Challenges and Opportunities for Caregiving through Information and Communication Technology

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Abstract: The increased susceptibility of world's population to diseases augmented with the decrease in the healthcare workforce leads to over-reliance on caregivers. This increased burden on caregivers adversely impacts their quality of life. However, information and communication technology (ICT) has the potential to facilitate caregiving. Therefore, the objective of this study is to investigate the opportunities and challenges for caregiving through ICT, the development of a prototype to support caregivers better monitor their care recipients (known as clients) and the evaluation of that prototype. A qualitative study with 10 caregivers was conducted to address the research questions from which data was coded and analysed. Using this data, a web-based prototype was developed and evaluated by 5 caregivers and 5 technology experts. The instruments used were interviews and focus groups. The results revealed eight categories for improving care identified by caregivers.

1 INTRODUCTION

The world's population is becoming more susceptible to disease and disability, high birth rates with lower mortality rates, the prospective workforce not choosing healthcare as a profession and the shortage of supported facilities. In Ireland, healthcare staffing levels have dropped significantly within the public sector since 2009 (Wells and White, 2014). This situation leads to over-reliance on family or professional caregivers, which adversely impacts their quality of life (Canam et al., 1999, Osse et al., 2006, Shiue et al., 2016), and it is noted that some of the problems that caregivers encounter include anxiety, depression and stress (Koyanagi et al., 2018, Washington et al., 2018). Information and Communication Technology (ICT) has the potential to alleviate these problems and help caregivers perform their duties efficiently and effectively (Finkel et al., 2007, Chi et al., 2015, Czaja et al., 2016, Demers et al., 2018). A recent systematic literature review provides an in-depth analysis on the type of ICT offerings in this context such as education, consultation, behavioural therapy, social support, data collection and monitoring and clinical care delivery (Chi et al., 2015). This work also reveals that only 20% of the technology developed falls under the domain of monitoring, so further work is needed on this topic. Our analysis indicates that only 2 tools mentioned in research studies (Chou et al., 2012; Shah et al., 2013) help in care management while also solving other problems of caregivers such as social isolation and quality of life. But, caregivers cited problems with the design, reliability, weight, and size of the equipment as serious challenges, decreasing their satisfaction and increasing their frustration. A literature review by some of this paper's authors also highlights problems with the technology which is available to support the social life and healthcare of patients such as older adults (Ahmad et al., 2017). This situation advocates the need to continue research in this area and explore the challenges and opportunities for caregiving through ICT before commencing the development of systems. The objective of this study is to understand how ICT monitoring in the home can alleviate the burden on the caregivers, and provide a better quality of life (QOL) for both stakeholders (caregivers and care recipients). Care recipients are often older adults. The nomenclature used by caregivers during interviews when discussing care recipients is 'client', and so, for consistency in this paper, we will refer to care recipients as 'clients'. An analysis of the literature and a qualitative study of a small sample of

stakeholders, led to the development and evaluation of a web-based prototype for an optimized home based monitoring system for caregivers.

Section 2 describes the methodology used during this research. Section 3 discusses the outcome from caregiver interviews. Section 4 describes how the findings of interviews were used to develop the prototype. Section 5 presents the evaluation of the prototype using focus groups. Section 6 concludes the paper, presents the recommendations and outlines future work.

2 METHODOLOGY

The objective of this study is to address the following research questions:

1. Can ICT support the monitoring of clients in the home for improved caregiving efficiency?
2. Could the provision of ICT monitoring reduce burden of the caregiver and improve QOL of the client?

To answer these research questions, we undertook a qualitative study with clients and caregivers. Based on this study, we developed a prototype device using proprietary product, aimed at monitoring clients in the home.

2.1 Data Collection: Interviews

We conducted semi-structured interviews over a 2-day period, with a purposive sample of 10 caregivers of clients (mainly older adults), based in Ireland (see Lero Technical Report 2020-TR-01 for the interview protocol). The primary objective was to identify the difficulties associated with caregiving to clients and how ICT might reduce some of the challenges for caregivers. Using 14 questions, also available in 2020-TR-01, derived from related literature, we uncovered a set of requirements. The average duration of each interview was 30 minutes and was audio recorded. We developed and evaluated a prototype.

2.2 Data Collection: Focus Groups

To carry out the evaluation, we undertook a focus group (see protocol in 2020-TR-01). This allowed us to gain feedback on the prototype and to identify features for future refinement. One 90-minute session was held with a mix of participants – 5 caregivers and 5 technology experts. The key requirement for technology experts was to involve researchers and/or developers who are directly linked with homecare technology development. All caregivers who participated in the focus group had been involved in the group of interviewees.

2.3 Data Analysis

Audio recordings of the interviews and focus groups were transcribed, and were analysed using descriptive coding (Saldana, 2015) to determine key topics. This was achieved through labelling the important concepts in the transcripts. These labels were scrutinized against the research questions to gain further context of the labels. Furthermore, memoing and commenting was done liberally. Descriptive coding was used as an input to perform pattern coding, determining the high level concepts and the relationships between them. Finally, axial coding was undertaken which helped to gain a deeper understanding of categories.

3 IMPROVING CARE

In this section, we outline our answer to Research Question 1: Can ICT support the monitoring of clients in the home for improved caregiving efficiency? Interview analysis using descriptive and pattern coding resulted in the identification of eight categories.

1. Technology for Monitoring: A major concern amongst all the caregivers was the lack of monitoring of their clients. Eighty per cent of participants were either family care or voluntary care persons who did not earn a financial salary from the care they provided. Therefore, they need to remain in full time employment, meaning that they could not monitor clients for large amounts of time. This same 80% were concerned with external factors such as temperature changes across seasons as, regardless of whether a source of heating or cooling patients' homes was available, some patients do not avail of these methods. An extreme example is that one patient did not use the heating for a few days, ultimately causing hyperthermia. Temperature monitoring would have averted this.

2. Technology to improve Safety: Caregivers were worried about the safety of their clients and highlighted the need for purpose built housing; clients are at a vulnerable stage in their lives and likelihood of injury is very high. One participant quoted that it is becoming increasingly difficult for their client to reach the first floor of their home where their main sleeping quarters are located. Dangers include clients

falling down the stairs and nobody knowing for a few hours until a neighbour visited. Real-time monitoring technology has the potential to provide a safer environment.

3. Technology for Security: Participants stated that clients face serious security issues such as strangers calling to the doors of clients leading to burglary, assault or confidence tricks, with all participants reporting security-related events. One particular example was when strangers attempted to convince their client to pay a sum of money. Being unsuccessful, they assaulted the person. Participants suggested that there is a need for a technology which can provide instant alerts to caregivers or emergency services. They also shed light on clients' lack of familiarity with current technology such as smartphones, indicating that technology should be designed in an easy to use and intuitive fashion.

4. Technology to Support Emergencies: Participants advocated the need for a 'single action alert' or a 'voice-activated alert' to alleviate the difficulty vulnerable people face while reporting emergency situations using technology such as smartphones. They also said that clients are not well versed with the latest technology and some are living without mobile phones and Internet, so alternative mechanisms to report emergencies would be appreciated and could be more easily adopted by their clients.

5. Resources: A lack of resources was identified, for example, where multiple clients are co-habiting, as in the case of spouses. One participant quoted that their deaf client had to take care of a blind person. It is obvious from this how much support these clients can provide to each other, and that any technological solution which improves this situation would be welcomed.

6. Primary Care: A positive outcome was ease of access to general practitioners through appointments, but transportation was still troublesome, e.g. *"While the request is relatively simple to submit and it only takes 24 hours to get approval, it is still the difference of 30 minutes to 24 hours in the case of something that may be more of a serious case than first thought"* - Participant C4. This delay in primary care concerned the participant who understood that insurance implications needed to be adhered to as well.

7. Assistive Technology: Participants agreed that assistive technology would be beneficial for providing homecare. Forty per cent of the participants revealed that significant injury had happened to their clients during the provision of care. An advance could

be to have lifting technology (operated via a computer user interface) to reduce injuries.

8. Processing of Requests: The government is providing lifting technology to eligible clients but the processing time is extremely slow. One participant said: *"It should not have taken that long to receive a chair I could have purchased online and received in a fraction of the time for my mother to have basic comfort in her own home"* - Participant C9. It was clear from participants' reviews that the request submission process should be changed.

4 PROTOTYPE DEVELOPMENT

Based on our interview analysis, a prototype was developed using design thinking (Siang, T. 2019), see Figure 1. Prototyping an application is crucial in helping participants understand the key aspects of a proposed system are and allows them to interact with features as if it were a real-life system. Design thinking was used as it helps to strip away non-essential aspects of the problem situation. Within design thinking, there are 5 stages – empathize, define, ideate, prototype and test. In this project, we undertook the first 4 stages.
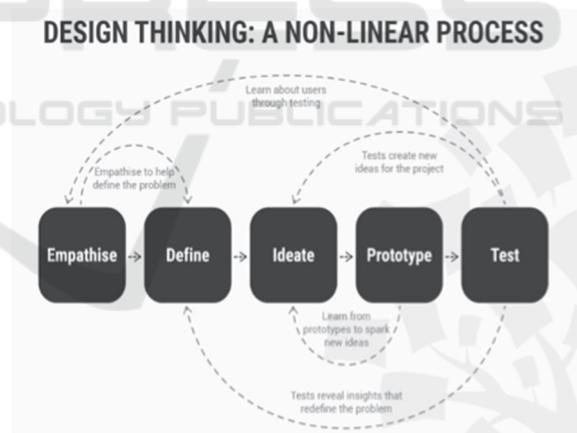
Figure 1: Design Thinking Process (Siang, T. 2019).

4.1 Empathize

The interview data was reviewed to understand the caregiver's feelings, needs, and problems and pain points. A spectrum of feelings and the associated behaviours of all of the participants were extracted through the review of interview data as indicated in Table 1 in Lero Technical Report No: 2020-TR-01. These include anxiety, guilt and regret and they were observed amongst all participants at some stage during the interviews. Particularly harrowing was the

guilt and anger, which were two common feelings portrayed. One participant spoke of the decision to put their client into a professional care home due to the lack of availability of help, time and facilities when the client was cared for at home. Such information was used in prototype design.

4.2 Define

After understanding caregivers' feelings and behaviours, they were translated into point of views (POV), which constitutes of three measures i.e. User, Need and Insight. Table 2 (in Lero Technical Report No: 2020-TR-01) presents the complete point of view analysis table. These user needs and insights were then used to generate 'How Might We' (HMW) questions. The POV table and the HMW questions were later used as an input to brainstorm and define the problem statement:

"Design and develop a product that aids family carers who care for clients in the clients' own home. This should enable a more stable life balance maybe only requiring touch points with client, to a full care suite. This should encompass features that allow monitoring, safety in the home, security features and alert features".

4.3 Ideate

Ideation was the third phase and it constituted of brainstorming by the researcher to generate numerous ideas by broadly exploring the solution space to determine the best outcome. Typically, this phase requires a team, but due to time constraints, the first author completed this activity and later validated the results using a focus group. Mind mapping was used as an aid during this phase, ultimately inputting to the development of the prototype. The raw outcome of the ideation phase in shown in Figure 2 and the model is depicted in Figure 3. This model applies technology to homecare situation to see the positive effects on the client. Based on the findings, the main aspects of the model and the resulting system should include monitoring of the clients' breathing and temperature, ensuring the safety of the client and incident detection, the security of the client and enabling alerts to the caregiver with specific consideration to emergency alerts.
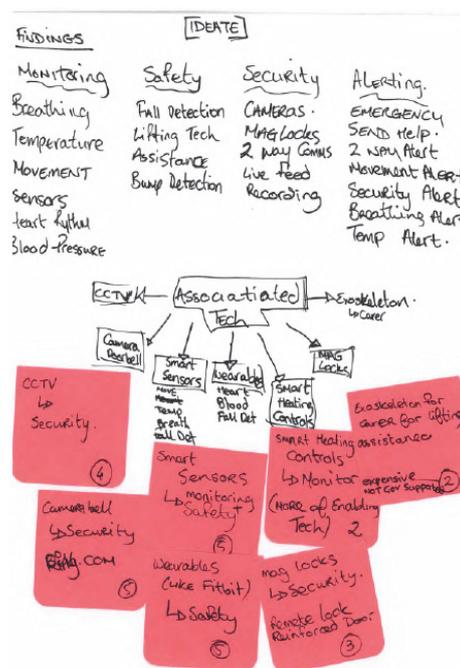
Figure 2: Ideating Phase Outcome.
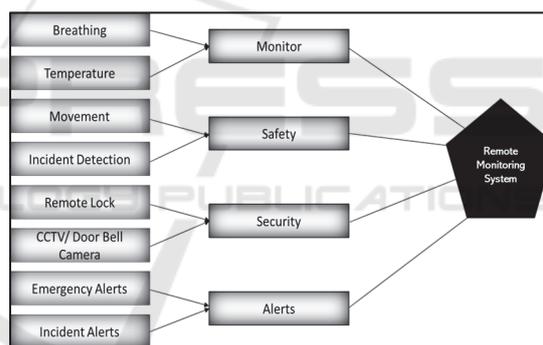
Figure 3: Model for Remote Monitoring System.

4.4 Prototype

The model was used as the basis for prototype development. The underlying assumptions during the development of prototype were that some ambient living solutions were available. The clients' home has been fitted with detection sensors and cameras and a doorbell with a camera and 2-way intercom on the exterior. Motion and temperature sensors, smart thermostats and intelligent heating controls have been fitted inside. Clients have been given a smart watch to monitor vitals and to increase accuracy on fall detection.

While we recognise that this set of systems is complicated in themselves, they are each readily available commercially, and the requirement from the

caregiver focuses on the ability to monitor clients' activities. A sitemap of the prototype was developed (available in the technical report), with each branch having its own individual dashboard. An example of one high level dashboard is shown in Figure 4.
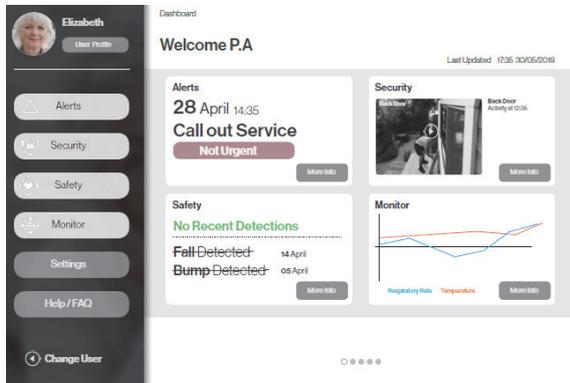

Figure 4: Remote Monitoring System - Client Dashboard.

5 PROTOTYPE EVALUATION

To answer Research Question 2: Could the provision of ICT monitoring reduce burden of the caregiver and improve QOL of the client?, the prototype was evaluated through a focus group with caregivers and technology experts. By following the guidelines by Jankowicz (1995), the researcher remained cognitive and provided appropriate interjections to keep the discussion focused, probing deeper into the topic to encourage participants to express their views in detail, thus enriching the data. Eight key items were identified, and are discussed here under the headings of features and usability.

5.1 Features

Overall, the participants liked the features of fall detection, body temperature and access to surveillance remotely from a mobile device. For example, a participant highlighted the importance of this prototype system in general: *"I had an incident where my client had fallen down the stairs and had not been found until the following morning. With this the response is almost immediate meaning my client will never have to experience that again"* - Caregiver C1.

5.1.1 Dashboard

Participants were pleased with the simple navigation through the slide-out menu allowing them to switch between dashboards quickly and easily. *"This menu displays basic information of the client for identification and reassurance. Having the option to view the profile from my client for further information such as medical history, personal details makes it easier for me to relay medical history and information on our GP Visits"* – Caregiver C5.

All of the participants agreed on the need for a feature ensuring that, if they do have an incident, their client is found and treated within a short period of time. They also appreciated the clean and easy to use interface and navigation, but shared a concern of additional Wi-Fi data charges, as the application constantly refreshes itself: *"Is this not supposed to help carers regain a balance? Their wallet will be heavily affected if they have more than eight to ten clients on the system at each time, data is expensive outside a set price plan"* - Caregiver C3

5.1.2 Alerts

Participants liked the idea of alerts, and shared the possibility of having additional alerts including delivery tracking, power outage alert and an increased audio sensitivity: *"There is potential to have more various on the alerts, while I understand this is just phase one of the application, it has infinite possibilities to adapt features to service many other medical situations"* – Technology Expert T1. Participants were satisfied that the alerts are automatically assessed by the system to determine the urgency of each detection for quick analysis by the user: *"This is so beneficial for us to decide whether the level of care and how urgently we need the client to be treated after the incident. This could become and invaluable feature for a lot of work we do, it allows us to rely on our judgement more"*- Caregiver C3. Moreover, they were pleased with the ability to get rid of 'clutter' and show only the necessary information: *"It's great that I can pick and choose what I want to display on dashboard of each of my clients, there are some things I don't need to see and may become cluttered and confusing"* - Caregiver C1. The option to call first responders, emergency services and family members really impressed all of the participants: *"It is great to see that we are starting to see the utilization of the rural first responder as first point of contact before emergency services are needed. There are certain situations that a first responder can deal with without having to call emergency services. It causes extreme anxiety and stress to care recipients having ambulances arrive to the home when they are possibly not needed in some cases"* - Caregiver C4.

5.1.3 Security

Caregivers were particularly overwhelmed and grateful because their clients' stories received distinct attention during the prototype development and features were included to ensure their security. They certainly believe that the security feature will make difference in their clients' life: *"This security tab would have certainly made noticeable difference ... Besides providing a solid opportunity to catch the culprit but it would have offered my client a sense of feeling safe in their home. Unfortunately, my client fears being home now alone, so I think this feature will make a major difference to my client's quality of life."*- Caregiver C1.

Technologists, however, pointed out that the current sensors might provide unnecessary alerts to the care providers. But, using less sensitive sensors can alleviate this: *"These sensors are so sensitive they would pick up a leaf in the wind, this may cause unnecessary alerts to the carer that would revert to them being on edge more than they are now. The doorbell-activated camera would be best to detect people coming to the front door. I think standard surveillance for the exterior home would be fit for purpose here"* - Technologist T2.

5.1.4 Safety

The safety tab offers real time information based on incident detection and movement in the home. The beneficial feature that was highlighted here was that incidents are automatically analysed by the system based on urgency. Non-urgent detections are sent to the alerts tab but do not notify the user. In the prototype, falls are considered major and then notification is sent to the caregiver immediately: *"This is a great feature, you can tell if the client is constantly bumping into something because they may have forgotten the item is there and it will need to be moved from the area to mitigate any other incidents from happening. I know my client's family bought them a new chair and the client kept bumping into it because it was not part of their home originally. It eventually ended in removing the item because from consistently bumping the same area repeatedly and caused a fracture for the client"* – Caregiver C2

5.1.5 Monitoring

The monitoring tab highlights the client's vital data in real time. This was well accepted by participants, highlighting that certain clients might be at high-risk status for pulmonary problems, needing constant and consistent monitoring. *"This is of particular benefit to my client as the client has an irregular heartbeat that constantly has to be monitored but this is extremely difficult for me to do when I have to maintain my full-time job at the same time. If the client has an episode, I don't want it to be my fault because I was unable to monitor the client closely"* - Caregiver C5.

Technologists were a little bit concerned about the type of technology that is going to be used to gather this vital information: *"I know this system is still in its infancy, but I would have concern regarding the technology you have decided to collect that data with. There is a fear that the client may not wear the watch or take it off while an event is occurring. This would raise a major concern for me, but I am sure there are better technologies for gathering this information"* - Technologist T4.

5.2 Usability

5.2.1 Aesthetic and Minimalistic Design

Participants complimented the overall design of the application as it follows the current trend of sleek, flat minimal design that can easily be familiar for the user. The participants commented that this makes analysing information much clearer and easier to understand, preventing possible errors: *"The design is very attractive, and it has the added bonus that you don't need to be a data analyst to understand the output information and can help carer's make a decision to the urgency of the incident at hand and deal with it remotely"* – Technologist T3

This design helps to keep everything organized. It also notifies the caregiver about the most important information. It has the potential to alleviate distractions and ease the decision-making process.

5.2.2 Flexibility and Efficiency of Use

The caregiver can fully customize the user interface to suit their needs while prioritising information based on their clients' needs. The application gives the caregiver insights rather than having to search for the information they need. The application is flexible where icons, tabs and menu panels can be rearranged. *"It's great how simple it is to use without prior training. I can move and rearrange items with ease. This is incredible as I have used other software that it complicated and I eventually stopped interacting with it. I actually want to interact with this application"* - Caregiver C2.

One technologist mentioned that a system like this would help improve the caregiver's efficiency. The prototype stays consistent using the side bar menu,

which is accessible on every page, and it follows standard user interface layouts. The opening dashboard gives full system visibility with quick information from all possible features.

5.2.3 Probability and Feasibility

Technologist T1's statement - *"Communication between devices and public service systems is key for this to succeed, reliance on Wi-Fi connections is a concern as rural internet infrastructure is not as developed as urban areas, the introduction of 5G in the future could contribute to the rural infrastructure but that is yet to be tested"* - generated rich conversations around infrastructure in Ireland and whether it will be developed to accept our proposed solution. The researcher clarified that this research assumes that the infrastructure is ready. Another important aspect that was noted was that General Data Protection Regulations (GDPR) would have a significant effect on this system and how it is implemented if it ever became a viable solution. Security concerns regarding CCTV and live data would need to be examined thoroughly and cyber security would need strong protection from system hackers. As stated by technologist T4: *"You would need to introduce a strong standard around signing and maintaining consent forms, there would be significant churn in the public eye around this issue and vulnerable persons, it may not be held in the best light"*. The participants felt that it was a very feasible system assuming that all approvals were obtained, and that privacy was maintained throughout the development of the system. The prototype sets out to apply advanced technologies to support home care providers in their caring roles. Ninety per cent of the participants felt that it met the goals it set out to do and feel that if it were ever to be a commercialised product that was affordable the caregivers would not hesitate to install it in their clients' homes.

In short, participants were pleased with the features and the usability of the proposed application and gave some useful recommendations for future work. They mentioned that the fully functional application would have the potential to give them back their life balance, allowing them to be free to work full time and maintain involvement in recreational activities. Most importantly, it would support the dignity of their clients.

6 CONCLUSION

This research focused on applying ICT to the home care sector with a view to optimising the work of family caregivers. The application of such technologies was theoretically intended to allow such caregivers to re-establish or to maintain their life-balance. It could also support private caregivers to split their time between several clients. The findings suggest an overall positive response by the participants about the prototype developed and its potential to be commercialized. Some recommendations were recognised as possibilities for further development of the application:

- System and technologies must grow at the same pace as other technologies grow and develop.
- 24/7 customer support will be needed in case of errors and system crashes.
- The system could predict incidents through gathering information for the implementation of artificial intelligence (AI) to predict incidents.
- Better monitoring technology or other forms of monitoring technology should be utilised.
- Improved user interface aesthetics helps to build a positive relationship, workflow and interaction of the caregiver.
- Remote locking of front and back doors could be included in the application.
- Other safety measures could be implemented, such as slip detection, recognition of overheating, and vital sign measurement.

Our future work, particularly through our membership of the Ageing Research Centre and our industry links within Lero – the Irish Software Research Centre, will investigate further how such technologies can support caregivers in their vital job of caring for older persons, while also providing effective care to the client.

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