

Can I Take a Break? Facilitating In-Home Respite Care for Family Caregivers of Older Adults

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Abstract Respite care can provide a chance for family caregivers to take a temporary and flexible break from their long-term caregiving work. Despite its beneficial aspects and value, there is little research on how technology might mitigate barriers to using respite care. The purpose of this paper is to understand the current practices and challenges that people face within the ecosystem of respite care work in the context of in-home care. Based on an in-depth interview study of 18 primary family caregivers, respite family caregivers, and respite professional caregivers, we identified different relationships, phases, and needs of each stakeholder and issues of trust and information sharing that need improvement. We discuss design considerations on how future information and communication technologies (ICTs) could mitigate the barriers identified in this work.

1 Introduction

By 2030, one-fifth of U.S. residents will be retirement age¹. Adults become older and can develop complicating medical conditions. Depending on their level of health or functioning, they may eventually need the aid of another person, and a family member typically has to step in and start providing care for them. When this care becomes long-term, family caregivers sometimes feel overburdened attempting to balance their caregiving tasks and other responsibilities, which can result in physical and mental health issues. Research shows that caregivers experiencing strain have mortality risks 63% higher than control groups².

It is crucial for family caregivers to find help to mitigate the burdens of caregiving work and maintain the quality of care for their love ones. Respite care provides temporary or relatively short-term care to relieve primary caregivers through diverse services depending on a family's needs which can include companionship, meal preparation, transportation, and/or household chores³. Through respite care services, family caregivers are able to take a temporary break and manage their own health⁴. However, there are barriers to adopting respite care. Some caregivers feel embarrassment about needing help, mistrust of the quality of these temporary care services, and uncertainty⁵. Moreover, little research on care has focused on this short-term and flexible type of in-home care and its value on family caregivers' well-being theoretically and practically.

ICTs such as smart-home systems and apps have the potential to offer a way to alleviate the hurdles of using respite care. They could provide proper methods for both family and respite caregivers to communicate and collaborate efficiently. Informatics research on this topic could provide ICT design ideas for a system for family and respite caregivers to transition their work in a trusting and effective manner. This system would allow family caregivers to be able to take a timely break, which would be beneficial for not only their health but also their loved one's health^{6,7}.

Our study focuses on the trust and communication challenges caregivers face and how information sharing via ICTs could solve those issues and enhance the quality of temporary care. Focusing on the context of in-home respite care, we first introduce previously studied issues and practices of family and respite caregivers of older adults. Next, we define three types of caregivers (primary family caregivers, respite family caregivers, and respite professional caregivers) and describe our interview study with 18 participants. Finally, we discuss our findings based on the analysis of these interviews and offer design considerations on how future ICTs could alleviate barriers and improve cooperation among family and respite caregivers.

2 Related Work

In the United States, in 2014, about 35 million people offered care to older adults without payment, 60% of whom provided care for loved ones with long-term health issues⁸. For primary family caregivers, taking care of their loved ones is a long-term obligation, and it is linked to physical and/or psychological problems⁹.

2.1 Respite care

Respite care allows family caregivers to have temporary relief and may help them maintain their role as primary caregivers for a longer period. Through respite care, family caregivers can have a “time-out” from their caregiving work temporarily, regularly, or in emergencies⁴. Professional or trainee caregivers could be considered formal respite caregivers and can provide services in a care recipient’s home, primary caregiver’s home, a daycare center, a nursing home, etc. Non-primary family caregivers such as friends, relatives, and neighbors could be considered informal respite caregivers and most often provide respite care at someone’s home. In the context of in-home care, care provided in one’s home, both formal and informal caregivers provide respite care that offers a broad range of care services such as companionship, personal assistance with dressing, bathing, and toileting, helping with chores, and/or healthcare services such as helping with medication¹⁰. Past studies on respite care have revealed its positive impact on the quality of life of both caregivers and care recipients. Systematic reviews concluded that there is evidence that respite care benefits both family caregivers and their care recipients¹¹.

2.2 Trust & Information Sharing

To have this type of invigorating experience, caregivers must first recognize their need for respite services and permit themselves to step out of their role as a caregiver temporarily¹². In addition to recognizing their need for respite care programs, they have to trust the individual care provider¹³. In the area of healthcare, research has focused on potential factors that are associated with trust between patients and physicians and trust of medical systems and policies, as well as the impacts of that trust¹⁴. Building trust is critical because patients who have higher trust in their physicians have more satisfaction with treatment and show healthier behaviors and higher quality of life with fewer negative symptoms¹⁵.

Information is one of the significant factors predicting respite care use. While trying out a new respite care service, family caregivers might want respite caregivers to communicate with them proactively⁵. Sharing information among healthcare stakeholders has been studied, focusing on sharing between family caregivers and care professionals. Studies have revealed that family caregivers’ trust in professionals can be impacted by sharing information via certain media (e.g., visit notes)¹⁶. Informal caregivers can perform the role of the monitoring and seeking up-to-date information to support care themselves¹⁷. When there are multiple caregivers, information sharing by volunteer and short-term caregivers also becomes helpful. Although they might not necessarily have medical expertise and do not have shared history with a care recipient, they can often provide up-to-date information that can be used to facilitate future caregivers’ interactions¹⁸.

2.3 Research Gaps & Questions

The role of in-home respite care seems to be valuable for family caregivers’ well-being and health. However, theoretical and practical informatics research has not focused much on these temporary and flexible aspects of care. It tends to focus on longer-term care and/or the well-being of care recipients. Some care systems actually increase caregivers’ sense of burden by encouraging family caregivers to do more for care recipients⁶. A few studies have focused on the link between caregivers who intervene temporarily and gaps in communication between those specific parties⁵, while other studies have dealt with the benefits of respite care and the perspectives and experiences of caregivers^{13,19}. Care Theory defines and specifies that care is helping someone with their basic needs; developing or sustaining basic capabilities; and reducing suffering and pain for their survival and development, and the society’s reproduction²⁰. This definition does not explicitly acknowledge family caregivers’ need to take care of themselves. Our study focuses on the temporary relationships and communication among caregivers in home contexts and how ICTs could support them.

Considering past research, we developed three research questions: (1) How do primary family caregivers of older adults build trust and share information with other caregivers when they use – or try to use – in-home respite care? (2) What information do in-home caregivers consider essential to share with other caregivers and vice versa? (3) How could ICTs address issues and support trust building and information sharing between multiple caregivers for effective care?

3 Methods

3.1 Recruitment

Recruitment was conducted in the U.S. and began by contacting local retirement home communities, adult care facilities, support groups, and agencies that offer respite care services via e-mails and flyers. We recruited 18 participants (17 female, 1 male), which include primary family caregivers and respite caregivers of older adults. Their ages ranged from 19 to 80. The family caregivers had experience in getting help from other caregivers and utilizing respite care. Participation was open to adults of all age groups and genders. The Institutional Review Board of Indiana University Bloomington approved this study.

3.2 Participants

3.2.1 Three types of caregivers

Based on the given information, we classified our participants into three types of caregivers. First of all, a primary family caregiver (PriFam) is a person who takes primary responsibility to care for an older adult who cannot take care of themselves fully. Second, a respite family caregiver (ResFam) is a secondary family caregiver of the care recipient and supports the PriFam by helping with a diverse set of caregiving work and household chores. Third, a respite professional caregiver (ResPro) is trained and hired to provide temporary respite care by helping with caregiving work and household chores to give a break to the PriFam.

3.2.2 Background of participants

Among a total of 18 participants, there were seven PriFams, three ResFams, and five ResPros. Two participants had provided care to older adults as both a PriFam and a ResPro. One participant had experience as both types of respite caregiver (ResFam, ResPro). All of the ResPros in our participants were trained via a care-related educational program and provided services to people they did not already know. Some of them were nursing students who worked as ResPros part-time. Except for one participant (P15-PriFam, ResPro) who worked independently, all ResPro participants worked through an agency or a care facility. PriFams were often spouses or children of the person receiving care. Most of participants' care recipients were older adults who have Alzheimer's disease, dementia, or Parkinson's disease, and needed most help with some activities of daily living. Table 1 shows our participants' information, including how many years (yrs) of caregiving they had.

Table 1: Participant Information (F = Female, M = Male, PriFam = PF, ResFam = RF, ResPro = RP)

ID	Age	Gender	Role	Experience	ID	Age	Gender	Role	Experience
P1	80	F	PF	7 Yrs	P10	23	F	RP	2 Yrs
P2	80	F	PF	3 Yrs	P11	25	F	RF	1 Yr
P3	20	F	RP	4 Yrs	P12	52	F	RP	33 Yrs
P4	76	F	PF	12 Yrs	P13	64	F	PF	3 Yrs
P5	23	F	RF, RP	3 Yrs, 2 Yrs	P14	57	F	PF	5 Yrs
P6	28	F	PF	13 Yrs	P15	65	F	PF, RP	2 Yrs, 40 Yrs
P7	53	F	PF, RP	2 Yrs, 35 Yrs	P16	21	F	RP	1 Yr
P8	31	M	PF	2 Yrs	P17	23	F	RP	3 Yrs
P9	19	F	RP	1 Yr	P18	23	F	RF	2 Yrs

3.3 Data Collection

A semi-structured interview was conducted with each participant in person or via phone call. Each interview lasted approximately an hour, and participants verbally consented to participation at the beginning of each interview. We asked about their responsibilities, the challenges they faced, any experiences and thoughts on respite care, how they cooperate and communicate with other caregivers, etc. All interviews were audio-recorded and transcribed.

3.4 Data Analysis

For the PriFams, we looked at what barriers they face when they consider using respite care and what concerns they had run into utilizing these services. We also looked at how they cooperate and share information with other caregivers, and what they want to know if they are not at home, and other caregivers are taking care of their loved ones. For the ResFams and ResPros, we focused on their relationship and communication with other caregivers. Using thematic analysis²¹ and Dedoose, three researchers analyzed each sentence of the participants' responses in the transcripts and identified common themes (e.g., trust, resources, information sharing, personal health challenges, different caregiving settings, availability of social support and informal care, capability to control situations and issues, caregiving activities and services, and desired technology). Then, we finalized the codebook and achieved a high inter-rater reliability rating (Cohen's Kappa=0.87).

4 Results

From our interviews, we identified an ecosystem and stakeholders of in-home respite care, the importance and issues of building trust, and disconnected communication channels among caregivers. After describing the contexts of care that were discovered through our analysis, we illustrate the main issues with some quotations from our interviews.

4.1 The Ecosystem of Respite Care

We identified and defined five main stakeholders in the in-home respite care ecosystem: PriFams, ResFams, ResPros, care agencies, and care recipients. Most of the participants, who were PriFams and had used respite care, found ResPros because they need a break. They contacted agencies and/or asked their family members to provide temporary help. They usually asked those respite caregivers to take care of their loved ones by helping them take medication, staying with and watching them, talking with them, or helping with household chores. Some of them worked with multiple respite caregivers. From the perspective of ResPros, most of them were hired for multiple care recipients. Many ResPros worked for care agencies which assign them to particular clients based on their requirements (e.g., time, what tasks they want to do). The agency replaces those ResPros if there is a last-minute time conflict or a ResPro is otherwise unable to work.

In the following report of the results, we describe the challenges in fostering a trusting relationship between family caregivers and respite caregivers. Then we identify the various ways disconnected communication among stakeholders could hinder trust and relationship management.

4.2 Trust in Respite Caregivers

Most participants agreed that building trust among caregivers is crucial to cooperate and to provide better care to care recipients.

P5(ResFam/ResPro): "It's always good to communicate as fully as possible, especially since you are aware of the short term that you have with that person. So to try to quickly build a rapport with that person then fill in those gaps really helps."

They acknowledged that building trust takes time. The longer a ResPro worked with a particular family, the more the PriFams would trust them, and the less they would worry.

P16(ResPro): "I think the most difficult part for them is getting used to us. They know that they have people coming in at all times ... But the hardest part for them is getting used to a new face, a new person."

One ResPro observed the importance of being able to communicate both face-to-face and electronically during the early phase of the relationship-building process. She has utilized a smartphone app to chat, send messages, and share memos with PriFams.

P12(ResPro): "We want to make sure we have good relationships with families, and so it's all about building trust. You don't start off that way when people start coming into our program. It gets built over time. ... Sometimes people will tell you more in the chat or text message function rather than in person. "

Once they have built enough rapport and trust, PriFams believe what their ResPro says and get used to the routine of switching off care with them, even if that trust does not transfer over to other respite caregivers. For example, one participant said that she saw her husband, who is a care recipient, and a ResPro built a good relationship over time. It made her believe the ResPro does their job well. However, when they needed to have a different ResPro, she and her husband felt this ResPro did not work as well.

On the other hand, most PriFams reported concerns around trust when discussing their perceptions and experiences from the early stages of using respite care. Notably, the concerns were brought out primarily when PriFams were considering new ResPros, while they rarely mentioned concerns about ResFams. The issues ranged from prior negative experiences of respite care to mistrusting new respite caregivers.

4.2.1 Negative Experiences of Respite Care

Past experiences that are related to respite care and/or any other people's care also influenced PriFams' trust in respite caregivers, especially in ResPros. If they and/or their care recipients had a prior negative experience (e.g., the ResPro not treating the care recipient properly, causing a harmful situation, neglecting the care recipient, etc.), they hesitated to use care services altogether.

P2(PriFam): "He needs to use the urinal, go to the bathroom at night. I have the urinal at the bedside, and I always put it in a wastebasket ... But they didn't give him a wastebasket and he set it on the bedside table and tipped it over and it went down in the drawers and got all wet and a mess! ... I couldn't trust them, I wouldn't hire the person."

In addition to one's own experience, others' experiences could affect one's intention to use respite care. While some PriFams said they had hired ResPros because other people recommended them, others said they hesitated to use respite care because they heard of bad experiences from other family caregivers.

P13(PriFam): "I've heard a lot of negative comments from [Company]. Especially when it comes to long-term. You know, people not showing up, people being late, people being messy, the house not being left clean. All sorts of little issues."

In summary, we found that PriFams' trust in respite care could be influenced by their own and/or others' experiences and reputations.

4.2.2 Mistrust of Strangers

Several PriFams discussed the difficulty of trusting new ResPros with their loved ones. Unlike ResFams who are already known, new ResPros are strangers who are more likely to bring out mistrust at first. PriFams were concerned about whether this new person treats care recipients well when the PriFams are not present. This mistrust led to worry and stress and sometimes caused a PriFam to avoid ResPros altogether.

P6(PriFam): "I feel that nobody can take care of her as much as I will do. And I cannot predict what a stranger can do. So I prefer to be available at all times to take care of her needs."

P8(PriFam): "My biggest concern is her safety, is she doing well? Is she fine?"

In this regard, we found obstacles to building trust in the early stages of hiring ResPros. As P5 indicated, communicating and sharing enough information between PriFams and ResPros from the beginning of respite care is critical to building trust. However, there are communication breakdowns among stakeholders that might be associated with barriers to building trust. In the following section, we describe disconnected communication channels among stakeholders and what kind of information they each want to share.

4.3 Communication Breakdowns

Both family and respite caregivers utilized several communication mechanisms such as verbal conversation (e.g., face-to-face, phone call), paper messages (e.g., notebook, list, sheet), digital messages and logs (e.g., texts, e-mails,

smartphone apps, social network services), or wearable devices (e.g., pendant for emergency). Depending on their relationships, responsibilities, and available infrastructure, they use different methods to communicate. Through those media, most of the participants tried to share their care recipients' important information such as routines and up-to-date information for providing better care. However, we found that there are a variety of communication breakdowns and information gaps that led to a lack of understanding and trust among stakeholders and ultimately ineffective care.

4.3.1 Indirect Communication among Caregivers

PriFams and ResFams often had in-person or phone conversations with each other. ResPros who worked through an agency had to follow that agency's specific privacy protection protocols and rules, which limited the ways in which they could communicate and share information with families. In this case, PriFams and ResPros did not always have each other's contact information and could only speak directly if they were in a home at the same time. Instead, the agency acted as a communication mediator, relaying questions, information, and reports between the two parties. In case of an emergency, ResPros usually contacted their agency and not the PriFams.

P10(ResPro): "I didn't have much contact with the families. ... Mostly, if I had a problem, then I would call the agency and then the agency would talk to the family or the client."

The ResPros would like to communicate with PriFams directly and know the current conditions of the care recipient before they start the respite care work. Thus, some PriFams keep detailed notes at home to hand over to the incoming ResPros to assist with the transition of care.

P13(PriFam): "What we had was essentially a notebook. It was kept in our kitchen, and I would write on here, "This is when she had her last medication," or "It seems like she's getting a cold. If she runs a fever, call me.""

However, some PriFams claim that they do not know whether the ResPros took the time to read their notes or follow their instructions. Most importantly, PriFams would like to know up-to-date information to determine whether their loved ones have gotten proper care from ResPros and if something unusual happens, especially if their care recipients are not able to communicate clearly due to their impairments.

When PriFams have two or more ResFams and/or ResPros, there are more complex challenges in communications among them. Although those respite caregivers take care of the same care recipient, they often work separately and work in shifts. In the case of a group of ResPros, unless a ResPro knows the other caregivers personally, they usually do not know who worked before their shift or who will work after. Also, the next person might not be told important information, such as recent changes in their care recipient's condition.

P16(ResPro): "Every caregiver is separate. I don't even know who their previous caregiver was. ... It turned out [care recipient] did have an allergic reaction ... she stopped breathing ... I had to take her to the hospital, and I didn't have that information prior to stepping into that shift."

In general, PriFams expressed concerns about this indirect relationship, as did some ResPros who had at some point experienced delays or gaps in communication. Young ResPros especially indicated they would prefer digital media such as smartphone apps to share information with both other caregivers and the agency directly.

4.3.2 Ineffective Information Sharing of Care Agencies

Although respite care agencies are hubs connecting PriFams and ResPros, the agencies often do not provide sufficient information to the PriFams and the ResPros. Many agencies only require families to share basic contact, demographic, and health information about the care recipient (e.g., symptoms, medications, etc.). However, the ResPros all felt that the information they received in certain instances was not sufficient. In addition to any up-to-date information, they would like to know the details of their care recipients' routines, preferences, mood swings, necessary precautions, the PriFam's knowledge of how to care for the care recipient's conditions that are outside the scope of the ResPro's previous training.

Moreover, most of the agencies have not adopted ICTs that could facilitate information sharing among stakeholders in these contexts. Indeed, only two ResPros recently used smartphone apps for caregiving work. One ResPro used

an app provided by her agency for the sole purpose of scheduling and seeing information about assigned clients, excluding the function of communication. Another ResPro of a different agency used an app also provided by her agency to communicate with PriFams and a care management team of the agency. However, they mentioned that their current apps are not sufficient to get information and communicate with other stakeholders. Although ResPros felt that frequent and in-depth conversations with their PriFams and self-reported information would be most useful, they mentioned that the apps were not well designed for many PriFams in terms of usefulness and usability.

To summarize our findings, both PriFams and ResPros consider building trust and sharing information essential and ultimately want to provide better care to their care recipients. However, there are several hurdles to trust-building and efficient and seamless communication between them.

5 Discussion

Our study found values and barriers of in-home respite care. Most participants in our study reported that trust between PriFams, ResPros, and care recipients is essential to commit to respite care services, consistent with previous research¹³. As multiple people work together as a care team in a home to take care of one older adult, each individual is inherently required to put cooperative efforts into caregiving work to provide efficient and effective care for their care recipient²².

5.1 Values and Barriers of Respite Care

Again, respite care is advantageous to provide a break to PriFams, as many informal caregivers have burdens and need a break⁴. It was clear that most of our participants who were PriFams also have experienced burdens and need help and care from other people. Mostly, the participants of PriFams who can have ResFam(s) have cooperated effectively and flexibly without many trust barriers or concerns. However, other PriFams, who cannot have ResFam(s) in their living area, have hired someone or used care facilities to take a break or have time to do something else. Thus, for them, the in-home respite care service could be a relatively more convenient, flexible, and cheaper option than other long-term and residential care services.

There are many studies on in-home care addressing trust, communication, and information sharing among caregivers and care recipients, and potential ICTs to support them^{22,5}. However, to the best of our knowledge, the aspects and contexts of temporary in-home care cooperation have not been clearly studied in the literature. In-home care literature has focused on long-term, regular, or more professional aspects of care. Those long-term caregivers, family caregivers, and experts are more likely to build trust and rapport and to improve their care quality as they accumulate experiences with the PriFams and care recipients. Unlike those caregivers, ResPros need to get used to their new care recipient, new PriFam, and new home but have difficulty building trust in such a short time. However, their role is crucial, because they can give a break, which is needed for PriFams' health, in a more flexible way than traditional long-term care facilities. In this sense, mitigating the barriers and maximizing the value of respite care would be beneficial for both PriFams' and care recipients' well-being. Based on our interview participants, we identified difficulties these respite caregivers, especially ResPros, have experienced. Since they are hired, temporary and short-term caregivers, they are more likely to: (1) keep making a "new" relationship with a new care recipients and PriFams; (2) keep briefly learning how and what to care about with respect to their new care recipients and environment; (3) struggle with communicating and sharing information with other caregivers; (4) experience difficulty in building trust from PriFams; and (5) ineffectively cooperate with other caregivers. The current communication system of respite care services have not fully considered these ResPros' contexts and failed to fully enable the trust and rest of the PriFam. Thus, new services should be more systematic in terms of information sharing and cooperation, focusing on the new and temporary relationships, so that the service can gain and keep credibility and provide seamless and high-quality care cooperation. In the following sections, we discuss our findings and propose design considerations for future ICTs that would be potentially beneficial to support respite care.

5.2 Different Phases & Needs in In-Home Respite Care

In our study, we focused on specific relationships and phases of in-home respite care. Previous research claimed that interpersonal trust is established via repeated social interactions over time²³. Even if a ResFam is a newbie, they could have a more natural time building trust because of their established relationship with the PriFams and care recipients. On the other hand, ResPros may have to provide care for an individual for a relatively longer time to build the same level of trust. Most of the long-term caregivers in another study also reported positive relationships with professionals who regularly come and share in their care routine²⁴. New ResPros are more likely to be at the starting point of building trust with the PriFams. In this new phase of a relationship, PriFams are more likely to have a lower level of trust in the ResPros and want to check-in remotely on the caregiving session. Typical concerns might revolve around whether a particular caregiving task is being performed well and the manner in which it is being delivered.

Future ICT systems to support cooperation among caregivers should consider these different relationships, phases, and contexts. For example, in order to mitigate a new ResPro's challenges (1) and (2), a system could allow PriFams to save information about the history and routines of care recipients and their home environment and set goals for a new visit. Then, the ResPro could know more about the care recipient and their work environment, including what and how to provide care in advance. Once the ResPro has a relatively longer relationship with the client, the system could allow the PriFam to provide occasional information about recent changes and urgent needs on that day. Moreover, respite care is temporary care, and it could involve multiple and complex transitions among caregivers. Thus, the future system should be designed to consider their different time period and form of transition.

5.3 Quick Alleviation of Entry Barriers of Respite Care

One of the PriFams' concerns with new ResPros is how well they will take care of their loved ones. Especially in the early stage of using respite care, previous experience, and mistrust of strangers are more likely to raise barriers to use respite care. In this case, knowing others' positive experiences could be useful in building initial trust. As others' experience and reputation influence one's trust²³, an agency or ResPro's reputation can lower the barrier to establishing trust.

Considering challenge (4), a profile, review, and matching system could be an obvious solution to help share rational and appropriate information about ResPros to alleviate family caregivers' concerns and mistrust in the early stages of using respite care. Reviews are essential elements of evaluating trustworthiness on sharing platforms²⁵. In the case of respite care, a system needs to be able to help screen potential ResPros who might engage in risky behaviors such as smoking, or have inappropriate attitudes toward a care recipient and caregiving work (e.g., impatience or laziness). Such a system might be useful for care agencies to be more aware of the need to improve education and training for the ResPros. PriFams' needs for respite care vary depending on the care recipient's condition and family caregivers' capabilities. Using elements of social matching such as skills, preferences, and demographic features help match people with instrumental support²⁶. We suggest systems could help not only PriFams find suitable ResPros but also help ResPros find care recipients and PriFams who match their experience level. For instance, someone might want a person who can talk easily to the care recipient, while others might want a caregiver who can perform specific tasks well. In this sense, matching ResPros with PriFams who have compatible preferences, needs, and communication styles could be beneficial. Another way ICT could mitigate PriFams' concerns could be a live check-in system. For example, if PriFams want to check whether a respite caregiver has arrived at a home, stays with a care recipient, or is doing certain tasks when they cannot be at home, they can set up a live check-in system to ask the respite caregiver to press a button on a device or app to notify the PriFam an event has occurred. Elements of usability, including ease of use, simplicity, and readability, could be essential considerations when designing the system so that caregivers in the loop would not be overwhelmed.

5.4 Seamless Communications among Caregivers

We found disconnected communication channels that hinder seamless information sharing and trust-building among PriFams and ResPros. Disconnection among those caregivers could negatively affect the overall efficiency and quality of care. Through cooperative systems that mediate communication between the stakeholders of in-home care, infor-

mation sharing helps caregivers to take swift action on tasks²². Therefore, facilitating well-connected communication channels develop seamless information sharing, and eventually improve trust among caregivers and quality of care.

Using the live check-in system we suggested above, we suggest an online platform that incorporates both monitoring and communication for all involved caregivers to mitigate the challenges (3) and (5). Such a system could integrate smartphone apps, smart home systems, and wearable technology to provide live health status updates, share important changes in the situations and needs, and monitor the progress of care. For instance, through the platform, a respite caregiver can see a checklist of tasks a PriFam expects them to complete during their visit so that they can share information about the relevant tasks and processes. They should also be encouraged to write a log entry answering simple questions about the visit, such as what went well, what did not, and their advice and concerns.

In accordance with the needs identified in our study, a respite caregiver needs to learn and be able to manage the routines of their care recipients as quickly as possible in the context of temporary care. Additionally, to reduce unnecessary information, future ICT platforms should be designed to deliver easy-to-understand essential tasks and cautions as quickly as possible, including the degree of importance of each of them. Also, there should be a function that provides essential information about their care recipients, such as what and when they need to take medications, their routines, and what happened at the previous caregiving sessions. PriFams can provide information about medications and basic routines, which they would otherwise have to share in person or in a shared notebook.

6 Conclusion

In this paper, we focus on understanding the trust and communication challenges among caregivers and exploring how to solve those issues through future ICTs to improve the quality of in-home respite care. Our paper identifies and describes the ecosystem of in-home respite care and brings attention to understudied caregiver groups. Focusing on its temporary aspects, we offer novel insights on information that different caregiver groups want to share. Neither had been given systematic treatment in prior theoretical and practical research. Our findings allow researchers to design future ICTs based on how different caregiver groups share information and coordinate tasks in order to build trust. Also, while previous research has focused on long-term care and relationships, our work has paid attention to in-home respite care, a beneficial service that helps PFs receive temporary relief from the burdens of caregiving work. We have uncovered the information needs that affect trust and relationships given the transient nature of respite care. Finally, our work offers significant design implications for future ICTs. We suggest that the different levels of trust in different relationships and phases must be taken into account when designing future ICTs. Also, we propose appropriate communication systems for fostering the optimal quality of care and relationship building among stakeholders.

Future work could focus on other contexts (e.g., urban vs. rural areas, institution settings, specific health conditions, etc.) or the perspectives of staff from respite care facilities. Also, as our sample size is small, and some participants were recruited by snowball sampling, our sample might not be sufficiently representative of our target population. Further study could be conducted by recruiting a larger, representative sample. Our future work will focus on designing and deploying ICTs for building and maintaining trust and efficient information sharing among caregivers based on our findings and implications. Ultimately, we aim to support the well-being of both caregivers and their care recipients.

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