Supporting Caregivers in Assisted Living Facilities for Persons with Disabilities: a User Study

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Supporting Caregivers in Assisted Living Facilities for Persons with Disabilities: a User Study

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Abstract Research activities on designing healthcare support systems in the field of ambient assisted living are mainly focused on addressing two problems: improving the quality of life for people in their own homes, especially the elderly, and supporting nurses and physicians in hospitals. However, few papers focus on designing specific systems for supporting caregivers that work with persons with disabilities in the context of assisted living facilities (ALFs). This paper intends to contribute to filling this gap and presents a series of guidelines for designing systems that could effectively support caregivers in tasks such as monitoring ALF inhabitants, attending to their assistance requests and managing notes and reminders regarding daily activities. These design guidelines derive from the qualitative analysis of a comprehensive user study, carried out in northern Italy, of three focus groups conducted with a total of 30 caregivers in three different ALFs for persons with physical and cognitive disabilities.

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1 Introduction

One of the challenges that the healthcare sector has been facing in the last decade is how to ensure full coverage of professional care for those who require special attention (e.g., the elderly, people with disabilities or patients with chronic conditions), while the associated costs continue to increase. According to the recent Action Plan for the EU Health Workforce, by 2020 around 14% of these care needs will be unmet[1].

To address this challenge, ambient assisted living (AAL) systems have been researched extensively. These systems exploit intelligent environments, ubiquitous computing and mobile/wearable technologies to reduce the expenditure on healthcare by enabling people to be monitored in their own homes, rather than in hospitals, for a fraction of the cost (see the survey by Acampora et al. [1] for further details). The combination of such technologies has also proven to be suitable for creating applications that support medical staff in performing the typical tasks of highly structured environments, such as hospitals, more efficiently (as in [2] or [17]).

Research in the field has thus focused on two main objectives: how to improve the quality of life of *patients in their own houses*, and how to support *doctors and nurses within hospitals* in the specific tasks their jobs entail.

[1] The Action Plan for the EU Health Workforce is publicly available at `http://ec.europa.eu/dgs/health_consumer/docs/swd_ap_eu_healthcare_workforce_en.pdf` (last visited on July 14, 2014)

However, less research has been done about systems to support caregivers which assist persons with disabilities[2] within *assisted living facilities*[3] (ALFs) and on how to design them to be effective. Although there are some studies that provide design principles for similar systems, these principles are focused on optimising assistance to the elderly, either directly (refer to design directions proposed by Morris et al. in [15]), or by supporting their caregivers (as in [6]).

There is still a need for design guidelines for healthcare support systems in ALFs, focused on addressing the specific requirements that caregivers actually have, such as keeping their hands free most of the time or being alerted in case of inhabitants' necessity.

This paper discusses a particular type of assisted living facility for people with disabilities, known as RAF (*Residenza Assistenziale Flessibile*). RAFs are Italian health and social care facilities with the aim of providing hospitality, welfare benefits and recovery to people in mental or physical conditions of dependency. They ensure adequate living conditions for the inhabitants, appropriate for their dignity, by promoting the maintenance or recovery of their residual capacities and the satisfaction of their relational and social needs.

The objective of this paper is to identify representative requirements that RAF caregivers have and to propose a set of design guidelines, derived from analysing the results of group interviews with them, for systems which effectively support healthcare assistants in daily tasks within ALFs. The paper is organized as follows: Section 2 presents some background and relevant studies that illustrate what has been already done in the field of healthcare support systems for assisted living facilities; Section 3 presents the method, procedures and participants of the user study that was carried out, with some general observations about it; Section 4 presents the data collected from the focus groups and the qualitative analysis of these data, to then elicit the design guidelines that should be taken into account by anyone interested in designing or deploying a healthcare support system in assisted living facilities for people with disabilities. Finally, Section 5 presents the conclusions, including possible future works.

[2] The persons with disabilities to which the authors refer to are adults between 18 and 64 years old with physical or mental (cognitive) disabilities. In 2004, persons with disabilities corresponded to about 5% of the total population of Italy (of which the major part were still living with their families rather than in ALFs), according to the 2004 ISTAT report *"Disability in Italy"* available at `http://www3.istat.it/dati/catalogo/20100513_00/arg_09_37_la_disabilita_in_Italia.pdf`(last visited on July 11, 2014)

[3] An assisted living facility (ALF) is a housing facility for persons with disabilities. ALFs ensure health, safety, and well-being conditions for people with mental or physical disabilities by monitoring and assisting them with the activities of daily living. In these facilities, unlike in hospitals or nursing homes, there are no full-time nurses nor physicians providing medical treatments.

2 Related Works

Most of the healthcare support systems found in literature focus mainly on Ambient Assisted Living (AAL), Emergency Detection, or Continuous Monitoring (according to the survey by Acampora et al. [1]). Such systems aim at enabling people with special needs, e.g., the elderly, to stay at home and to be monitored remotely by medical staff, rather than being hospitalized with the costs this entails (see the AMON [4] and the CARMA [12] systems as examples).

Therefore, many design recommendations have been elicited for systems able to address different needs of elderly living in home environments (according to Zulas et al. in [18] three main needs emerge: the support for the activities of daily living (ADL), the safety of the elderly and the delivery of data to nursing staff). Numerous of these systems have been implemented by exploiting intelligent environments (e.g., [9]) and mobile technologies (e.g., [12]). Furthermore, the combination of such technologies has already proven to be suitable for building applications in structured environments such as hospitals (as reported in [2] or in [17]) to support medical staff. Wearable technologies have also been researched as possible enabling technologies, from their first apparitions in systems such as WearNET [13] and AMON [4], to more recent tools which combine wearable and environmental sensing for long-term sleep studies, as in the work presented by Borazio et al. [7].

However, systems designed to support users different than doctors and elderly have been little researched. In particular, few systems addressing the requirements and necessities of caregivers in ALFs have been proposed; consequently, design recommendations for these systems are very limited.

Moreover, the few recommendations available in literature only identify the needs of persons with disabilities, not the needs of their caregivers; even if it has been shown that the quality of assistance in ALFs (and therefore the inhabitants' quality of life) is highly related to caregivers' attitudes and to their perception of their working environment (see the study of Beeber et al. in [5]). The summary of recommendations reported in [16], for instance, enumerates some practical changes in primary care practices that can enhance disability care, such as promoting positive images of disability (e.g. by hiring staff members with disabilities) and easier ways to contact the staff.

Some of the relevant studies that have been carried out on designing systems to support the elderly or their caregivers in nursing homes[4] are reported, since the guidelines with which these systems have been designed are the most similar to those that should be used for systems in ALFs. This is the case of the design directions derived by Mor-

[4] Nursing homes are residences for people who require continual medical care and assistance in their daily activities, usually elderly.

ris et al. in [15], from the ethnographic study of elders with cognitive decline, which include recommendations such as *to provide adaptive functionalities for offering the optimal level of assistance* and *to provide mechanisms for catalysing social relations*. Other researchers have also focused on user needs and acceptance of such systems for eliciting design recommendations: Mayora et al. [14] list the anecdotes, challenges and lessons learnt from a project involving people suffering from bipolar disorder; Altakouri et al. [3] show the results of their Wizard-of-Oz study for supporting nursing documentation, Bhadoria and Gupta [6] present a tracking and emergency alert system for the elderly, and Zulas et al. [18] assess caregivers' needs within assistive smart homes for the elderly.

3 User Study

The goal of the study presented in this paper was to understand the needs and concerns that caregivers of assisted living facilities have, how do they currently tackle problems and difficulties, and how technology can help or support them in their daily work. Particularly, the authors were interested in caregivers that work at RAFs, i.e., assisted living facilities for people with disabilities who cannot live alone or that require special attention.

The research questions addressed are the following:

1. How can the introduction of a healthcare support system, that might involve mobile/wearable technology, in assisted living facilities support caregivers in their daily activities?
2. What are the current needs, concerns and desires that caregivers of assisted living facilities for people with disabilities have?
3. What particular needs or issues can prevent (or foster) the adoption of any mobile/wearable device to support the caregivers through their daily activities?

To achieve this goal, three group interviews were conducted with a total of 30 participants, in the form of focus groups. Focus groups are distinguished from other techniques based on group interviews by the explicit use of group interaction as research data [11]. This technique was utilized because it draws upon participants' attitudes, feelings, beliefs, experiences and reactions to gain large amounts of information in a way in which would not be feasible using other methods such as observation or one-to-one interviewing, according to [10].

3.1 Method

Three focus groups were carried out in three assisted living facilities, managed by the Cooperativa Sociale P.G. Frassati[5] near Turin, in Italy, that have identical operative rules and procedures. In this phase, it was decided not to investigate about any technology-related issue to let the participants concentrate on the needs and concerns they have as caregivers, without worrying about the practical feasibility (or cost-related issues) of their ideas.

A single 90-minute session was conducted with each group, with an average of 10 people per group, in the same assisted living facility they work in, in order to get better understanding of the context, needs, problems, and possible tools already used. All focus groups were held in Italian and took place after lunch while the inhabitants of the RAF take their nap, since this was the only time during the day in which caregivers were able to have free time to meet visitors. The sessions were carried out in a relaxed and comfortable atmosphere, around a table with some coffee. Each session began with one of the members of the research team explaining the aim of the focus group and encouraging the participants to talk to each other, rather than to simply respond to the researcher questions.

Two researchers were present at each session: one of the researchers (moderator) conducted the interview, carefully avoiding to give personal opinions to not influence participants towards any particular position, while the second researcher constantly collected notes of the group dynamics and dialogues. In addition, all the focus groups were fully audio recorded and later entirely transcribed, and photos of particular areas of the visited assisted living facilities were taken (when allowed).

3.1.1 Procedures

Each focus group was conducted in a different assisted living facility with the participation of all the healthcare personnel of the facility. It was decided to keep the three groups separated instead of merging them into one big cluster to preserve the "naturally occurring" groups, i.e., people who already know each other through working together. The motivation behind it was that exploiting pre-existing groups allows the observation of fragments of interactions that approximate naturally occurring data, according to Kitzinger [11].

The recruitment of the participants was straightforward since the study was conducted with the cooperation of the management at Cooperativa Sociale P.G. Frassati, that helped to gather the groups and to fix the appointments for the interviews.

The sessions lasted for 90 minutes and followed this structure: first, the researchers and the participants introduced themselves, and the researcher in the moderator role explained the dynamics of the focus group and the goal of the study. Then, an individual questionnaire was distributed

[5] `http://www.coopfrassati.com` (last visited on July 2, 2014)

among the participants to collect both general demographic data and information about their experience as healthcare assistants in assisted living facilities. Finally, a set of open questions focusing on caregivers' daily activities, related problems and desires, were posed (one by one, in Italian) to guide the session by keeping the conversation moving forward, and also to facilitate the interaction between the group members.

The actual questionnaires, the conversations between participants and the moderator interventions, as well as the rest of the collected research data, were in Italian. Therefore, it is inevitable that translations of the research material rigorously carried out in English as reported in this paper might not always exactly represent the original Italian versions. However, this has no effect on the final design guidelines elicitation.

Finally, the list of the questions with which the researchers guided the interviews are presented below. The order of such questions was not always the same, and not all of them were posed to the three groups. Furthermore, since the moderator of the focus groups interacted as well with the participants, additional questions that rose naturally during the conversation were asked:

- Could you tell us how is your "typical day" structured?
- In your daily activities, have you developed or implemented some "workarounds" to facilitate or speed your work?
- Are there activities that risk to be forgotten? Which ones?
- What would you like to know about the RAF inhabitants when you are not with them (overnight, for example)?
- What technological tools (tablets, smartphones, etc.) have you already proposed to the RAF inhabitants or have tried yourselves? How did it go?
- For what activities would you like some kind of reminder?
- In general, do you have special requirements? for example about the tools you use? What would they be?
- May the guests request your assistance or presence? How?
- When inhabitants request assistance, what is a reasonable time to reach them?

3.1.2 Participants

From the total of 30 participants, 22 were female and 8 were male, with different years of expertise as professional caregivers in RAFs (as summarized in Table 1 and in Table 2). Regarding the technology experience, all the caregivers that participated in the study use the computer daily and own a smartphone, except for the two participants over 56 years old which use an old-fashion cellphone.

All participants were healthcare assistants, working in one of three RAFs managed by Cooperativa Frassati in the area near Turin, in Italy. As reported in Table 3, two of the assisted living facilities (RAF1 and RAF3) accommodate people with various degrees of mental disorders, while the third one (RAF2) houses people with motor impairments. Each RAF hosts around 10 people and assistance is guaranteed 24/7: during the day, two caregivers are present within the RAF, and another one is present overnight.

Table 1 Participants by age.

Age	Count (by sex)
26-35	3M, 7F
36-45	4M, 13F
46-55	1F
56+	1M, 1F

Table 2 Participants' expertise.

Years of Expertise	Count (by sex)
less than 1	3M, 1F
1-5	1M, 8F
6-10	5F
11-15	2M, 6F
16+	2M, 2F

Table 3 Details about the visited facilities.

	Caregivers	Type of disability	People housed
RAF1	7 (1M, 6F)	Cognitive	10
RAF2	10 (3M, 7F)	Physical	10
RAF3	13 (4M, 9F)	Cognitive (severe)	12

Although RAFs differ between them in various aspects such as the facility size, the spaces accessibility and their distribution, all of them generally share some characteristics such as the presence of a backyard, a fully equipped kitchen, a living room, and single or shared bedrooms for the inhabitants. In particular, RAF1 and RAF2 have backyards accessible to the inhabitants; RAF3 and RAF2 have two floors, one for the common areas such as TV/hobby room and another with the inhabitants bedrooms. All the visited RAFs have bedrooms hosting one, two or three people, a roomy kitchen, a laundry, an infirmary in which medicines are stored, a space used as office by caregivers, and spacious shared bathrooms.

In addition, the RAFs visited have several areas from which it is difficult to hear what happens in the inhabitants' bedrooms, e.g., the backyard in the case of RAF1 or, in the case of RAF2 and RAF3 (which have two floors), the rehabilitation room and the laundry, respectively. Moreover, within the three RAFs, no place allows caregivers to simultaneously see all the inhabitants bedrooms.

3.2 Observations

Some general observations made throughout the study are presented here, before discussing the data obtained from the focus groups and the elicitation of the design guidelines derived from them. In this way, some contextual information useful to understand the following sections of the paper is provided.

Common needs emerged from the caregivers across the three groups, with some minor differences due to the diverse type of disabilities present in the RAFs where the participants work in. In fact, people with motor disabilities are less autonomous and independent than people with mental disabilities who, in most cases, can leave the house and walk around the town without any assistance. Moreover, the former perform most of their activities inside the RAF, while the activities carried out by the latter often occur outside the structure. In general, although the inhabitants of RAF1 and RAF3 have to be closely monitored given that they may suffer epileptic seizures, for example, or that a few of them may try to break or escape the RAF (as some of RAF3 inhabitants have already attempted), the inhabitants of RAF2 require more assistance from their caregivers in order to perform daily activities, that they would not be able to carry out otherwise, due to the motor impairments.

During the day, two healthcare assistants are always present in the RAFs, performing various activities, from personal assistance (e.g., helping the inhabitants to brush their teeth), to drug administration, or help in housework (e.g., cooking or doing laundry). A nurse is present one hour per day, every day, while a doctor is available on request, only. During the night, one caregiver is present in the facility, performing some houseworks and running ward rounds.

Each healthcare worker brings in her pockets a cordless phone, multiple keys and, in some cases, her personal mobile phone. Caregivers express the desire to bring with them less "objects" as possible because "*it is not easy to walk around with the pockets full of stuff, and if the phone rings you have to take out many things to finally answer it!*", as said by one of the caregivers of RAF1.

Caregivers, at the end of their shift, must compile a paper form reporting relevant issues and the activities they performed. However, by the time they fill the form, they are prone to forget some events and issues to report. In some cases, they leave a post-it note to their colleagues to highlight some news (e.g., an inhabitant has the flu) and changes in some of the planned activities (e.g., the swimming pool was unexpectedly closed).

RAF inhabitants can require the assistance of a caregiver by calling them by voice or using a buzzer, inside the house. It was noticed that one buzzer is present inside each bedroom (near the bed, typically) and another is located in each bathroom, as required by the Italian law[6].

In RAF1 and RAF3, inhabitants do not own any technological tool, such as smartphones, tablets, or computers. Healthcare assistants and inhabitants' families promote this "policy", because of the possibility that such objects may be stolen, broken or traded. In fact, since some inhabitants can freely move alone around the town, they may meet ill-intentioned people or sell these objects to obtain stuff like junk food. In the past, caregivers tried to give them such tools and obtained negative results. On the other hand, inhabitants of RAF2 spend almost all of their time inside the house and they actively use smartphones and computers to communicate, play, or search the Web.

4 Results and Discussion

This section presents the most relevant information collected during the focus groups regarding caregivers' unmet needs, problems and desires, along with their qualitative analysis: the research findings and the implications derived are listed in the following. Finally, stemming from these research findings, a set of design guidelines is proposed to address the research questions stated in the user study, from a system point of view. These guidelines, numbered from DG1 to DG10, are reported in Table 4 and summarize the most important aspects that should be taken into account to effectively design support systems for helping caregivers in their daily activities within ALFs.

The reported guidelines do not explicitly account for privacy issues. Privacy is a very important topic to address in any healthcare support system and it is given as a prerequisite, rather than a reccomendation, for building a successful and useful system. In the case reported in this paper, privacy-related issues are strongly regulated by the rules of the ALFs, realized in agreement between ALF managers, inhabitants families and by following the Italian Privacy Law (196/2003). Moreover, all the changes that concern people in the structures (i.e., inhabitants, guests and caregivers) must be approved in advance by the ALF managers, the inhabitants and their families.

4.1 Enabling hands free operations for caregivers

Research finding. One of the most common requirements across all three focus groups, constantly mentioned and discussed, was the caregivers' need of having the hands empty or free from any objects. Caregivers must have their hands

[6] The Italian law, with the Ministerial Decree *dei Lavori Pubblici n. 236 del 14/06/89* requires buzzers, at least in the bathroom and in the bedroom of people with disabilities.

empty while they are working because they should be always ready to attend any situation in which an inhabitant is involved, as fast as they can. In particular, one participant of the RAF1 group, when asked if caregivers had special requirements (like having their hands free), answered as follows:

> "*It depends on the people* (i.e., the RAF inhabitants) *you work with... but, I would say that we* (i.e., the caregivers) *need our hands empty the most of the time, because some guys could fall or suffer a seizure, and we must be ready to intervene.*"

Two other participants, one from RAF3 and another from RAF1, confirmed and explained that everything they carry around (e.g., cordless, mobile phone, etc.) has to be inside the pockets in order to avoid distracting them during their daily work. In addition, all the objects and tools used by the caregivers should be resistant to water and shocks given the fact that their attention has to be directed to the RAF inhabitants and not to devices integrity.

Implications. Since caregivers in assisted living facilities for people with mental disabilities, such as RAF1 and RAF3, need their hands empty for most of the time, they should not use or carry around objects such as smartphones or tablets, and definitely, they cannot operate them for long periods of time engaging their full attention to their operation. Caregivers do need devices that support them in their daily tasks, and it is very important to them that such devices can be easily and quickly operable, that can be resistant and sturdy enough, and that can be used everywhere inside the RAF, immediately. These implications are taken into account by the design guidelines DG1, DG2 and DG3 as presented in Table 4. Wearable devices might address these requirements while allowing the users to keep their hands free; this is in good agreement with the increasing number of studies in which wearable technology is being proposed as part of support systems in the healthcare domain such as [13], [4], and more recently [7].

4.2 Helping caregivers to remember non-routine tasks more easily

Research finding. Daily activities in assisted living facilities follow a pretty fixed schedule to help caregivers remember more easily the routines of each inhabitant and all the tasks that need to be carried out to have the RAF functioning properly. Details that otherwise could be forgotten, such as wake up times, bathroom turns, medication and diets, among many others, are well structured in a "collective" routine that indicates the caregivers what to do, with which inhabitant and at what time. As expected, for RAF1 and RAF3 the routines are very similar due to the fact that they host people with mental disabilities with common needs. RAF2 also has a collective routine in which the order in which the inhabitants are woken up and transferred to their wheelchairs is specified.

Schedules are very useful to organize and simplify daily activities, however caregivers encounter difficulties with some tasks that are out of the routine, such as extemporaneous appointments or temporary drug administration. Three caregivers (C1, C2 and C3) from RAF1 discussed about this difficulty when the conversation was about the "typical" day and the moderator (M) asked about activities that can be forgotten:

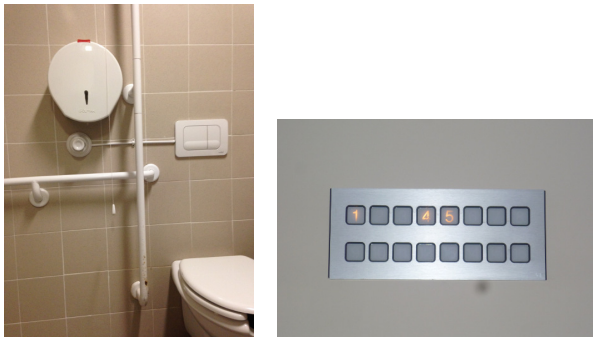
> M: "*From these activities* (activities from the typical day), *which one worries you that could be forgotten? If there are some...*"
>
> C1: "*Those in the infirmary! Because it is very sensitive if something there is forgotten.*"
>
> M: "*Which is the risk of something going wrong?*"
>
> C1: "*If there are different schedules or if something goes out of the routine... if someone has to receive some temporary therapy, for example.*"
>
> C2: "*Right! Especially with the temporary medication...fever, the flu. Normally the activities and therapies are verified and contrasted with the inhabitants records and routines, but that is for routine activities or long-term treatments. You have to remember the other activities.*"
>
> C1: "*For example, sometimes it has happened to me with one of the inhabitants, Maria* [7] *, who sometimes forgets some things, that she takes a pill, then comes back and asks for it again... if the caregiver is the same, usually there is no problem because it is easy to remember you already gave her the medicine; but if the caregiver is not the same, the doubt could arise and there is the risk to err.*"
>
> C3: "*But it is difficult to make mistakes because they have to sign when they take their medicines!*"
>
> C1: "*Yes! They have to sign! But with medicines for short-term treatments that maybe are not taken after meals, it can happen...*"

Currently, caregivers have addressed the problem of forgetting things that are out of the routine by writing post-it notes and sticking them on a board within the room that they use as office. Figure 1 shows the main board of RAF1. However, caregivers expressed that they are not completely satisfied with such a solution because they need to be in the office to read the notes and they have to remember to check the board to see if there are new reminders.

Implications. A properly designed system for supporting caregivers in ALFs should address the problem of reminding

[7] The inhabitants real names have been changed for privacy reasons.

Fig. 1 Main board in the caregivers' office in RAF1.



(a) The buzzer is operated by pulling a string (b) The panel indicates who is requesting assistance

Fig. 2 Example of assistance request mechanism within a RAF2 bathroom.

the caregivers about tasks or events out of routine, especially if there are many inhabitants housed in the assisted living facility and keeping many things in mind becomes difficult. The design guideline DG9 presented in Table 4 covers this particular implication. The solution should allow to create and check reminders ubiquitously, in other words caregivers should be able to create new reminders (for themselves and their colleagues) *in situ*, and check the list of reminders while are around the facility without having to be at any specific spot. These implications could be addressed by design guidelines DG2 and DG9 (see Table 4).

4.3 Alerting caregivers in case of necessity to offer the optimal level of assistance

Research finding. The inhabitants of a RAF need the caregivers attention countless times a day: for asking them for help in simple tasks such as opening and closing doors or reaching objects (this is the case of people living in RAF2 in particular) or for more sensitive matters such as being assisted on time in case of epileptic seizures (this is the case of some people with mental disabilities, such as RAF1 or RAF3 inhabitants).

People living in assisted living facilities, currently, can call the caregivers attention by voice or by using a buzzer located in some fixed locations inside the RAF (bedrooms and bathrooms, in this case). Figures 2(a) and 2(b) show the string operated buzzer of a bathroom in RAF2 and the panel in the caregivers office that illuminates the number of the room from which assistance is requested, respectively.

However, there are situations in which caregivers cannot hear the inhabitants, or where the buzzer is not reachable. In fact, inhabitants may be outside the house, away from caregivers (e.g., in the backyard), or may have fallen out from the wheelchair and be unable to use the buzzer, as the following conversation between the moderator (M) and a caregiver (C1) from RAF2 illustrates:

> C1: "*The problem with the buzzer is that it is fixed in a room or within the wheelchair as a horn... it has happened that someone has fallen out from the wheelchair in the backyard in such a way that is unable to operate any buzzer, not even the horn embedded in the wheelchair.*"
>
> M: "*What do you do in such a situation?*"
>
> C1: "*There is nothing we can do... I mean, if we realize that someone is not in the house and no one has seen him for a while, we search him.*"
>
> M: "*Don't they call for help?*"
>
> C1: "*Yes, but sometimes you don't hear... if you are in the laundry and the TV is on, there is no way of hearing someone even if he is yelling.*"

These missed calls constitute a problem that the caregivers, at the moment, feel is not addressed. Furthermore, in RAF2 the buzzer and its usage are sources of discomfort and disagreements between the caregivers. The main reasons for discord are the loud noise produced by the buzzer to be properly heard, and the way it is turned off, that allows a caregiver to deactivate the buzzer only by reaching it and directly acting on it (i.e., it does not support "remote" control).

In fact, one of the biggest debates across all focus groups took place while talking about the buzzer and the possible alternatives to replace it. The following present part of the argument between four caregivers of RAF2 (C1, C2, C3 and C4) moderated by the researcher (M), that started when the buzzer rang for the first time, in the middle of the interview:

> C1: "*Here! This is the buzzer that we talked about, it sounds all over the house and here in the office the number of the room from which the call was made, illuminates.*"
>
> M: "*It illuminates just here in the office?*"

C1: "*No no, above the door of the room that calls, or above the bathroom door... then we go there and turn it off.*"

M: "*And what if you could turn off the buzzer from another place that wasn't the room form which the call was made?* "

Caregivers: "*Eh! (laughs) That would be nice!*"

M: "*Where would it be?*"

C1: "*From inside the pocket!*"

C2: "*Absolutely no! Absolutely no! No, no...* "

C3: "*Maybe something that indicates the number of the room...* "

C2: "*... No, absolutely no! Because, what do you do? You turn it off, and then, for sure, you forget to go. No, absolutely no, I think no.*"

C3: "*Ah! You do not forget! Maybe you can turn it off while you are going...* "

C2: "*No no no, within the room, within the room.*"

M: "*So, if there was the possibility of turning it off from the pocket, you...* "

C2: "*At least, the light above the room door must remain on. Otherwise, no, no and no. Absolutely no. You have to turn the light off from the room because like this you assist the people effectively.*"

C3: "*So, a solution that leaves the lights on, is OK.*"

C2: "*Mmm but not even like this, because you would have to look up continuously... I think it is not a good idea. And what if the lights turn on, and you don't see them because you are elsewhere? No, I think no.*"

C4: "*It could be something that allows you to turn the buzzer off from the distance, and that shows you in a display the room number*" (from which the call comes).

C2: "*Yes, but after a while, if no one has gone to assist the person that called, it* (the buzzer) *must start playing again, because you have to go to assist the person!*"

C1: "*I agree, you have to go, off course. But there are situations in which it would be very useful to have something to turn the buzzer off from the distance... for example, if you are with Daniele* (a large inhabitant that cannot move his body.) *and the buzzer sounds very hard, and is annoying everyone, you are busy and cannot attend immediately, it is enough that the buzzer makes noise for 1 minute and then goes off!* "

C2: "*Yes, yes. In that case, yes.*"

Although there are many inconveniences produced by the loud noise of the buzzer and the sometimes impractical usage associated with it, caregivers fear that the implementation of new systems that may relieve them from these nuisances, could negatively impact the quality and efficiency of the assistance that they provide to the RAF inhabitants. In particular, as expressed strongly by caregiver C2 in the dialogue reported previously, there is a fear of increasing the number of missed calls by having the possibility of turning the buzzer off remotely because it could lead the caregivers to more easily forget the call requests from the inhabitants.

By contrast, in the case of RAF inhabitants suffering from epilepsy (a condition shared by some people with mental disabilities housed on RAF1 and RAF3), it is not possible to call for assistance in the middle of a seizure. In other words, in such cases the caregivers have to draw their attention to the RAF inhabitants without any explicit request. Therefore, caregivers need to constantly run ward rounds to check the inhabitants, especially overnight when they are out of sight. Nevertheless, it was found that running ward rounds is not enough to ensure an optimal level of assistance during a seizure, because inhabitants could suffer seizures between rounds and in such a case they could not be assisted on time. This finding is consistent with other studies that state that running ward rounds could be greatly improved, e.g., with the adoption of a wearable support system, as the one shown in [8].

Even if this remains an open problem, some workarounds have been adopted by the caregivers of RAF3: a baby monitor can be used to try to look after the inhabitants with higher risk of seizure. If they hear something "suspicious" they go and check. In general, they prefer a false alarm than missing a potentially hazardous situation.

The discussion between four caregivers (C1, C2, C3 and C4) of RAF3 and the researcher (M) about how to draw the caregiver attention without an explicit call, as in the case of an overnight epileptic seizure is described below:

C1: "*Maybe a night video surveillance system in the people* (the inhabitants of RAF3) *rooms, could be useful!*"

C2, C3: "*No, no. It is not possible... for privacy issues.*"

C1: "*But it is for monitoring the seizures!*"

(General discussion)

C1: "*It is intended just for internal use... because there are some people that can suffer an epileptic seizure and we* (the caregivers) *don't realize it because we are elsewhere... so we need something that supports us!*"

M: "*But you run ward rounds, like in the hospitals, to check them?*"

C2: "*Yes, but we are not always watching, also because there are some of them that close the door.*"

C3: "*Something that indicates us that they* (the inhabitants of the RAF) *are getting off the bed, would be useful. Then you go and check and maybe everything is OK, but at least you have gone and checked.*"

C4: "*But it is not enough... there are some that have had seizures on the bed and not even the baby monitor is good then.*"

C2: "*It is true, sometimes with the baby monitor you hear nothing... if everything is very quiet you also go and check!*"

C3: "*We need a system that knows when someone is having a seizure and send us an SMS or some kind of signal for us to go and check what is happening.*"

C4: "*Yes, but the seizures are not all the same.*"

C1: "*But it only has to indicate us to go and check, it doesn't have to assess the seizures.*"

It can be argued that caregivers do not mind to respond to false alarms produced by a healthcare support system if such a system supports them in the difficult task of monitoring the RAF inhabitants while they are out of sight. This means that caregivers would prefer to have a system with false positives that points their attention to "suspicious" situations in which something may be happening, rather than having no support at all.

Implications. The implications of the findings reported above are straightforward and are summarized by design guidelines DG4 to DG6 in Table 4; nevertheless they are at the same time very significant. First, caregivers do need a healthcare support system that helps them to monitor the RAF inhabitants when they are out of sight. Such a system should be able to recognize when some hazardous situation is taking place and then notify the caregivers. It is important to point out that the accuracy of the system is not crucial and that the caregivers would accept to check on false alarms as they are used to do now with the solutions that have implemented, e.g., the baby monitor. This point also emerged as one of the needs (the need of *Alerts* under the *Delivery of Data* theme) in elder care assistive homes in the study [18] conducted by Zulas et al.

Regarding the RAF2 buzzer and the possible solutions on how to call the caregivers attention effectively, the alternative of having something that allows the inhabitants to call the caregivers personally, i.e., to call them directly without making any noise for other people in the facility, was welcomed by all caregivers. This is in good match with the third recommendation emerging from the focus groups reported in [16], that refers to the development of easy ways to contact the staff for ensuring the quality of care.

However, the way to turn the request off, once it has been received, has to be further explored. For now, it is clear that the turning off mechanism must ensure that the inhabitant that calls, gets attended. This means that a healthcare support system must verify whether caregivers attend the person who is calling after they turn a call off, in such a way the request call persists until proper assistance is provided.

4.4 Relieve caregiver loneliness in hazardous situations

Research Finding. Caregivers work in pairs during the day, but overnight only one caregiver is present in the assisted living facility. The reason for this is that during the day there are more activities to be carried out and the inhabitants require more attention than during the night, while they are asleep.

However, caregivers fear that something bad could happen to them and no one could help them while they are alone (without a colleague nearby). Caregivers worry for themselves but also for the RAF inhabitants, because if a hazardous situation occurs, the inhabitants could suddenly remain without anyone to assist them.

When the caregivers of RAF1 where asked directly (by the moderator M) about what would happen if a caregiver that is alone has some problems, a group of them (C1, C2, C3) answered like this:

M: "*What happens if a caregiver is alone and suddenly is not OK? What do you do?*"

C1: "*We must always carry around the cordless phone in the pocket, and if it is the case one of the inhabitants can call for help.* "

C2: "*It has never happened... but I think I would call a colleague.*"

C3: "*The problem is if you drop dead in the middle of the night!*"

C1: "*In any case we have a private security and surveillance company that watches the house, if something happens, the guard will notice it... I hope!* "

In addition to this, another fear arose when caregivers of RAF3 were asked the same question. A caregiver from RAF3 put it like this:

"*It is not only the fact that the people* (the RAF inhabitants) *remain without anyone to assist them, for our case it is also the fact that they remain with no one to watch them! The problem is that some of them may escape.*"

Caregivers do not like to think or talk about these possible situations, thus the conversation about the topic was quite short. Nevertheless, it was long enough for the researchers to find out that caregivers will feel safer with some kind of support in such situations, that could occur if something goes wrong and an inhabitant calls for help. The implications that follow from these research findings were used to elicit the DG7 presented in Table 4.

Implications. In the same way that caregivers expressed their desire to have "something" to allow the inhabitants to call them effectively in case of need, a healthcare support system

for assisted living facilities has to provide some mechanisms to support caregivers when they are alone.

At least, a healthcare support system for caregivers has to provide with a convenient way to ask for help in case of need. Even better, it should be able to detect the hazardous situations where is not even possible for a caregiver to call for help, and should call by itself. Design guidelines to address the ALF inhabitants safety match other recommendations about the same topic in similar scenarios (elder care assistive homes) as in the results found in [18].

4.5 Controlling the environment

Research Finding. A common topic across the three focus groups that was discussed when the researcher asked about "special requirements" was the need of better ways to control and operate the RAF building. This topic is summarized in the design guideline DG10 in Table 4. Caregivers pointed out that it is very difficult to control the temperature of the RAF in such a way that everyone is happy. A caregiver from RAF2 said:

> "*It is impossible to have the right temperature for everyone. For people in wheelchairs it is always too cold, but if we rise the temperature you die of heat.*"

From RAF1, a caregiver said that it was not easy to constantly change the temperature because of the mechanism to do it *"is old, difficult to operate and impossible to calibrate in the exact point you desire"*.

Another issue related with the operation of the RAF building is opening and closing doors. In general, all doors are kept locked in RAF1 and RAF3: the kitchen door is locked to avoid that some inhabitants steal food from others (especially, in RAF1 where some inhabitants steal sweets and candies), the infirmary door is locked to keep the inhabitants away from medicines, and the main door is locked to prevent the inhabitants from escaping (this is a very sensitive matter in RAF3, where some of the inhabitants with severe mental disabilities have already tried to escape more than once).

This situation bothers the caregivers that have to carry around a big bundle of keys that is not comfortable, but has become a big problem with regard to the main door. The main door, that gives access to the house, should be closed to prevent the inhabitants to escape, though cannot be locked for safety reasons. For now, the problem has been addressed with some bells that ring when the door is opened and one of the caregivers needs to check who is opening the door.

Implications. Smart Home technology has already been used in contexts similar to the RAFs with success. For example, see the framework described in [9] that assesses cognitive health using Smart Home technology. Nevertheless, there is still room for systems that integrate Smart Home capabilities with the solutions to the other problems encountered and presented in this work. In other words, the smart home capabilities should be one part of a holistic solution capable of meeting all other requirements of assisted living facilities.

5 Conclusions

This paper presented ten guidelines that could enhance the design and implementation of healthcare support systems to aid caregivers in their daily activities, particularly within assisted living facilities for persons with disabilities. These design guidelines were elicited after a comprehensive qualitative analysis of research data collected from three focus groups, conducted with 30 caregivers of ALFs in Northern Italy. The proposed guidelines are presented in Table 4. They constitute a potentially valuable contribution, which could help to fill the gap in the literature about the design principles of systems that support and meet the caregivers' requirements and needs.

The next stage of this work will be to actually design and deploy a healthcare support system following these guidelines, in an assisted living facility similar to the ones visited during the reported study, to further validate the feasibility of their practical implementation, and to assess their usefulness and the resulting overall user acceptance.

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References

1. Acampora, G., Cook, D., Rashidi, P., Vasilakos, A.: A survey on ambient intelligence in healthcare. Proceedings of the IEEE **101**(12), 2470–2494 (2013). DOI 10.1109/JPROC.2013.2262913
2. Adamer, K., Bannach, D., Klug, T., Lukowicz, P., Sbodio, M., Tresman, M., Zinnen, A., Ziegert, T.: Developing a wearable assistant for hospital ward rounds: An experience report. In: C. Floerkemeier, M. Langheinrich, E. Fleisch, F. Mattern, S. Sarma (eds.) The Internet of Things, *Lecture Notes in Computer Science*, vol. 4952, pp. 289–307. Springer Berlin Heidelberg (2008). DOI 10.1007/978-3-540-78731-0_19
3. Altakouri, B., Kortuem, G., Grunerbl, A., Kunze, K., Lukowicz, P.: The benefit of activity recognition for mobile phone based nursing documentation: A wizard-of-oz study. In: Wearable Computers (ISWC), 2010 International Symposium on, pp. 1–4 (2010). DOI 10.1109/ISWC.2010.5665866
4. Anliker, U., Ward, J.A., Lukowicz, P., Troster, G., Dolveck, F., Baer, M., Keita, F., Schenker, E.B., Catarsi, F., Coluccini, L., et al.: Amon: a wearable multiparameter medical monitoring and alert system. Information Technology in Biomedicine, IEEE Transactions on **8**(4), 415–427 (2004)
5. Beeber, A.S., Cohen, L.W., Zimmerman, S., Gwyther, L.P., Washington, T., Cagle, J.G., Reed, D.: Differences in assisted living

Table 4 Design guidelines for systems to support caregivers in ALFs for persons with disabilities.

Number	Design guideline	Description
DG1	*Interfaces for operating in the periphery of caregivers' attention*	A healthcare support system should exploit devices and interfaces that can be operated hands-free and without engaging caregivers' full attention in a stressful manner.
DG2	*System ubiquity*	A healthcare support system should support caregivers through their daily activities, regardless of their location inside the assisted living facility.
DG3	*Portability of devices*	The devices used as part of healthcare support systems should be easily taken around the assisted living facility by the caregivers, without representing a source of discomfort.
DG4	*Unobtrusiveness of the assistance request mechanism*	A healthcare support system should offer to the inhabitants a mechanism for requesting caregivers assistance that does not disturb other people within the assisted living facility.
DG5	*Verification of assistance provision*	A healthcare support system should verify that for each request received from inhabitants of the ALF, the proper assistance is actually provided.
DG6	*Self-direct caregivers' attention to potentially hazardous situations*	A healthcare support system should be able to indicate to the caregivers potentially hazardous situations in which the inhabitants may be involved without any explicit request.
DG7	*Emergency call option for caregivers*	A healthcare support system should allow the caregivers an immediate way to call for help in case of necessity, either manually or automatically.
DG8	*In situ form filling*	A healthcare support system should allow caregivers to fill notes and forms digitally around the facility, even if not at the end of the shift and in the office, to prevent them from forgetting the information to write in.
DG9	*Effective management of reminders*	A healthcare support system should manage the caregivers' routines and remind them effectively about special events or off plan tasks.
DG10	*Basic smart home capabilities*	A healthcare support system for assisted living facilities should provide the caregivers with home automation capabilities to facilitate the management and operation of the facility building.

staff perceptions, experiences, and attitudes. Journal of gerontological nursing **40**(1), 41–49 (2014)

6. Bhadoria, S.S., Gupta, H.: A wearable personal healthcare and emergency information based on mobile application. International Journal of Scientific Research in Computer Science and Engineering **1**(4), 24–30 (2013)
7. Borazio, M., Van Laerhoven, K.: Combining wearable and environmental sensing into an unobtrusive tool for long-term sleep studies. In: Proceedings of the 2Nd ACM SIGHIT International Health Informatics Symposium, IHI '12, pp. 71–80. ACM, New York, NY, USA (2012). DOI 10.1145/2110363.2110375
8. Carlsson, V., Klug, T., Ziegert, T., Zinnen, A.: Wearable computers in clinical ward rounds. In: Applied Wearable Computing (IFAWC), 2006 3rd International Forum on, pp. 1–9. VDE (2006)
9. Dawadi, P.N., Cook, D.J., Schmitter-Edgecombe, M., Parsey, C.: Automated assessment of cognitive health using smart home technologies. Technology Health Care (2013)
10. Gibbs, A.: Focus groups: Social research update. Retrieved June **8**, 2007 (1997)
11. Kitzinger, J.: The methodology of focus groups: the importance of interaction between research participants. Sociology of Health & Illness **16**(1), 103–121 (1994). DOI 10.1111/1467-9566.ep11347023
12. Lau, S.L., Konig, I., David, K., Parandian, B., Carius-Dussel, C., Schultz, M.: Supporting patient monitoring using activity recognition with a smartphone. In: Wireless Communication Systems (ISWCS), 2010 7th International Symposium on, pp. 810–814 (2010). DOI 10.1109/ISWCS.2010.5624490
13. Lukowicz, P., Junker, H., Stäger, M., Büren, T.v., Tröster, G.: Wearnet: A distributed multi-sensor system for context aware wearables. In: Proceedings of the 4th International Conference on Ubiquitous Computing, UbiComp '02, pp. 361–370. Springer-Verlag, London, UK, UK (2002)
14. Mayora, O., Arnrich, B., Bardram, J., Drager, C., Finke, A., Frost, M., Giordano, S., Gravenhorst, F., Grunerbl, A., Raring, C., Raux, R., Lukowicz, P., Muaremi, A., Mudda, S., Ohler, S., Puiatti, A., Reichwaldt, N., Scharnweber, C., Troester, G., Vedel Kessing, L., Wurzer, G.: Personal health systems for bipolar disorder anecdotes, challenges and lessons learnt from monarca project. In: Per-

vasive Computing Technologies for Healthcare (PervasiveHealth), 2013 7th International Conference on, pp. 424–429 (2013)
15. Morris, M., Lundell, J., Dishman, E., Needham, B.: New perspectives on ubiquitous computing from ethnographic study of elders with cognitive decline. In: A. Dey, A. Schmidt, J. McCarthy (eds.) UbiComp 2003: Ubiquitous Computing, *Lecture Notes in Computer Science*, vol. 2864, pp. 227–242. Springer Berlin Heidelberg (2003). DOI 10.1007/978-3-540-39653-6_18
16. Morrison, E.H., George, V., Mosqueda, L.: Primary care for adults with physical disabilities: perceptions from consumer and provider focus groups. Family medicine **40**(9), 645–651 (2008)
17. Sanchez, D., Tentori, M., Favela, J.: Activity recognition for the smart hospital. Intelligent Systems, IEEE **23**(2), 50–57 (2008). DOI 10.1109/MIS.2008.18
18. Zulas, A.L., Crandall, A.S., Schmitter-Edgecombe, M., Cook, D.J.: Caregiver needs from elder care assistive smart homes: Nursing assessment. Proceedings of the Human Factors and Ergonomics Society Annual Meeting **56**(1), 125–129 (2012). DOI 10.1177/1071181312561003