

Communicating Care: Identifying Information and design requirements of Informal Caregivers of Older Adults with Cognitive Impairment in changing scenarios

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Abstract

Due to the increase in the population of older adults with Cognitive Impairment (OwCI), a surge in the development of Unobtrusive Sensing Solutions (USSs) that can monitor care scenarios in real-time can also be observed. For effective implementation of these solutions, it is crucial to communicate necessary sensing information to caregivers according to their specific needs. In that direction, this study aims to gain insights into the information communication (IC) needs of informal caregivers who provide homecare to community dwelling OwCI living alone. A convergent mixed method study encompassing survey (N=464) and semi-structured interviews (N=10) using four different scenarios namely, Fall, Agitation, Nocturnal unrest, and Normal daily life was conducted. Based on the scenario-specific needs, design requirements in line with the Persuasive System Design (PSD) model were elicited. The study revealed that each care scenario has unique IC needs, with differences in the mode, content, and timing of information communication. Furthermore, four features (reduction, tunnelling, tailoring, and personalization) from the primary task support category and two features (reminder and suggestions) emerged from the dialogue support category of the PSD based on identified IC needs. Overall, the study highlights the need for adaptable and personalized designs to address the diverse IC needs of informal caregivers of OwCI living alone and receiving home care.

Keywords

Informal caregiving, Information needs, Persuasive system design

1. Introduction

The global population of older adults with cognitive impairment (OwCI) is experiencing a significant increase [1]. The available care facilities are inadequate to meet the growing demand for care among this population [2]. In general, OwCI individuals prefer and are often advised to remain in their own homes for as long as possible [3]. To support OwCI in living independently at home, various sensing solutions such as wearables, camera-based systems, and device-free sensing systems are being developed [4][5]. Among these, device-free or Unobtrusive Sensing Systems (USS) are considered more suitable for OwCI individuals due to their ability to continuously monitor without requiring the person to wear any devices and even when the person is out of the line of sight [6]. Due to the novelty of USS, most of the existing research has focused on technological advancements [7,8], with limited efforts made to understand the needs of the primary stakeholders, including OwCI individuals, informal caregivers (family, friends, relatives), and formal caregivers (trained professionals). Understanding the

BCSS 2023: The 11th International Conference on Behavior Change Support Systems, April 19, Eindhoven, The Netherlands
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CEUR Workshop Proceedings (CEUR-WS.org)

needs of these stakeholders is crucial and can guide technology developers in developing application-oriented systems as well as ensure its swift implementation [4,9,10].

In dementia care, USS can assist formal and informal caregivers in providing 24/7 care from a distance by continuously tracking and tracing OwCI and communicating obtained relevant information [11]. By utilizing this information, caregivers can not only provide timely care but also optimize care by gaining insight into the behavior of OwCI. For example, if the USS senses that the OwCI is exhibiting signs of agitation, caregivers can proactively take steps to address these symptoms, such as adjusting the older adult's medication or providing calming activities. Furthermore, if the reason for triggering agitation can be known after observing OwCI for a few days, the care plan can be tailored (like avoiding specific triggers) to improve the care recipient's quality of life. This can help in providing personalized and effective approach to care, which can ultimately lead to better outcomes for both the OwCI and their respective caregivers.

To enable an appropriate and on time care communication, it is important to carefully consider when (time), how (mode), to whom (stakeholders), and what (data/content information) should be communicated. However, considering the care burden on informal caregivers, the sensing information should not become overwhelming for them [12,13,14]. Additionally, information preference can also change depending on care scenarios, for example, fall being an emergency might need immediate response unlike nocturnal unrest. Therefore, in this complex care situation, it becomes more imperative for assistive systems like USS to provide optimized care information that relieves the burden of informal caregivers while enabling them to provide timely care. To facilitate that, present work aims a) to explore the information needs of the informal caregivers of OwCI living alone in different care scenarios namely, fall, nocturnal unrest, agitation, and normal daily life towards a sensor-based information communication (IC) platform; b) elicit the design features for IC platform in accordance with persuasive system design (PSD) model.

2. Methods

2.1. Study design

A convergent mixed method design encompassing qualitative (QUAL), and quantitative (QUAN) methods was used for this study [15]. The convergent method helps in overcoming the weakness of one method with the strength of another method.

Survey: The survey was conceptualized by realizing the possible needs and requirements of informal caregivers from a sensor-based IC platform. An interview-based study with informal caregivers of person with dementia, identified the important monitoring goals for unobtrusive sensing systems in four different categories: safety, health-related, psychological, and psychosocial. Within these categories, situations like falls, hygiene, food-water intake, nocturnal unrest, cognitive decline, and agitation appeared more important among others [10]. Inspired from this, four monitoring scenarios namely, *fall*, *nocturnal unrest*, *agitation*, and *normal daily life* when monitored by USS were used in this study. Since these situations vary largely with respect to urgency/time/monitoring duration, a difference in preference for IC can also be imagined. In that regard, survey aims to provide quantitative insights into when, how, whom, and what, of IC in four care scenarios. The questions were custom-designed by the involved researchers' team comprising of various stakeholders in older adult care such as care platform designers/managers, design/e-health researchers, and experts in the field to manage the aims of this study. Furthermore, the questions were refined, and face validation by seeking feedback from informal caregivers before launching the survey. In the survey, all the respondents were asked to choose and respond to any one scenario among fall, nocturnal unrest, and agitation along with normal daily life scenario (when everything is going well). Other studies have used the Fogg behaviour model [21] and Bandura's Social Learning Theory [5] in their design as well. For example, persuasive techniques were used to create a mobile game for children which aimed to inform them and transform their mindsets, by providing a new approach for campaigning against smoking [36]. In the game, children have to shoot cigarettes, which is alternated with screens providing information about the effects of smoking. The principles of praise, information quality, attractiveness, mobile simplicity, convenience and cause and effect have been applied in the game. Similarly, to the previously mentioned studies, they measured the children's current knowledge and attitude towards smoking, then asked the

children to play the game, after which they repeated the measurements. Their results were positive, indicating that the game gained positive feedback and that it is effective at altering the mindset and attitude regarding personal and social situations.

Interviews: Semi-structured interviews were conducted in Dutch to collect data that can provide in-depth and complementary insights into IC needs of informal caregivers of OwCI towards IC platform with respect to above defined four monitoring scenarios. Similar to the survey, participants were asked to choose a situation from the three scenarios fall, nocturnal unrest, and agitation. Based on the choice of the scenarios, questions on when, how, whom, what and why of IC were asked and discussed. In parallel to situation-based questions, comparative questions for normal daily life when no anomalies are detected, were also posed (where necessary). This is done to understand the IC needs when a normal day is going in OwCI care.

2.2. Participants

The ethics committee of the BMS, University of Twente provided ethical approval for this study (Request no: 220250). A survey was placed on the Caren platform (<https://www.carenzorgt.nl/>) of NEDAP to collect quantitative data. Caren is a widely used digital caregiving platform that provides insights as well as control of users' own health or the health of their loved ones. The survey received a total of 6934 responses out of which 464 response form informal caregivers of OwCI living alone were extracted by using purposive sampling method. Further, for interviews ten participants who participated in the survey were invited.

2.3. Materials

Survey: The idea of USS and possible IC platform were explained to respondents using text and figures. After that, demographics and care related questions including age, gender, age of care recipient, relationship with care recipient were asked. All the scenarios had five similar questions: type of situation (emergency, acute, normal), time (when) of IC (immediately, few minutes after, self-check), mode (how) of IC (voice call, notification, SMS, email, self-check), care information recipient (whom) along with primary caregiver (formal caregivers, wait for primary informal caregivers response, secondary informal caregivers, ambulance, self-check, no information), content (what) of information (raw, interpreted, interpreted with suggestion, others). Here, raw data means data directly obtained from sensors (like numbers), (*e.g., Mr. X fall, and his heart rate is 120bpm*), interpreted data means raw data is further processed to interpret the raw numbers so that informal caregivers can understand them better (*e.g., Mr. X fall in the bathroom and his heart rate is higher than normal which can lead to heart attack*), whereas interpretation with suggestion option provides suggestions with interpretation so that informal caregivers can make an informed decision on what can be done in that scenario, (*e.g., Mr. X fall in the bathroom and his heart rate is high. You might consider visiting him as soon as possible and informing doctors*). Additionally in nocturnal unrest and agitation scenario, a question on need for detailed report (every day to informal caregivers, observe few days and then send to informal caregiver, observe few weeks, and then send to (in)formal caregiver, no reports required) was also asked.

Interviews: Like survey, first informal caregivers were explained about the USS and IC platform by the interviewee with the help of images. Then open questions on type of scenario, when, how, whom, and what were asked. Informal caregivers were encouraged to provide a reason (why) for the choices they made. Furthermore, Primary task support and dialogue support category from PSD model is used to elicit the design requirements based on the survey and interviews results.

3. Data analysis

Survey: SPSS (version 28.0.1.0) was used for analyzing the survey data. Participants demographics (age, gender) and care elements (age of care recipient, number of CRs, relationship with care recipient,) were analyzed using descriptive analysis. To obtain the quantitative insights on the IC needs for Fall, Agitation, Nocturnal unrest, Normal daily life monitoring scenarios descriptive analysis was used.

Interviews: The interviews were transcribed verbatim with the help of AmberScript software (an automatic transcription tool) and translated in English. Atlas.ti was used for analyzing the interviews. The transcripts were coded in three steps: open coding; axial (thematic) coding and selective coding [16]. The transcript was read by one researcher (NS) and useful relevant fragments were selected and initially coded. Next, the selected codes were categorized into the predefined relevant themes i.e., fall, nocturnal unrest, agitation, and normal daily life. Subsequently, all fragments were further inductively categorized to understand the requirements per scenario (including when, how, whom, what, and why). Second research (AB) coded 10% of the transcript independently to validate the codes. The joint probability of agreement was 75%. The two researchers defined the final themes. When coders disagreed, discussion took place until consensus was reached.

Meta Inferences and PSD Features: Meta inference aims to integrate the understandings gleaned from survey and interviews by comparing, contrasting, and finally concluding them [15]. Lastly, PSD categories were used to elicit the IC features from the obtained meta inferences [17].

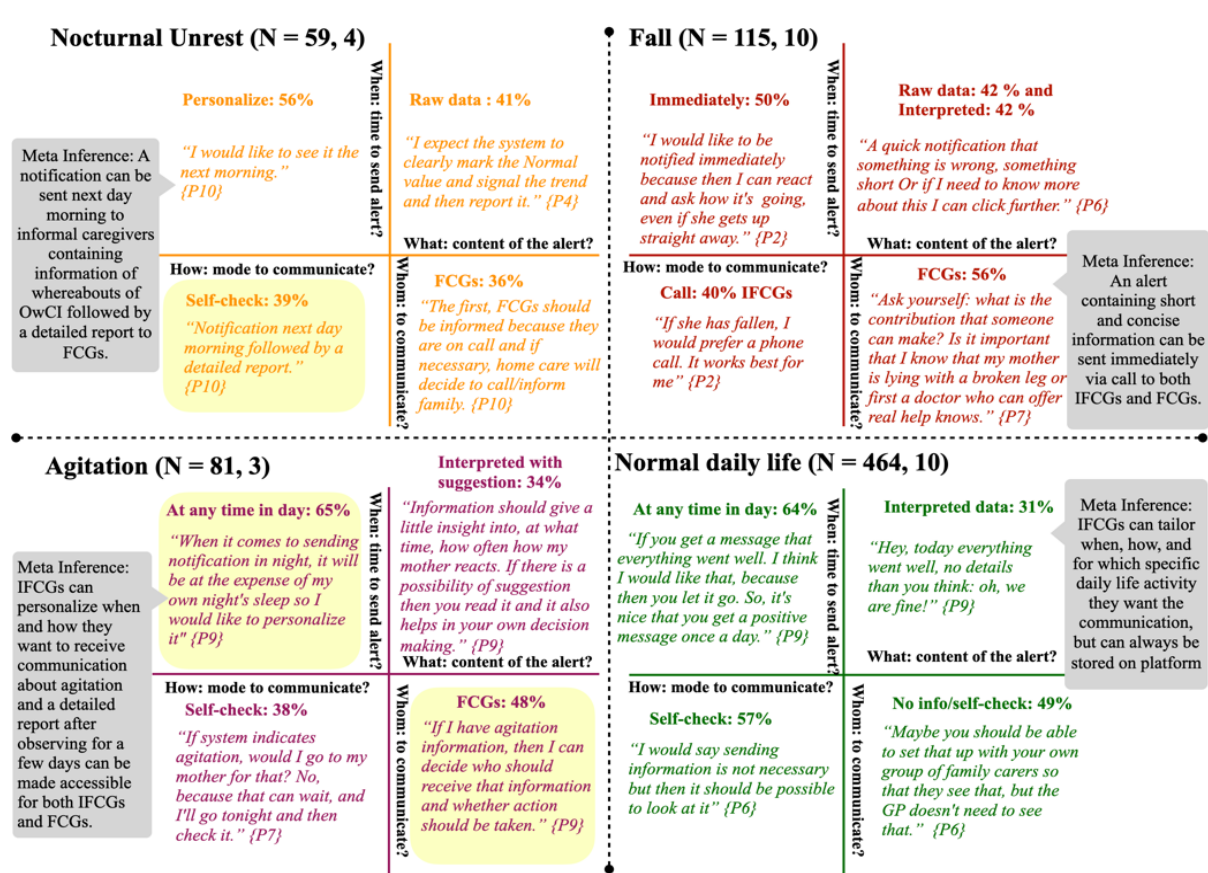


Figure 1. Most frequently reported qualitative and quantitative IC needs (What, Whom, How, When) for included four scenarios along with scenarios-wise meta-references are presented. Note that, highlighted tiles represent the contrasting responses from interview and survey results (N= Survey, Interviews sample) (Abbreviation: IFCG (informal caregiver), FCG (formal caregiver), GP (General Practitioner)).

4. Results

4.1. Participant demographics and care elements

Survey: The survey data from 464 informal caregivers (mean age: 58.37 ± 8.143) of OwCI (mean age: 86.71 ± 6.20) living alone was obtained. From the descriptive analysis, it was observed that 76.9% of informal caregivers were females and majority of them (84.3%) provide care to one OwCI. A large group of informal caregivers were children (77.5%) of the care recipient. Out of 464 respondents, 115 selected falls as their most recognizable scenario, 81 selected agitation, and 59 selected nocturnal

unrest. The remaining 209 did not find these options recognizable in their care hence they completed the survey for a normal daily life scenario.

Interview: A total of 10 informal caregivers (mean age: 57.1 ± 6.45) of OwCI (mean age: 88.8 ± 6.01) living alone participated in the interviews. Among the participants, seven were females and three were males and they provided care to one OwCI who is their parent. All ten participants talked about IC needs during fall and normal daily life scenarios, whereas four participants specifically spoke about nocturnal unrest and three about agitation. Figure 1 highlights the more frequently reported needs and corresponding meta inferences of IC needs in four scenarios.

4.2. Fall scenario

Type of situation (What?)

Out of 115 respondents, most informal caregivers (84.7%) indicated fall as an emergency, and only 15.6% indicated fall as an acute scenario. In the interviews also, all the participants except one (as the care recipient was bed ridden) considered fall as emergency and top priority monitoring scenario as it can be life-threatening. “She would fall down the stairs and then I think she wouldn't survive.” {P5} Moreover, they were always worried about the fall and to ensure everything goes smoothly they called or visited care recipient frequently. “*I think it's the worst-case scenario, finding your mother after a day, because she fall and you haven't had any contact. Terrible, and that's why we call quite a lot now. I want to know that she got up and got through the day, and so every morning, every evening, I call, or I drop by.*” {P2}

Preference in time to send alert to informal caregivers (When?)

Most informal caregivers (50%) wanted an immediate alert about fall whereas others (44.3%) also considered getting information a few minutes after in case care recipient does not get up. In the interviews, informal caregivers also indicated to be alerted immediately in case of fall to ensure timely action even if the care recipient gets up. One of the informal caregivers said, “*I would like to be notified immediately because then I can react and ask how it's going, even if she gets up straight away.*” {P2}

Preference in mode to send alert to informal caregivers (How?)

Most informal caregivers (40%) wanted to be notified via a voicemail/call followed by notification (25%), and SMS (31%). Similarly, in the interviews, participants preferred a phone call as a fastest way for fall communication. “*Calling is faster.*” {P3} Some participants also highlighted that due to caregiving they were already burdened and does not want further distractions, so a notification was sufficient. “*If someone has fallen, then it is great that there is an immediate response. But I think that you're always burdened in caregiving with all the beeps and information, so really just a notification is required.*” {P4} Moreover, they indicated that alarms with vibrations or sound could be used to draw their attention in case they were not alerted via notification, especially during night. “*If it is an emergency, I would also like to see a sound signal or a vibration function attached to it, so that you are alerted and not wait until you look at the notification.*” {P7}

Preference in alert receiving stakeholder (Whom?)

In total 38% of informal caregivers preferred that systems should alert all the informal caregivers along with formal caregivers, whereas 32% thought the system should alert only primary informal caregivers along with formal caregivers. When primary informal caregivers do not respond immediately (within 5 minutes), most of them (56%) wanted system to alert formal caregivers. While 26.1% of informal caregivers thought it would be wise to contact other assigned informal caregivers and 15.7% of informal caregivers thought the system could wait for their response for up to 5 minutes before taking further action. The interviews also suggested that in emergencies, like a fall, both informal and formal caregivers should be alerted. Because formal caregivers can ensure medical care if needed whereas informal caregivers could arrange other practical arrangements. “*You must ask yourself: what is the contribution that someone can make to the problem, and who has priority? Is it important that I know that my mother is lying there with a broken leg or first a doctor who can offer real help knows. I do think you should inform me, but not first.*” {P7}

Preference in content of the alert (what?)

Equal number of informal caregivers (41.7%) preferred the alert about a fall to be sent in the raw and interpreted form (see section 2.3) and only 14.8% wanted interpreted data with suggestions. In the

interview, informal caregivers focused on receiving a short and quick notification or an alert about a fall with the possibility to check for further details. *“A quick notification that something is wrong, something short, Or I need to know more about this I can click further.”* {P6} It was also observed that some informal caregivers were unaware of the significance of interpreted data, and after explaining it, they were inclined towards getting notification in an interpreted way. *“I hadn't really looked at it this way yet. Interpreted data can be important, especially with a heart attack, then I know, I must call in other help, I must act quickly.”* {P2} Some of the informal caregivers also highlighted the need for suggestions of how to respond in emergency situations by the IC platform. *“A kind of action framework is needed. There are people who don't know (how to react in emergencies), who panic when they see something like that (fall).”* {P7}

4.3. Nocturnal Unrest Scenario

Type of situation (What?)

Out of 59 informal caregivers, a majority (61%) of them categorized nocturnal unrest as an acute situation and 32% thought it was a normal situation. In the interviews, they explained the need for getting notification about nocturnal un-rest scenario but did not consider it as an emergency unless care recipient was leaving the house. One of the informal caregivers said, *“It is not an emergency, but it is important to become alert.”* {P10}, another added, *“If you get something every night, which is nothing to worry about, then you won't sleep anymore either. But if it is so serious that it is life-threatening, then you would like to know as soon as possible.”* {P10}

Preference in time to send alert to informal caregivers (When?)

Most informal caregivers (55.9%) wanted to personalize alerts, to receive information about whether a care recipient was in/out of the bed, whereas 37.3% of informal caregivers did not want this type of alert. In the interviews, participants further elaborated that they did not want to receive a getting in/out of bed alert at night as it leaves them worried which impacted their sleep and hence overall health. But they were willing to receive a notification the next day morning. Informal caregiver stated that, *“I would like to see it next morning.”* {P10}, another added, *“Next morning, I would like to know, if she is slept, when she wakes up, when and how much she sleeps, and what does she do if she is awake?”* {P1}

Preference in mode to send alert to informal caregivers (How?)

Most informal caregivers (38.2%) preferred self-check option on the platform whereas 36.8% preferred a notification. In the interviews, they were found more inclined towards getting a notification next morning followed by a detailed report (which they can self-check) unless care recipient goes out of the house. Informal caregivers said, *“Notification next day morning followed by a detailed report.”* {P10} *“You should be able to receive alarm if she walks out of house.”* {P1}

Preference in alert receiving stakeholder (Whom?)

Most informal caregivers (35.7%) wanted platform to directly inform formal caregivers. While 30.5% think that system should not send anything, they can self-check an update on platform when they want. Interview responses were in line with survey, such that primarily formal caregivers should be alerted as they can act faster due to their 24/7 availability. *“The first, formal caregivers should be informed because they are on call and if necessary, they will decide to call family.”* {P10}

Preference in content of the alert (what?)

40.7% informal caregivers wanted raw data, 27.1% interpreted data with suggestions and 20.3% only interpreted data about nocturnal unrest. The interviews gave more insights into the choice of respondents made in survey. One of informal caregiver willing to get raw data about nocturnal unrest indicated that they wanted to interpret the data by themselves. *“If I receive a message in two weeks about nocturnal unrest, then I should be able to look back. I can also think about reasons, maybe something is going on and I can analyze that.”* {P8} Another informal caregiver, indicated the need for a short but more meaningful information which directly conveys the situation of care recipient i.e., interpreted data. *“A short message like well the person and woke up once in night, took two paracetamols etc., if I see this much then I would be fine.”* {P10} Lastly, some informal caregivers wanted to customize the option of information presentation. *“I expect the system to have clearly marked the normal value and signal the trend and then report it. If such a device can help to interpret things, that seems very useful to me. {P4}.*

Need of detailed report

Most informal caregivers prefer that system observes nocturnal unrest for a few days (35.6%) or few weeks (15.3%) and then send a detailed report to them, whereas 23.7% preferred that system directly sends report to formal caregivers. In the interviews, the need of the detailed report about nocturnal unrest was identified, but support that it should be measured for a bit longer period (some weeks) by considering personal situations before sending. Because at times nocturnal unrest was experienced due to some personal difficulties. *“Suppose the system signals that she has been sleeping more restlessly for two weeks than the entire period before. And if I know her friend died recently, then I think it can be explained, but is then the system can be made aware by caregivers that there is no needs to monitor more carefully.”* {P4} informal caregivers believed that these reports were more useful for formal caregivers as they were trained to take required actions. *“If something needs to be done, then a report must be made, but it should actually be sent to home care, because they can act faster.”* {P10}

4.4. Agitation Scenario

Type of situation (What?)

Out of 81 respondents, 69.1% categorized agitation as an acute situation and 28.4% as normal scenario. Interviewed participants about agitation also saw agitation as an acute situation as it might not need immediate attention, but they expect system to observe it. *“Yes, restlessness is difficult. If she walks back and forth in the corridor. She is showing a certain pattern and if she is showing that pattern then there is a chance that she is doing something you don't want her to do. Then I would like a prediction/recognition of agitation situation in advance.”* {P6}

Preference in time to send alert to informal caregivers (When?)

Most informal caregivers (64.2%) indicated to receive alert about agitation at any point of time whereas 32.1% wanted to personalize the time to receive this alert. Unlike survey, in the interviews they disagree on getting alert at any point of time in a day. Specifically, they do not want to receive it during night. *“Well, when it comes to sending notification in night, it will be at the expense of my own night's sleep unless there is actually no life-threatening situation so I would like to personalize it.”* {P9}

Preference in mode to send alert to informal caregivers (How?)

37.5% informal caregivers preferred to self-check and 35.7% wanted to receive a notification about agitation. Interviews elaborated that such notification can be used to schedule visits and provide more adapted care. *“Normally a notification can be sent and based on that care can be organized little bit smarter.”* {P9} Some informal caregivers were also of opinion that even sending a notification does not necessarily help as agitation was not considered as an emergency. *“If system indicates agitation, would I go to my mother for that? No, because that can wait, and I'll go tonight and then check it.”* {P7} Also, they were worried about receiving alerts about agitation in night. *“I don't want to receive a notification or pop-up on my phone when it happens in night, but I can check it later.”* {P9}

Preference in alert receiving stakeholder (Whom?)

Most informal caregivers (48%) wanted IC platform to contact formal caregivers in agitation scenario whereas 25.9% wanted it to wait for their response on sent notification. In the interviews, they indicated that if systems send them a notification, they can further decide to whom this information should be passed. *“If I have agitation notification, then I can decide who should receive that information and whether action should be taken.”* {P9}

Preference in content of the alert (what?)

Most of the informal caregivers (33.3%) wanted to have interpreted data with suggestion, 32.1% wanted only interpreted data, and 29.6% wanted raw data. Interviewed informal caregiver further explained the need of interpreted data with suggestion, as they need a bit more in-depth information than just a notification like informing them about time, duration, frequency, and reactions of care recipient, so that they can provide more specific solutions than in general care solutions. *“Information should give a little insight into, at what time it takes place, how often does it take place? How does my mother react when she notices that she has stuck a leg, for example? Otherwise, you think for general solutions. If there is a possibility that advice can be given, hey that you read it and it also helps in your own decision making.”* {P9}

Need of detailed report

Most of the informal caregivers (34.6%) wanted USS to observe agitation for a few days or weeks (10%) before sending a report whereas 30.9% preferred that this report should be sent to formal caregivers. In the interviews they wanted to get a report where they can observe the trend of agitation in order to optimize care. *“It is good to know if something occurs structurally. If it happens every night for a week, then of course you want to make sure that there are indeed precautions. And if you notice she, does it once every three nights and after three weeks it's over. Then you don't want any extra solutions. So, if you get this report, you can make decisions based on that information than your own intuition.”* {P9}

4.5. Normal Daily life Scenario

Preference in time to send alert to informal caregivers (When?)

Most informal caregivers (63.6%) wanted to receive normal day (i.e., everything goes well) notification at any time of the day whereas 36.6% wanted to customize if and when they wanted to get this notification. In the interviews they indicated that getting a positive notification once a day preferably at the end of the day was reassuring. *“If you get a message that everything went well. I think I would like that, because then you let it go, while otherwise you think, I didn't look at the notifications today. So, it's nice that you get a positive message once a day.”* {P9}, *“At the end of the day.”* {P2} But respondents were also skeptical about information overload, hence wanted to look at it by themselves when they had time., *“I look that up myself when it suits me you look over the day.”* {P5}

Preference in mode to send alert to informal caregivers (How?)

Most informal caregivers (57.3%) preferred to self-check and 25.8% wanted to get a notification. Interview responses also showed the same trend, with most of them preferring to look at the normal daily life information on the platform by themselves (self-check) to reduce information load whereas a few of them did not mind having one notification at end of the day. One informal caregiver said, *“I would say sending information is not necessary but then it should be possible to look at it like, oh, I haven't had a notification today, let's see what she did.”* {P6}, *“If I don't get a message, then I assume that it's going well. Otherwise, you get lots of messages.”* {P3}, *“Notification could be sent once a day and I think especially at the end of the day.”* {P7}

Preference in alert receiving stakeholder (Whom?)

48.9% informal caregivers wanted no information, 22.2% preferred it send information to informal caregivers and if required, they can take further actions. The interviews indicated the same preference that, IC platform did not need to send anything about normal daily life. But they should be able to set it up who can see this information by themselves. *“Well, you should be able to set that up with your own group of family caregivers so that they see that, but the GP doesn't need to see that, I think.”* {P6}

Preference in content of the alert (what?)

Almost equal number of informal caregivers wanted interpreted data with suggestion (31.7%) and only interpreted data (30.6%). Interview response also suggested that normal daily life notification can be presented in interpreted way with a possibility to save observations from all daily life activities so, if required, formal caregivers can look at it. *“You must be able to see, if drinking is gone well, movement is gone well, everything is fine. But you could save that (raw data) as a history, so when something is wrong then formal caregivers can look back and see, oh, those days were going well and then suddenly from here things went wrong.”* {P6}

4.6. Identified PSD features based on obtained IC needs

To pave a way towards designing an IC platform, identified IC needs can be used to elicit the design requirements in accordance with PSD model [17]. However, the intended IC platform does not aim for behavior change of informal caregivers, but it does require persuasion to form (F) or alter (A) the behavior of informal caregivers for complying to the information communicated (F & A-Outcome, C-Change) [18]. Therefore, two PSD categories primary task support (supporting user's primary tasks) and dialogue support (supporting the interaction between user and system) were leveraged to elicit the features helpful in forming or altering an act of complying [17]. Table 1, in appendix illustrates the

identified PSD design features by the authors based on acquired scenario-specific needs of the IC platform.

Features from primary task support category: In this category, four features Reduction, Tunneling, Tailoring, and personalization were recognized. *Reduction* was used for reducing complex tasks into simpler tasks. In fall situation informal caregivers indicated the need of getting an alarm immediately either via call or notification which can take over other functionalities. In that respect, IC platform can add a functionality to directly contact informal caregivers in emergency without expecting them to look at the platform. An option to set care goals in advance can be given to the informal caregivers as different caregivers deals with different care scenarios. While informal caregivers set their care goals in the system, they can also be guided/persuade through the information IC platform can offer i.e., *Tunneling*. In the way of data presentation, informal caregivers were not able to understand all that the system could offer and how interpretation or suggestion could be of use to them. Here, along with possibility to set care goals, a demonstration of the capabilities/features of the IC platform could be made. *Tailoring* helps users to adapt according to their needs. In IC platform, primary informal caregivers indicated the need of communicating to formal caregivers (though in different levels like immediately or a detailed report later), thus the information can be tailored according to when and who receives it. Lastly, *Personalization*, appeared as a key functionality in designing IC platform in all the scenarios. As IC needs changes according to the evolving care situations, informal caregivers should be able to personalize them on the platform.

Features from dialogue support category: Two features Reminder and Suggestion were recognized according to the obtained IC needs. *Reminder* was used for reminding user for timely actions. In fall situations, informal caregivers wanted to receive a reminder message if they did not respond within a few minutes. *Suggestion* feature was used to provide suggestions to the user to facilitate task at the hand. Ambivalent opinion on receiving suggestion were obtained but to facilitate the need of informal caregivers who require suggestions in emergency, a suggestion feature was be added.

5. Discussion & Conclusion

The difference in IC needs due to different care scenarios became apparent from this mixed-methods study. Fall being an emergency requires an alert containing short and concise information which can be sent immediately via call to both formal and informal caregivers. In nocturnal unrest, (unless a life-threatening situation) a notification can be sent next day morning to informal caregiver, containing information of whereabouts of the OwCI, followed by a detailed report to formal caregivers. In agitation scenario, informal caregivers preferred to personalize when and how they receive an IC about agitation, with a possibility of a detailed report available for both informal and formal caregivers. In normal daily life scenarios, more flexibility in receiving care information was requested, as informal caregivers wanted to personalize when, how, and for which specific daily life activity they receive information.

Furthermore, using persuasive strategies during the design phase can help in achieving the overarching aim of IC platform. By forming or altering the complying behavior with the help of PSD features, like reminder and suggestion, on-time care can be ensured. Whereas reduction, tunneling, tailoring, and personalization features can be used to relieve the care burden on the informal caregivers. Moreover, with change in care scenarios, changes in personal circumstances of both informal caregivers and care recipient also impacted the care needs. This indicates the need for a more adaptive and 'strongly personalized' care platform and rules out the idea of designing one IT system for all [19] [20]. Thus, future designers, developers, and researchers aiming to develop an USS for OwCI care are recommended to go beyond 'tailoring' for the broader user groups and move towards 'strong personalization' by recognizing individually evolving needs and preferences. The obtained PSD features will not only help in designing/developing informed systems but will also ensure effective implementations in practice. Moreover, AI-driven designs can be considered to develop such an advanced platform, though a serious consideration should be given to privacy and trust issues. In this study, only the needs of informal caregivers in four scenarios were studied. For future work it would be interesting to look at the needs of other stakeholders such as formal caregivers, technology developers, and designers and in different scenarios.

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Appendix

Table 1.

Identified persuasive features based on the obtained IC needs in accordance with persuasive design model for Fall, Nocturnal unrest, Agitation, and Normal daily life.

Scenarios & Meta Inference	Fall: An alert containing short and concise information can be sent immediately via call to both (in)formal caregivers.	Nocturnal Unrest: A notification can be sent next day morning to IFCG containing information of whereabouts of OwCI followed by a detailed report to formal caregivers.	Agitation: Informal caregivers can personalize when and how they want to receive communication about agitation and a detailed report after observing for a few days can be made accessible for both (in)formal caregivers.	Normal Daily life: Informal caregivers can tailor when, how, and for which specific daily life activity they want the communication, but can always be stored on platform
PSD Features scenario-wise	Reminders (remind users timely of the target behavior): If informal caregivers doesn't respond within a few minutes, along with informing other caregivers, a reminder could also be sent to them.	Personalization (personalizing the content): IC needs of informal caregivers were observed to be changing according to the evolving care situations like in co-morbidities, age, and other personal situations. Therefore, IC platform should be able to adapt to the changing needs. For e.g., option to personalize time/mode/content of information can be given.		
	Reduction (Reducing a complex task into smaller tasks): informal caregivers can directly receive the alarm/call rather than opening the platform for checking themselves, whereas in other scenarios they can receive notifications			
	Tailoring (adapting as per user group needs): IC platform can be tailored as per the user group it is catering. For e.g., at times (though at different levels like immediately or detailed reports) IC platform is expected to communicate with both (in)formal caregivers, then the information can be communicated as per the needs of targeted user group.			
	Tunneling (Guiding a user through process and persuading them along the way): Both care situation and respective care needs vary a lot. Therefore, along with possibility to set care goals as per the required care situation in the platform, demonstration of the capabilities/features of the IC platform can be done. For e.g., understanding the benefit of detailed reports, difference between raw or interpreted data, and use of suggestion feature.			
	Suggestions (offer suggestion to facilitate the task): Though the survey and interview results were not in accordance with sending suggestion along with information. But some informal caregivers felt the need of suggestion so that they can act in an informed manner to optimize care.			