendars as a way to allow families of different households and generations share schedules [4]. They found that even in close knit families, coordination of multiple schedules through traditional means is difficult and that a shared resource can provide support to keep everyone in sync.

Our work aims to focus on ICGs who provide substantial IADL support in collaboration with other

ICGs to a chronically ill or frail elder adult without the use of outside resources (e.g. home health aides). We aim to gain a deeper understanding of their needs to create a software-based solution to support the ICGs in coordinating the care they provide to a loved one.

Study Methods

We recruited 18 individual ICGs from the New York City area for the December 2014 study. For details, see Study Design in the left margin. The frequency of visits and proximity to the CR for each ICG recruited aligned well with segments identified in prior literature [1]. The three segments of ICGs recruited include:

- *Cohabiting (n=7)*: The ICG lives in the same household as the CR. Can be a spouse, friend or adult child.
- *Reasonable driving distance (n=8)*: ICG lives within driving distance of the CR either:
 - close by (less than 30 minutes one way) allowing visits several times per week. Neighbors included.
 - farther away (30 – 90 minutes one way) allowing for visits at least once per week.
- *Remote (n=3)*: ICG lives several hours drive or a flight away from the CR. They can be the primary ICG for the CR.

Though the remote scenario is not uncommon, it was not represented well in our study group as recruitment of that category proved difficult considering the face-to-face nature of the interview. With respect to relationship to CR, 10 of the ICGs interviewed had a parent/child relationship and three were actually neighbors.

Caregiver Portal Concepts

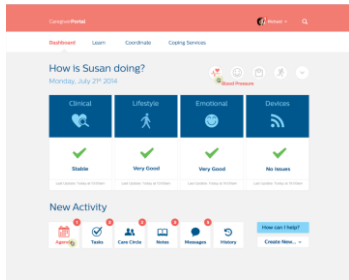


Figure 1: Example of a dashboard concept shown to ICGs on a laptop. Cards are provided for each feature along with a quick status update. Users can navigate to other parts of the tool.



Figure 2: Example of a paper-based concept shown to ICGs on the topic of coping support.

Scenarios and Discussion

Three scenarios created from prior contextual inquiries conducted by the research team were presented and discussed with participants to identify the context of their experiences. The scenarios presented were:

- *Scenario 1:* Siblings are caring for a single, retired elder individual with a medium stage chronic condition. The siblings are in reasonable driving distance from the elder and share care tasks, although one feels the workload is unbalanced.
- *Scenario 2:* The primary ICG is the spouse of a CR with several comorbidities. Their adult daughter, a secondary ICG, lives four hours driving distance. The daughter also has two young children she cares for, making her part of the “sandwich generation” – caregivers caring for ailing parents and minors.
- *Scenario 3:* The CR is frail elderly with a high risk for falling. The CR has a large care circle that includes a cohabitating spouse and an adult son who lives a 2 hour flight away among others such as other relatives and neighbors. The son wants to be more active and feels like a primary ICG in spite of distance.

The scenario exercise was conducted as an ice breaker to get participants comfortable with vocalizing the caregiving situation in his/her family and as a way to segment the participants so that their particular needs could be identified.

Needs discussion and Card Sorting

Participants were given 16 cards that contain a caregiver need as identified in research [1]. Participants sorted the list in order of the priority they

personally would want to see the need addressed in a solution. The list of needs provided to the participant by the researcher includes: medication management, learning about treatments, emergency management, meals management, learning about the disease, self-help for coping, household tasks, emotional support, communication with other caregivers, reminders, coaching groups, services from 3rd parties, workload management, and nursing activities. The participants selected their top five needs and were asked to discuss the reasons for each selection.

Discussion on Caregiver Portal Concepts

Early concept sketches for a software-based solution to help users keep track of caregiving tasks were shown to participants as a probe to continue the discussion about the gaps and needs of informal caregiving. All participants were introduced to the early concept in two ways – by allowing the user to click through sketches of screens presented on a laptop (Figure 1) or by showing printed wireframes (Figure 2) of concepts. For each concept presented, a discussion about the expectations of the user, current conceptualized design, and overall usefulness with respect to the participant’s caregiving situation followed. The features of the caregiver coordination tool shown to participants include: dashboard, calendar, task list, workload management, family dynamics visualization, coping resources, privacy controls, and communication with health professionals.

Findings and Conclusions

This study sought to gain better understanding of the context surrounding the needs of ICGs in coordinating care they provide to a loved one. Several themes that to our knowledge have not been previously published, resonated from the feedback provided by ICGs who

Resonating Themes

Partnership: Building and maintaining trust is very important in ICG and CR relationships. Informal caregivers work hard to build trust in their relationship with the CR.

Companionship: Providing companionship and motivation to the CR is an important aspect of care that may make or break other caregiving goals.

Anticipating a crisis: Deciding what events are emergencies, which are considered more serious, and how to solve problems for the CR are all things ICGs report struggling with.

Planning and knowing the rules: Informal caregivers constantly struggle with reassurance that they are taking the right actions for the CR. Additionally, they desire a way to assess one option over another and to have some way to project the outcome.

completed the study. A discussion of the five themes can be found in the left bar. The bottom line is that the CR's needs are the goals of the ICG. This fact was made apparent in the ranking of caregiver needs during the card sorting activity. The top three were medication management, learning about treatments and emergency management. ICGs were less likely to rank needs that correspond to their own health high, even though in discussions prior to the card sorting activity, emotional support and coping were mentioned as important for them. Conducting a separate activity where the ICG focus on their unmet needs explicitly may have yielded a different response.

Though it is true that there are universal needs for ICGs, the proximity of the ICG to the CR as well as the severity of the CR's condition dramatically impacts the ICG's approach to supporting their loved one. An ICG of a CR with dementia may behave differently than that of a CR with Type II Diabetes. Needs are varied amongst different ICG segments, driven by age, CR condition, location of ICGs, amongst other factors. Deciding on the stage or segments of ICGs to target in the first version of the solution would bring clarity to the tool and allow for more content-specific features.

Prior work suggests calendars as a framework or structure around providing care [2]. We found that calendars were not universally used to organize care by those interviewed, though some reported the CR maintained a paper calendar. Value was seen in collecting all medical information in one place. ICGs feared that including non-medical content could reduce the overall importance of the calendar. Additionally, consideration should be taken around the data entry burden of moving from a paper to a digital solution.

Privacy was a topic of importance for all participants. Caregivers felt it was important to be careful when putting sensitive CR information online. Some felt that setting privacy around who is invited to use the tool and who can see what content should be done in partnership with the CR to maintain their autonomy and privacy. Others expressed confidence in their CR not wanting to be involved. Understanding to what extent the CR would like to both access the tool and participate in on-boarding is a topic for future work.

Last, the current insights are context specific to New York City resulting in a participant pool from urban areas living in small spaces, with smaller families living in close proximity to one another. Insights from a more rural or suburban area are needed as well as insights from those living longer distances from the CR.

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References

1. AARP and National Alliance for Caregiving, 2015. Caregivers of Older Adults: A focused look at those caring for someone age 50+. Retrieved March, 17, 2016 from http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Care-Recipients-Over-50_WEB.pdf
2. Bødker, S. et al. 2013. Calendars: Time Coordination and Overview in Families and Beyond. *ECSCW 2013*, pp 21-25.
3. Plaisant, C. et al. 2004. Shared Family Calendars: Promoting Symmetry and Accessibility. *HCIL 2004*.
4. Schorch, M. et al. 2016. Designing for those who are overlooked-Insider perspectives on care practices and Cooperative Work of Elderly Informal Caregivers. *CSCW 2016*. pp 787 – 799.