Design Considerations for Volunteer Support in Dementia Care

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ABSTRACT

Volunteers at nursing homes are particularly challenged when interacting with residents who have dementia. Unlike primary caregivers, they often lack sufficient familiarity with the unique needs of the individual with dementia and demonstrate low proficiency in responding to their needs. Many studies have addressed needs of dementia caregivers, but they have almost exclusively focused on primary caregivers who have the advantage of previous experience. In this study, we observed and interviewed 12 first-time volunteers to understand the experience and information needs of non-familial, inexpert caregivers. Thematic analysis identified three main themes: volunteers want support in attaining a mutuality of identity, a sense of achievement and an understanding of the unique needs of each resident. We conclude with implications of these findings for the design of systems to support volunteers as non-primary caregivers.

Author Keywords

Dementia, burden of care, volunteers, volunteering, caregivers, primary, non-primary, devices.

ACM Classification Keywords

H.5.2 User Interfaces: User-centered design; H.5.m Miscellaneous

INTRODUCTION

Volunteers are a long known resource of care homes [7]. They are much valued because they can help reduce the burden of care by offering important additional services. Examples of such services are feeding for frail elderly [24], walking [11] and providing engagement activities [32] for care home residents. To be able to do such tasks with residents who have dementia, volunteers must first overcome lower levels of familiarity and proficiency. However, volunteers often struggle to determine the unique needs of each individual with dementia. As non-experts

with little training and experience, volunteers also have difficulty knowing what to do and how to respond to people with cognitive impairments [6]. Proficiency can be improved with exposure and training, but familiarity with the unique resident's personality and needs is endemic to new interactions. Table 1 provides a general summation of the information gaps that volunteers have when interacting with people with dementia.

	First-time Volunteers	Repeated Volunteers	Primary Caregivers (eg. family, nurse)
Familiarity with the Resident	✘	✘ (when new)	✔
Proficiency with Dementia	Lower	Higher	Highest

Table 1 Types of expertise among volunteers

The usual response to this challenge among new caregivers is to supply training for volunteers, and increasingly, to support profiling of persons with dementia.

However, training represents a large resource commitment, both on the part of the home that hosts the volunteers, and on the part of the volunteer. It can take as many as 30 hours [14] and is a burden to care homes who are already under-staffed and need the help of volunteers in the first place [7,30]. The time commitment to train can also be a barrier, with some studies reporting high attrition rates [25] and volunteers complaining about the length [4] and boredom[6] of the training. In Singapore, where our research is conducted, the situation is exacerbated by low rates of volunteerism. The reported rate for Singapore was 15%, which is much lower than the 24% reported in Hong Kong, a country similar in citizen composition and development [37]. According to the National Volunteering survey [37], more people are volunteering, but due to work and family commitments, volunteers are moving away from working within a program toward more opportunistic, flexible volunteering. The emerging picture in this country is of a relatively small pool of volunteers who are willing to contribute but available only on an inconsistent basis.

In order to find a design response to this difficult state of affairs, we undertook a qualitative study of volunteers and volunteering activity at a nursing home. We observed and interviewed first-time volunteers visiting residents with dementia. The goal was to discover the information needs, the challenges, and the coping mechanisms volunteers may have in interacting with older, impaired adults in order

discover opportunities for design. It is well established that the presence of a mediating device such as an activity, a video or a custom-designed interactive system has been known to promote interpersonal interaction [10,12] and act as a focal device [1]. Hence, in this study we wanted to further explore how volunteers may use these devices to engage and interact with older adults with dementia.

The key findings of the study are that volunteers tend to search for ways to understand the personality of the individual they are meeting, in order to find commonality and empathy with the resident. We also found that volunteers placed emphasis on their sense of achievement during their interactions, and linked these achievements with their knowledge of the specific, unique needs of each resident. The need for achievement is not emphasized in other volunteer studies in other countries [6,9] and may be linked to findings regarding quality of care as a source of caregiver burden among East Asian populations [20,27]. Finally, we found that volunteers used a device during a volunteer interaction as a ready supply of alternative activities to engage and interest the resident. Taken together, these findings point to new opportunities in profiling and device development towards the support of volunteers in dementia care.

Our findings have the following contributions to the field of research in technology-supported dementia care:

- Implications for design of profiling systems, with new directions on the type of information volunteers need when interacting people with dementia
- Design implications for in-visit support systems that address volunteer activity needs

RELATED WORK

Personhood in Dementia Profiling
The goal of creating profiles of persons with dementia can be seen as the support of *personhood*. Person-centered care [15] emphasizes the importance of taking into account the needs of the patient as a *person*, and not just focusing on the biophysical effects of the disease. In Kitwood's seminal work on person-centered care [15], he defines personhood as 'a standing or a status that is bestowed on one human being, by another in the context of relationship and social being' (p.8). In dementia, communication abilities may be lost, but personhood and dignity can be maintained via the relationships and interactions with other people. Within person-centered care therefore, the personal and social identity of a person with dementia arises out of what is said and done with them. Unfortunately the impairments of the disease gradually erode the ability of the individual to represent themselves as people.

HCI research to support the negotiation of personhood has taken on many forms. *CIRCA* [8] and *What Remains?* [3] were conversation support systems for family and care staff, Hanson et al. [35] and Maiden et al. [21] proposed holistic health records for hospital caregivers in order to support the caregiving in delivering person-centered care. Wallace et al. [34] collaborated with family and the person with dementia to design wearable art as expressions of selfhood.

While these studies offer important information about compensating for cognitive impairments in conversation, the main interaction partners were all people who either have expertise with dementia care (formal caregivers) or pre-existing knowledge of the senior with dementia (informal caregivers, usually relatives).

The research gap lies in the underlying advantage that experienced caregivers have when communicating with or interpreting non-verbal communications from people with dementia. The differentiating issue between primary and non-primary caregivers is that primary caregivers, with the benefit of history and experience with the disease, are more able to compensate for the impairments of the individual. The absence of such information as a background to care was brought to the fore in a Swedish program where volunteers were trained together with family caregivers. According to the volunteers, one of the key benefits and sources of satisfaction with the program was knowledge transfer regarding the particular needs and interests of the person with dementia [13]. A similar finding was reported in a Portuguese program. Particularly during initial visits, volunteers wanted to know more about the abilities, skills, interests, routines and preferences of the person with dementia [9]. A Canadian study on volunteers in a friendly visiting program had volunteers requesting for medical background information [6]. None of these needs have been documented with work involving primary caregivers.

When volunteers need more information, issues of balancing privacy and benefit come to the fore. To make such decisions, researchers need to understand better what volunteers use the information for, and how it improves the interaction with the resident who has dementia.

Volunteer Training
In HCI studies, there has been an increase in work to support caregivers, but again, these have been focused on primary caregivers, both professional and informal.

In social work studies, studies on volunteer training has often focused on the question of *content*: empathy [25], education [4] and behavioral adjustment for volunteers. However it is difficult to reconcile such training needs with training commitment. Some programs can take as many as 30 hours [14] and is a burden to care homes who are already under-staffed and need the help of volunteers in the first place [7,30]. The result is often high rates of attrition [16,25] and volunteers complaining about the length [4] and boredom[6] of the training.

Given the Singapore context of low volunteerism and low commitment to programs, a key question becomes the

delivery of training, rather than the content of the training. How can volunteers be trained more efficiently while avoiding further burden on nursing homes? How can they gain the skills needed to fulfill their duties in a shorter time period?

OBSERVATIONAL STUDY

We began our research with the primary author volunteering with a nursing home. The goal of this preliminary research was to gain understanding of the on-the-ground realities of volunteering in a nursing home. During this 6-month period, the author participated in various volunteer activities, and spoke with care staff and administrators within the care home and therapists outside the care home who specialize in community care. We report on these findings with regard to factors that influence profiling practices, and volunteer training.

The nursing home is a 250-bed, means-tested nursing home in Singapore. At the time of study, the majority (95%) of the residents were long-term residents. Ethnically, the residents are a mix of Chinese, Indian and Eurasian descent, and speak a variety of languages such as Mandarin, Hakka, English and Malay. The age distribution was 35 to 102 with 60% female, which is reflective of the nursing home population in this country [36].

Factors that Affect Volunteering

The home receives approximately 40 single-visit volunteers a month, mostly from varying corporate social responsibility programs and youth service learning programs. These volunteers engage in various programs such as games (digital and traditional), performances, and reminiscence sessions with the residents of the home. In addition they have up to 20 long-term volunteers who contribute their services on a weekly or monthly basis, doing instrumental activities such as hair cutting, gardening, or conducting bingo sessions. The home does not collect data on these visitors, but they characterize their volunteers as being mostly youth and adult volunteers, with an estimated age range of 11-67 years old. This pool of volunteers is constantly shifting in number and abilities since volunteer return is not guaranteed. The home's Volunteer Coordinator explained, "*A regular commitment over a year is extremely difficult to negotiate with our partner schools. They have their own schedules too, so we just accept when we can, and try to request for help from them when we need it.*"

Hence, the home experiences volunteers as an unstable resource, highly variable in supply and composition. It is difficult to recruit volunteers for a casual commitment, much less enroll them into a training program. Training is an important component of increasing the proficiency of these volunteers, but there is a need to innovate the way the training is delivered.

Factors that Affect Profiling

In Singapore, it is an act of filial piety to keep care for the elderly in the home [29]. The majority of elderly are cared for at home [23], usually with the aid of foreign domestic workers, if the family has the means to pay for such help.

Therefore, admission to a long-term care facility is often preceded by pressing conditions, of a social, emotional and financial nature [29]. An occupational therapist in our partner home described an oft-observed situation: "*Very often, our residents are here due to a limited psychosocial support network – they are estranged from family, have less supportive children, and previously led an isolated lifestyle.*" In other words, there is often a lack of a willing and able family caregiver. The word 'abandoned' would not be an exaggeration in describing the social context of many of the residents. In our later experience of recruiting our resident participants, we often waited for more than two weeks for guardians to respond to informed consent requests, despite repeated calls and emails from the home.

The effect of this estrangement is the loss of a source of holistic, biographical information about residents who have dementia. Care workers wishing to know more about the background of residents often have no recourse in family informants. In effect, for many cases, identities need to be constructed anew upon entering the nursing home. For persons with dementia who often forget details about who they are, this would likely prove to be an even more challenging task.

We spoke to a community care therapist about the elicitation and retention of such holistic and biographical records, and we were told that such data rarely exists. Even when holistic profiles were created at some point, they may not transfer with medical records, due to differences in record keeping formats and procedures between care agencies. In her words, "*Sometimes, no one even asks for the holistic profile.*"

Additional pressures on shared knowledge of the resident are high care staff turnover rates, something that is shared in the rest of the world [30]. In the 6 volunteering months at the home, there were approximately "5 staff departures out of a total of 70 staff. Due to the lack of non-medical record keeping, whatever gathered knowledge regarding residents that was not documented would also depart with the staff member.

Summary

In this observational study we found that, as with primary caregivers, there is a need for interventions that promote the presentation of self and negotiation of self for people with dementia. The difference for this context lies with the lack of family informants, making it even more difficult to obtain a source of reliable background information. If personhood is relational and actively constructed, then residents with dementia in nursing homes are doubly disadvantaged in this respect - by the disease and by the

context of social isolation. Volunteers, particularly first timers, represent a third level of disadvantage, caused by the infrequency of contact with residents and lack of knowledge about working with individuals with dementia. Hence, for first-time volunteers at nursing homes, the state of unfamiliarity they find themselves in can be perpetuated by the shortage of systems to collect and maintain holistic profiles of residents. We also identified a need to innovate in the way training is delivered.

VOLUNTEER STUDY: CONVERSATIONS WITH AND WITHOUT DEVICES PRESENT

As with related work on profiling systems (e.g. [22,35], the first study helped us to identify a strong need for ways to support interpersonal interaction via the representation of self. What remains unclear is the nature and depth of the information needed. With primary caregivers, there is minimal concern regarding the violation of patient privacy. However with volunteers, many of whom may be once-off visitors, caution must be exercised to balance the residents' right to privacy with the potential benefits of interaction via the sharing of personal information.

This balancing act of privacy versus sharing indicates a need to study what are the most helpful types of information that a first time volunteer might need, in order to effectively interact with people with dementia. Thus, our study focus moved to a close observation of first-time volunteer visits, and post-visit interviews, in order to uncover what types of shared information boosted interaction with the residents. In addition, we had the additional interest in examining tablets as a possible volunteer resource in the visit scenario.

Method

Participant Recruitment

We recruited residents with a diagnosis of dementia. No other inclusion criteria were specified, but the home's therapist explained to us that she selected residents who were relatively social and relatively open to participating in activities.

Visitor volunteers were recruited from college students in a service-learning program. Volunteers were matched to the residents based language match. The therapist advised us that, based on her experience on how residents respond, we should also cross-gender match to improve the likelihood of a good interaction. During recruitment, volunteers were informed that the purpose of the visit was to study "interactions with people living with dementia". All volunteers were first time visitors to a nursing home (n=12, 50% Male, Age Mean=18.6, SD=0.86).

Volunteers were compensated for their travel expenses. Residents were compensated with a grocery voucher equivalent to approximately USD 15.

Visit Conditions

In order to generate meaningful comparisons, we structured the visit conditions. There were three visit conditions -

V	Age/ Gender	Object	R	Resident Characteristics & Communication Difficulties
1	20/F	None	A	72/M, AMT 8/10 (mild), English, with some minor speech difficulties
2	18/F	iPad	A	
3	19/F	Robot	A	
4	18/F	None	B	59/M, AMT 4/10 (severe), English, Mandarin and Hokkien, difficulty constructing sentences
5	19/F	iPad	B	
6	18/F	Robot	B	
7	20/M	None	C	74/F, AMT 3/10 (severe), Hokkien and Malay, minor speech difficulties
8	19/M	iPad	C	
9	19/M	Robot	C	
10	18/M	None	D	91/F, AMT 3/10 (severe), English, extreme forgetfulness (repeated questions and topics)
11	17/M	iPad	D	
12	19/M	Robot	D	

Table 2 List of Volunteers (V) indicated with numbers and Residents (R) indicated with letters

with nothing, with an iPad, or with an interactive pet robot, as listed in Table 2. This was done to permit comparisons of the visits with a device present, versus visits without a device present. Having more than one interactive device would allow us to draw insights based on the particular affordances of the device, and not just on the presence of an interactive object. To avoid introducing too much variability, the iPad was loaded with just one app - a pet game that depicted an interactive cat, with functions set to approximate those of the robot (Figure 1).

Each resident met three different volunteers over two weekends, in the order presented in Table 2. We chose this study design to reflect the transient, once-off nature of a majority of volunteers that we had observed earlier. Volunteers were instructed to visit for up to 30 minutes, or earlier if they felt that the session should end.

Those with devices were asked to 'introduce the cat app/robot pet' to the resident. They were given approximately 10 minutes to familiarize themselves with the device before being introduced to the residents, and then

Figure 1 Showing affordances of the pet robot (top row) and the pet app (bottom row) with responses to tickling, hitting/tapping and stroking

The pair was left alone up to 30 minutes. We video recorded each session. Visits took place in groups of 2 or 3 pairs in a sitting room on the nursing home premises.

Interview Format

From the preliminary observations of school-aged volunteers, we decided it was important to moderate the demand characteristics of the interview. The first barrier to speaking honestly was the implied rudeness when giving an opinion about another person. Secondly, Asian values teach that the elderly must be respected. To reduce the effects of these impediments to frankness, we did not conduct the interview ourselves, as our older appearance and position of authority might cause them to fear being offensive and be less open about their attitudes.

Therefore, we deployed our student research assistants (4) who were within the same age group. They were trained in the interview method by the lead author, with two opportunities to practice on each other prior to the actual session. The research assistants were supplied with open-ended interview questions and the interview was audio-recorded for later review by the research team. In addition, the interview questions included three ways of asking for the volunteers' more fraught opinions - what did they *dislike,* what did they find *unusual,* and what would they *change* in the future.

Resident Questionnaire

We asked the residents three questions: We wanted to know if they enjoyed visit, if they had enjoyed the current visit, and if they liked computers. We also spoke to them post-session to understand their feelings about the session.

THEMATIC ANALYSIS RESULTS

A thematic analysis of interview data [2] was chosen for the exploration of difficulties of first-time visitors, coping methods, and identification of key informational needs of new volunteers. Thematic analysis is defined as a means of "identifying, analyzing and reporting" (p.79) trends within a data set. The two authors transcribed the audio recordings verbatim. The text was then read and coded separately before finalizing the codes together.

Each code consisted of a quote, or interpretation of a quote based on contextual information. Each code was only used once in the process of generating categories. In research meetings, the categories were generated from thematic similarities, and re-grouped into larger themes. To increase robustness of the themes, groups with three or fewer codes, or responses from fewer than three volunteers were dropped from the analysis.

FINDINGS

Our findings are organized in the following manner. We briefly explain the findings from the conversations with residents. Then we go on to report the findings from the volunteers in terms of 1) describing the overall quality of first-time visits, 2) experiences that promoted interaction, and 3) challenges and coping with challenges, and finally

the particular 4) role and function of the devices present when coping. For each section, we address the implications with regard to our research questions about information needs and technological opportunities in the first-visit context.

Residents

Generally, the residents seemed positive about the visitor program, and were not adverse to receiving young visitors. Unfortunately, only Resident A could recall the visit post-fact, so only his feedback is recorded here. In his opinion, having young volunteers visit was generally a good idea, but there was a risk of "arguments". By this, he meant incidents of unintentional offence caused by strangers meeting. The impact of the loss of the resident voice in our analysis is discussed later in this paper.

Volunteers' first-time visit experiences

As expected, even with their peers, the volunteers avoided negative statements about the older adults they visited. However, when asked what they thought of as 'unusual' during the visit, volunteers seemed to share more freely, and expressed a large number of frank opinions.

Behaviors and appearance of residents

Five (Volunteers 1, 4, 10, 11, 12) out of twelve volunteers described certain conversational behaviors as 'unusual'. These were repetition, inconsistent conversation threads and logic breaks.

Volunteers were aware that they were visiting older people with dementia, but their response points to a lack of familiarity with the outward symptoms that are often associated with impaired seniors. This is consistent with a local study on lay persons' lack of awareness of the symptoms of dementia [31].

How much of these perceived anomalies are ameliorated with simple exposure? Volunteer 10 explained that he was at first taken aback by Resident D's repetitive questioning, but that he eventually "got used to it." Volunteer 1 reported being nervous at Resident A's "fierce expression" (unintentionally caused by a rictus), but relaxed when they started conversing. For other volunteers, some issues were not resolved by the end of the session. When asked if she had additional input for the researchers, Volunteer 6 said: "I still have a lot of questions. I want to know why he acts like a child?"

This theme points to the need to prepare volunteers before meeting residents. It indicates that it may not be possible to be completely reliant on in-visit information, but that some of the information needs of to the volunteer must still be delivered before the interaction. However, these may be achievable in a much shorter time period than a full training session.

Positive Unusuals

What volunteers reported as *unusual* also included pleasant surprises. These seemed to be caused by unexpected aspects of the visit. Volunteer 1, 3 and 10 remarked on the lack of a

language barrier (when speaking English). Visitor 12 remarked it was nice to "see elderly as nice and kind as opposed to grumpy and cranky". Also listed as unusual was his perception of the home: "The place is clean and comfortable".

Resident A and D are the more personable residents, even though they are not exceptions among the other residents who have dementia. The volunteers' reactions to their pleasant interactions revealed the existence of pre-conceptions that were skewed toward a less appealing image of nursing home residents, possibly described by the antonyms of *grumpy*, *cranky*, *dirty* and *uncomfortable*.

This finding is consistent with other research showing that the perception of the elderly and nursing homes in this country can be very negative. Historically, nursing homes were known as 'dying houses'. Cultural beliefs of 'bad luck' from these deaths often leads to vocal objections when nursing homes are placed in the housing estates, leading to lowered real estate value [28].

In this context, we can see the *positive unusuals* experience category as examples of breaking of misconceptions about care homes. The ability of a short 30-minute visit to change these damaging preconceptions underscores the importance supporting the first visit.

Interpersonal Interaction Promoting Experiences
Responses to the question of what the volunteers *liked* about the session helped to elaborate the nature of interaction promoting experiences and events. We found two main causes of positive interpersonal interactions.

Surprising Similarities
In a similar vein as the theme of *positive unusuals*, was the realization among these young, college-aged students that they shared similarities with the residents (Volunteer 1, 7 and 11). Volunteer 1 stated that the visit was a good experience because "it shows how the younger and older generation are very similar". When reviewing the video, we saw that this dyad had long discussions about their common religion.

Volunteer 7 arrived at a conclusion of similarity in terms of reciprocity of giving between generations. He characterized Resident C as 'grandmotherly' and said: *Maybe we think they are really different from us, but the intention is the same… they care(d) for us, so it makes me think that maybe we can care more for them.*

Even racial differences seemed less important for one visitor. Volunteer 11 was initially concerned that his resident, an older lady of Chinese descent would reject him, since he was of Indian descent.

At first I was scared. You know la, being Indian and then she's older, they don't always want to talk to us. She was very welcoming. I asked her if she minds and wanted to talk to me, and then she said ok she's fine. After that we talked

about growing up in a kampong (village). I didn't know we could have so much in common.

Research on technology and intimacy places great importance of finding mutuality in boosting relationships [10]. This is particularly true among intergenerational dyads [16]. This finding on mutual identification supporting interaction indicates that the types of information needed to boost interactions may not be private, full-patient records, but rather information where parallels between the residents' background and that of younger volunteers can be drawn, e.g. schools attended, or places lived.

One way to formulate the guiding principle when creating holistic background information is that the purpose of such information should be to link the residents' history with the young volunteers' own experiences. However, this position is challenged by the aforementioned convergence of a high turnover rate of care workers, lack of holistic profiling practices, and a paucity of knowledgeable informants, causing residents with dementia to arrive at the home as effectively blank slates. To this end, a model of profiling similar to Webster & Hanson's work on *Portrait* [35] may be appropriate – any visitor, whether formal or informal – should be permitted to contribute to the development of the profile.

Achievements within the visit
The second source of positive interaction was when volunteers managed to cause the resident to respond. For the volunteers, after feeling their way around, it was an 'Aha!' moment. Volunteer 5 reported feeling triumphant when Resident B "...really answers the questions. Then I know he can understand and wants to speak with me." For Volunteer 5 who felt particularly challenged due to Resident B's muffled speech and restlessness, she found it rewarding when "...he would share his story with me."

When asked to reflect on the session as a whole, Volunteer 7 and 10 reported that they were relieved when their first visit to a nursing home went well. Volunteer 2 struggled to express the emotion as part-relief, part joy, and said that she felt a "sense of achievement" from the session. This sense of performance attainment could have more than one cause.

On the one hand, the finding is germane with research on family caregivers and conversational support via technology, which also reported a sense of satisfaction attained when family members held richer conversations than previously possible with their loved ones [1]. On the other hand, the sense of 'attainment' is an additional, possibly culturally rooted quality. Recently, research on caregiver burden among primary caregivers in Singapore found a unique dimension of worry about caregiving performance [19], and replicated in Chinese data [20]. The authors attribute it to an Asian cultural attitude, where values of obligation to caregiving for older family members are highly influential [19]. Volunteer 7's earlier quote on the reciprocity of care supports this position, as does

Volunteer 8's observation that older adults in general "treat others like family". It should be noted here that all the volunteers observed cultural protocol and addressed the residents as 'Auntie' and 'Uncle', despite the newness of the relationship.

Given this finding, it seems that volunteers require information that quickly results in a sense of performance achievement for the volunteer. This might take the form of 'known to work' activities such as popular reminiscence videos or bingo. Alternatively, suggesting highly individualized activities, that have been previously known to trigger responses in a particular resident may also be of use. This finding argues for profiling systems that collect, store and disseminate not just biographical information, but information about occupations that each individual found to be engaging.

It should be pointed out here that the opposite may also be true with activity preferences – information should also be provided to the volunteer as to what are important areas to *avoid* for a particular resident, so as to reduce the likelihood of disappointment for both parties.

We discuss next the areas of challenge for the volunteers, and examine their coping behaviors in face of a disappointing event during the visit.

Challenges and Coping
Seven out of twelve volunteers reported some sense of initial awkwardness (Volunteers 2, 4, 5, 6, 7, 9, 11 and 12), indicating that there is much to be improved in the current experience. The volunteers report overcoming it by either working harder (Volunteer 5) or finding conversational topics of mutual interest (Volunteers 6, 7, 11 and 12). Finding topics of mutual interest also has a limited utility. When Volunteer 12 ran out of questions to ask Resident D, he again returned to feeling awkward and nervous.

Devices: Interaction *with* and *around*
The findings on the use and role of devices were reserved till last because the previous findings shed light on the way these devices were used.

Effect of the presence of device
Researchers use the term *intersubjectivity* or joint attention to describe the role of the device as point of focus, or a prop during the social interaction [8]. Consistent with previous research on conversation aids among formal caregivers [18,33,35], our volunteers also found that the device acted as a conversation trigger and a thing to do. Triggering conversation also included triggering laughter. Volunteer 2 enjoyed it when: "The cat thingy made us both laugh."

The particular function of focusing the resident was crucial when working with residents who were easily distracted, such as Resident B. In the videos, we observed Resident B scanning the room repeatedly in the no device condition, but seemed much more focused when offered an iPad or the

pet robot. Volunteer 5 was seen repeatedly gesturing to the iPad and guiding the Residents' hand to it.

As much as the presence of a device led to more social interaction, it also could very quickly cast a pall on the tone of the visit, as reported earlier. Resident A rejected the robot early in the session, saying "*This toy is not for me.*" The context of the conversation implied that the soft-toy appearance was for girls, and not for him (a man). Resident B initially said no to the pet robot, stating "*Mother doesn't allow me to touch (animals)*". On the other extreme, Resident D spent most of her session petting and holding the robot close as if it were a pet. In this study, as with others [26], the animaloid form of pet robot led to more extreme and decisive rejections.

In comparison, the rejection of the iPad was less vehement, but had some unusual reasons, that we haven't seen in other literature on the viability of using iPads in dementia care [eg.15,29]. Both Resident B and C disliked that it was made of glass, and felt that it was fragile and therefore not for poking or touching. Resident C explained that she didn't want to touch it because "*If it breaks I don't have the money to pay for it.*" Reflecting on this response, the authors attributed it to this cohort growing up around more fragile glass products, with no experience with toughened glass products that are used in many devices today.

Resident A and D whose background included office work (and therefore monitor screens), were more amenable to using the iPad.

Individuals with dementia often reject objects offered for engagement the reasons for which are not always clear but may be tied to role identification and the facilitators ability to present the activity [5]. This leads us to the next theme, the behavior of the volunteers in coping with rejection.

Coping via device schema and ready recall
On the whole, the volunteers coped better with the rejection of the iPad as opposed to the rejection of the pet robot. Successful copers found ways to talk *around* the features of the device. Volunteer 8 initiated a conversation about the various sizes of tablets and phones. He also talked about how it could be used for various work projects. This slower initiation period helped Resident C eventually start responding and attempting taps on the screen. Volunteer 5 presented the iPad as an instance of something more familiar. For example, she said that it's "*...like a TV, but you press at the screen*". Resident B was the most responsive during this session out of all his other sessions.

In the interview debrief, Volunteer 11 suggested that we should add other app options, because he felt he would have done better if he had had the opportunity to respond more flexibly to what he perceived were Resident D's preferences.

From these accounts of coping with rejection of the device, it seems that the iPad lent itself to volunteers being more

creative and pro-active about finding new ways to engage the resident. Beyond talking directly about the content, some volunteers also talked *around* the apparent features of the device. Volunteers talked about the form of the tablet, the fragility of the glass, the cat in the app as compared to other apps, or different sizes of the tablet and different things that they use tablets for. Some of these conversations helped residents and volunteers find mutual topics of interest. The pet robot also triggered some *talking around* conversations (e.g. pets – farm animals - chickens), but it seemed that the Volunteers had a harder time finding viable related topics. After trying, Volunteer 12 ended his session abruptly, saying: "She (Resident D) doesn't like the toy, so I can't do anything with her."

This pattern of coping led the researchers to speculate that young volunteers have so much previous experience with tablets that they have a ready recall of device schema in various contexts of use. It seems that they have a ready repertoire of conversations and knowledge of the functions of an iPad, which allows them to have, mid-conversation, a more easily available set of alternative interactions and conversation topics.

Volunteer 5's assessment of the session lends credence to our conclusion about mental readiness: *"We need to have the skill…and be familiar with the thing (iPad)…so that we can use it as a kind of complement."*

On an ending note, we saw that in the videos that even coping by finding alternative aspects of the iPad was quite quickly exhausted.

IMPLICATIONS FOR DESIGN
We now examine the findings in light of our motivating research questions regarding the type of information needed in profiles, and the need to find new ways to deliver training.

Systems for Volunteer Support
We found that several needs of the volunteers with regard to the type of information a profile of residents with dementia might need. The findings point to new ways to structure the information to support the use of biographical or profile data. Specifically, we found that volunteers enjoyed finding way to identify with the residents who were effectively strangers. Mutuality of experience was an important building block of empathy and positive interactions. Volunteers also wanted information about what to avoid with regard to each resident, in order to avoid offence or doing something wrong.

Taken together, these findings point to a highly dynamic profiling system, one that has affordances for the collection, and sharing of personhood information about the individual with dementia. Future profiling may need to have features that help volunteers inform other volunteers of what worked with each resident, thus building a repository of valuable information about interacting with each resident. Such information contains elements of lived experience,

indicating that the source of the information should ideally be from the persons who experienced the value of that information. In a sense, there is a potential here for crowdsourcing resident profiles in the absence of other sources. Unfortunately, this also implies extensive data input and collection. Consequently, the design of profiling systems should also find ways to connect automated data collection in supporting holistic, lived experience reporting.

The volunteering context, one where volunteers are often transient and inconstant in supply, implies that current training delivery systems are not viable. It argues instead that as much as possible, volunteers should be supported in-visit, with optional deeper training provided external to the visit.

The findings suggest that the content of the in-visit support should be to promote knowing what to do, and when to do it. Volunteers needed a ready repertoire of activities, one preferably already customized to the needs of the resident with dementia. In effect, there is a need to support an efficient transfer of expertise, where volunteers are guided in-visit rather than pre-trained to proficiency. The coping patterns of volunteers, particularly when faced with device rejection or lack of familiarity, showed us that having ready alternatives was useful. In addition, volunteers suggested to us that we should add other options, indicating that supplying a series of options to cater to varied resident interests would also increase their ability to cope.

Design Features of the In-Visit Support
If some variant of an expert system is needed in this context, then what can we derive from this study regarding the design features that this expert system should have?

The finding of note was that the tablet device and its attendant functions seemed to lend itself to better *coping* by the volunteers. They found more ways to interact with the resident when there was a device present that they were better acquainted with. The value of the tablet was not just in the functions it afforded, but in the volunteers' own familiarity with its possibilities and schema as a tool. Thus, we conclude that among inexpert caregivers the use of a familiar device may *in itself* be a positive force toward volunteer efficacy.

However, when discussing this idea of tablet-supported volunteer activities with the nursing home staff, the occupational therapist expressed concern that it would not be used by non-English literate users, and by those who are not comfortable using such devices. As we saw with the robot, volunteers who have no experience with tablets may find it a burden, causing them to assess the session negatively. Therefore, while innovation is important, researchers may need to exercise caution when developing too novel interfaces or too novel interactions for caregivers who already have multiple responsibilities in-session.

Limitations

The limitations of these findings are associated with the features of a qualitative, single-center study. The size of the sample studied and the siting in urban Asia limits the generalizability of study to urban, possibly Asian contexts only. Unfortunately, due to their impairments, the residents' voice could not be better incorporated into the findings. The sum result is that the implications for design have not yet accounted for the residents' wants.

CONCLUSION

The care center observation and volunteer interview study provided new design implications on the challenges of that volunteers face when visiting people with dementia. We identified that for profiling systems, opportunities exist for volunteer-shared data that enables sharing between volunteers, and for information that enables empathy and finding mutuality of experience with the nursing home resident.

Devices that are present during interactions with people with dementia represent an opportunity not just for supporting interactions as with previous research, but supporting in-visit expertise development for the volunteer. However, we also found that device novelty in this context should be approached with caution, since this may result in negative outcomes for the volunteer. Instead, the findings indicate that innovations to support in-visit training and profiling should take place via technologies that volunteers are already comfortable using.

Our future work will focus on the development of such systems towards the improvement of the in-visit volunteer experience. Such work will represent a step toward improving the quality of care for residents of nursing homes with dementia.

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