

# Harvesting Caregiving Knowledge: Design Considerations for Integrating Volunteer Input in Dementia Care

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## ABSTRACT

Improving volunteer performance leads to better caregiving in dementia care settings. However, caregiving knowledge systems have been focused on eliciting and sharing expert, primary caregiver knowledge, rather than volunteer-provided knowledge. Through the use of an experience prototype, we explored the content of volunteer caregiver knowledge and identified ways in which such non-expert knowledge can be useful to dementia care. By using lay language, sharing information specific to the client and collaboratively finding strategies for interaction, volunteers were able to boost the effectiveness of future volunteers. Therapists who reviewed the content affirmed the reliability of volunteer caregiver knowledge and placed value on its recency, variety and its ability to help bridge language and professional barriers. We discuss how future systems designed for eliciting and sharing volunteer caregiver knowledge can be used to promote better dementia care.

## Author Keywords

caregiving; volunteers; dementia care; health

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

## INTRODUCTION

Volunteers at dementia care centres are important additions to the care workforce. Dementia care centres have often mobilized volunteers to offer various assistive roles: at mealtimes [26], for structured engagement activities [6,20] and elder-sitting [23]. Residents with dementia (henceforth, “clients”) also benefit from the increased social interaction [19]. However, unlike primary caregivers, volunteers have neither the benefit of domain expertise (care staff) or familiarity via shared history (family members) that informs caregiving practice [13].

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Training can help address some of these challenges, as seen in community healthcare work [10,36]. However, these methods require a commitment to training that is difficult to achieve, as volunteers are increasingly transient. Volunteer data trends in more than one country show that they prefer ad hoc, sporadic engagement [3,15,37,38], which reduces commitment to volunteer training programs and retention of trained volunteers [30]. Increased volunteer turnover rates also raise the burden of training programs, because they pose an additional workload to the staff at care centres [12].

It is therefore important to ask how interactive systems can help volunteers to gain the knowledge they need to work with dementia care recipients, while minimizing the additional burden to care centre staff. Systems currently exist to motivate community health volunteers [10], and support their communication with experts [29]. Our focus is different: We investigate the extent to which volunteers can learn from other volunteers, thus reducing expert caregiver involvement.

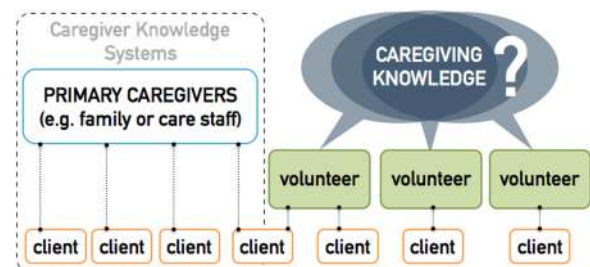


Figure 1: What are the design considerations for eliciting and sharing volunteer caregivers' knowledge?

The literature provides insufficient evidence about whether insight from inexperienced, unfamiliar caregivers is valuable. Previous research on supporting volunteers has focused on what information volunteers *need*, with less attention to what volunteers can *contribute* to caregiving knowledge. Volunteers certainly are expected to gain some caregiving knowledge after each interaction with clients. However, due to the volunteers' increasingly transient nature and the lack of systems to support elicitation, such knowledge is often lost. Studies show that the sharing of caregiver-provided knowledge can improve engagement outcomes for clients [14, 24], and reduce caregiver burden,

both for family [14] and care staff [34]. However, these studies on caregiver knowledge have typically supported the transfer of informed knowledge between *primary* caregivers of people with dementia. Hence, our research question is: **How can we elicit useful information from transient volunteers in dementia care so that future volunteers can interact more effectively with clients?** (Fig.1).

In this study, we investigated what we call ‘care messages’ - messages written by current volunteers - which are intended to help future volunteers to more successfully interact with each client. Using an experience prototype, we conducted a field study with existing volunteers in a long-term care home. We evaluated whether the information passed in these care messages could improve future volunteer effectiveness, and collected therapists’ perspectives on the content of care messages to understand its value in the greater caregiving context. We qualitatively analyzed the content of these messages, and used this analysis to identify design implications for future systems that elicit volunteer-provided knowledge.

The contributions of this paper are:

1. A field investigation into the effects of having dementia care volunteers share care messages about clients to help future volunteers.
2. Quantitative evidence that future volunteers find these messages containing client-specific information useful, and that access to these messages leads to better client engagement. We provide evidence that even therapists can gain useful information from volunteers' care messages.
3. Qualitative analysis that yields a first description of the structure of information that volunteers share and why this information is useful.
4. Implications for the design of systems that elicit volunteer knowledge in dementia care.

## RELATED WORK

Below we review the current state of research on volunteers in dementia care (within the broader context of eldercare), and the observed benefits of existing interventions that use primary caregiver knowledge. We also examine lessons learnt from supporting caregiver knowledge in healthcare more generally.

### Volunteers in Dementia Care

Volunteers face many challenges in dementia care, and researchers looking at their information needs have documented requests for “readily accessible quality information”, ongoing support during and after visits, and access to clients’ medical and personal information “to enhance the visits and their interaction” with the clients [9]. Volunteers’ concerns include the fear of not performing well, particularly because they do not know what might offend the clients, or what their clients’ needs or preferences are [13,17,22,31].

Such information needs can be partially met by supplying dementia care material [6,11], training for reality orientation [30] and activity speed adjustment [23]. While training and training manuals have been listed as important in more than one study (e.g. [6,11]), volunteers still expressed additional requests for information via social interaction channels. In an interview study of volunteers, Damianakis et al. highlighted requests for additional “guidance from a volunteer coordinator” (p.352, [9]). Guerra et al. identified that volunteers had “a need to share experiences” with family members pre- and post-visit, to absorb knowledge via interactions with primary caregivers before performing their volunteering duties, and to communicate with other volunteers as they believed it would help to improve the quality of the interaction with the client [17]. However, such shared information from inexperienced volunteers has not yet been validated as effective in improving care.

Furthermore, this request for increased social interaction must be balanced against volunteers’ limited ability to attend training. Studies of training programmes report high attrition rates [6,30], and volunteers complain about the “heavy workload” of a programme (12 weeks in [6]), so it seems problematic to include more meetings. Furthermore, managing training requires time and resource investment from already burdened care centres [12].

The effort to gather volunteer knowledge may be worthwhile, since even family caregivers who lack formal training have knowledge that can support dementia care. Such knowledge is gained from simply having shared history, and is valuable for supplying client-specific psychogenic information such as biographical anecdotes [8], preferences and information about interests [14,34]. However, there is little work on non-kin caregivers as a source of information. This approach was only incidentally mentioned in one study for interactive art, as one of many potential contributors to content for the system [33]. Another study proposed indirect caregiving via “friendsourcing”, using a private social network of close friends to tag photos for reminiscence material [27].

### Supporting Care Coordination in Healthcare

Since past research has made a call to coordinate and share experiences, one design response is to create online information sharing platforms to support asynchronous collaboration. In healthcare, the closest correlates for such sharing systems are those that support care coordination and communication for care recipients who cannot reliably self-represent, such as children. Amir et al. [1] present an implementation case that incorporated input from non-expert groups such as family members. They conducted an extensive study of creating and managing children’s care plans over a long period of time. The researchers identified barriers that were a mix of domains, namely information systems (the lack of a common platform), economic (fragmentation of the current healthcare system), and

organizational (lack of consistent policies across organizations for information sharing). Our key learning point here is that while designing common platforms are a start, it is also important to study how the proposed platform might fit into the larger context of care.

**OVERVIEW**

The purpose of the current research is to closely study the value of volunteer caregiver knowledge and an examination of how it may non-trivially contribute to the larger multi-expertise caregiving context. We want to describe and characterize the value of volunteer caregiver knowledge towards the potential goal of building online platforms to support the collection and sharing of such knowledge.

In the remainder of the paper, we first explain the care messages activity and how volunteers engaged in it. Table 1 shows the three sources of evidence we evaluate about the value of care messages: 1) quantitative results about how volunteers perceived and used the care messages, 2) qualitative analysis of the care messages to reveal what information was shared, and 3) therapist perspectives on the content of volunteers' messages. We then close with discussion and design considerations.



**Figure 2: Care messages were collected and shared between 3 volunteer rounds. Volunteer R2 received 2 messages, from R0 and R1.**

Evidence	Method
<b>Volunteer Ratings of Perceived Usefulness of Messages</b>	Quantitative: 5-point Likert Scale 1. The information in this message is <b>similar</b> to your own experience with this client. 2. How <b>useful</b> is the information in this message for you to engage care home residents with dementia? 3. How <b>important</b> was the information in this message for you to engage care home residents with dementia?
<b>Client Engagement during Visits</b>	Quantitative: Volunteer ratings of client's active and passive engagement using MPES, a behaviour observation scale.
<b>Content of Care Messages</b>	Qualitative: Thematic analysis to understand what content was useful and how volunteers used it
<b>Therapist Perspectives on Content</b>	Qualitative: Therapists' review of care messages to contextualize the observed values

**Table 1: Mixed methods to closely examine value of care messages to volunteers and to dementia care**

**CARE MESSAGES ACTIVITY**

To study the way a shared platform might elicit and share caregiving knowledge, we prototyped the experience [4] of a basic messaging activity where information was passed between volunteers (Fig.2).

The goal of the Care Messages Activity was to ask volunteers to help the next volunteer by providing the message to the next volunteer. Volunteers were given the instructions to: "Write a message to the next volunteer who interacts with your assigned client, that would help him/her. You can assume that the next volunteer will see all previous text."

Using this approach, we deployed the prototype as a basic web form. The prototype was an application built using the ReactJS and webpack frameworks. Data was stored as JSON objects. Volunteer input was collected after every session and the researchers included the display of the text of previous volunteer-provided messages in between successive rounds of volunteers.

Thus, volunteers in each successive round were able to view the messages from previous volunteers. We have three rounds of volunteers, which we label, R0, R1, and R2, since they benefit from 0, 1, or 2 previous care messages. We chose to use text (rather than video or audio) because in practice, it is likely the most immediately viable communication method as text entry is simple to setup and use, relatively easy to maintain, and quick to review. For each round of volunteers we collected care messages, questionnaire data, and measured the client's engagement in the activity.

**Field Study Context**

Our research partner was a long-term care home with a dementia care unit. One focus of their volunteer workforce is on a therapeutic recreational activity that has each volunteer use tablet game apps to interact with and engage a resident with dementia. Each volunteer might benefit from previous volunteers' experience using these apps with specific residents.

**Client & Volunteer Participants**

We recruited residents with a clinical diagnosis of dementia (clients) with the following inclusion criteria: able to sit up, not on medication that increases sleepiness/drowsiness and having a clinical diagnosis of dementia. In all, 12 participants were recruited. 10 clients (7 female, age mean

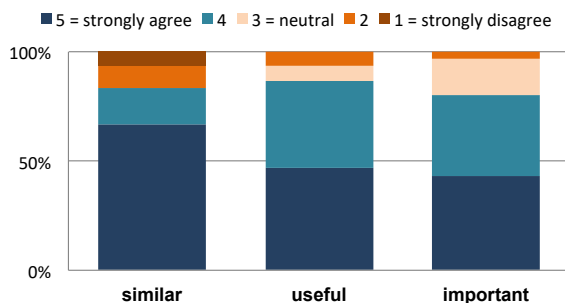
= 86.4, SD = 7.2; MMSE<sup>1</sup> mean = 13.4, SD = 6.4) participated in all three rounds. The remaining 2 were unable to participate due to health reasons.

We recruited 36 volunteers (20 female, age mean = 21.8, SD = 3.6) from volunteer groups, typically consisting of adult and youth volunteers. Since we were comparing volunteer groups between rounds, we did not want to introduce new factors such as age variance, and made the considered decision to focus on tertiary-aged volunteers. Volunteers were recruited from tertiary school volunteer groups that were already visiting the home, regardless of our study or recruitment. This improved the ecological validity of the study. Local data from Singapore also shows 43% of all volunteers are 16-24 years old, 70% are occasional, 36% have tertiary education and 48% are students [37]. In the US the tertiary segment comprises 44.8% of all volunteers [38].

There were three successive rounds of volunteers, distributed over 2 months. The inclusion criterion was having a language match with the previously recruited client participants. Among the recruited participants, 1 reported training with dementia care as a student, and 5 reported some experience with dementia as defined by “living with someone with dementia for at least 3 months”. Data from 6 volunteers whose assigned clients did not participate in all 3 rounds were eventually dropped from the analysis. Each session lasted up to 30 minutes or was gently discontinued after 30 minutes.

**1. VOLUNTEER RESPONSE TO CARE MESSAGES**

As explained earlier (Fig. 2), a volunteer in the first group wrote a care message (R0) that was shared with a volunteer in the second group, who, in turn passed both messages (R0 and R1) to the third group.



**Figure 3. Volunteer ratings (n=30) of perceived usefulness of care messages. More than 80% agreed or strongly agreed (blue) that the messages were similar, useful and important**

*Volunteers' Perception of Care Messages*

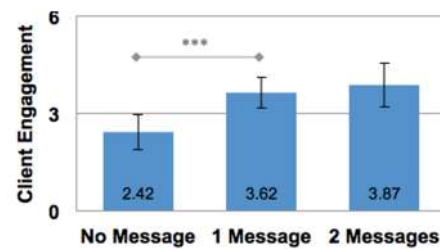
To measure perceived usefulness we asked volunteers to rate the messages they received from previous volunteers

<sup>1</sup> Mini Mental State Exam is a common indicator of degree of cognitive impairment, ranging from 0 to 30 (unimpaired) [6].

on similarity to their own experience, usefulness and importance for engaging the client, as shown in Table 2. Fig. 3 shows the proportion of volunteers with different levels of agreement about the similarity, usefulness, and importance of care messages. Only 3 distinct messages were rated as dissimilar to the volunteers' own experience, which we found reflected a volunteer disagreeing with a previous volunteer, and discovering a new or better way to interact with the client.

*Effects of Providing Care Messages on Client Engagement in Activities with Volunteer*

Volunteers reading the content of care messages might report it as useful, even if these messages never had any real effect on the ability of volunteers to interact with clients. We therefore measured client engagement in the activity with the volunteer, and analyzed client engagement scores as a function of how many care messages volunteers received from previous volunteers (0 for R0, 1 for R1, 2 for R2). We measured client engagement using the Menorah Park Engagement Scale (MPES), which was coded by the volunteer.<sup>2</sup> Although this was coded by the volunteer, it provides a substantially different measure from self-reported usefulness of information, since volunteers were not aware we were analyzing client engagement as a function of care messages, and the messages could very well have failed to have any impact on their behavior with the client.



**Figure 4 Client Engagement increased between Rounds with 0 care messages, 1 care message, and 2 care messages.**

Fig. 4 shows client engagement, as a function of the volunteers' round – how many care messages they received. It suggests that client engagement was higher once care messages were available – from R0 to R1 and R2.

To evaluate these effects, we conducted a within-subject ANOVA on the engagement scores, with clients as the within-subjects factor and treatment rounds as the

<sup>2</sup> The scale has been successfully validated for use by both expert and non-expert raters [3]. To validate the score, we asked a professional therapist (10 years dementia care experience) to code videos of 18 pilot study trials using the MPES. The therapist's scores were compared against the pilot study volunteers' in-session assessment. The result was 0.95 Alpha (Kappa) score, indicating high agreement between the therapist's scores and the volunteers' scores. This score is consistent with previous psychometric reports of the MPES [3, 12].

independent variable. The test with a Greenhouse-Geisser correction determined that mean client engagement levels differed significantly between time points ( $F_{2, 18} = 5.28, p < .05$ ). Post hoc tests using the Bonferroni correction revealed that the presence of care messages elicited an increase in client engagement from R0 to R1 (+1.20), which was statistically significant ( $p < .05$ ). There was a smaller increase in client engagement from R1 to R2 (+0.25) that did not approach statistical significance ( $p > .05$ ). The trend suggests that provision of a message (versus no messages) causes the greatest gain, with diminishing effects for multiple messages (Fig. 4).

To understand the reasons that volunteers found the messages useful and effective, we turn to the qualitative analysis component of the study.

## 2. INFORMATION SHARING IN CARE MESSAGES

To shed light on the quantitative findings, we used qualitative methods to examine the reasons for our findings. The volunteers' information use was analyzed using thematic analysis of the messages.

### Results of Thematic Analysis of Care Messages

The 30 written care texts were entered into qualitative analysis software MAXQDA 12 [39] for thematic analysis [2]. 3 coders (one co-author and two research assistants) coded the information independently. Then the coders met as a group and discussed each code for meaning and appropriateness. The coding was discussed, to reach an agreement of meaning and to eliminate duplicate codes. The codes were then sorted into larger groups of information, and these groups were labeled.

Code System	Count	%	Subtotals
<b>Client specific information</b>			
background/history	9	4.7	
likes/dislikes	34	17.7	
how to interact with client	31	16.1	
how to communicate with client	20	10.4	49.0
how client behaves			
how client responds to specific apps	35	18.2	
client's responsiveness to activity	28	14.6	
motor skills	11	5.7	
cognition	13	6.8	45.3
<b>Advice for volunteers</b>			
Advice on volunteer attitude	6	3.1	
Advice on general activity approach	5	2.6	5.7
<b>Total</b>	<b>192</b>	<b>100.0</b>	

**Table 2: The most commonly occurring codes resulting from thematic analysis had a predominance of psychogenic content on the client, and some advice for volunteers.**

The bulk of the information lay in client-specific, psychogenic (personality, life, biography [32]) information. Of 192 codes, 181 were on **client-specific information**, and 11 were on **advice to volunteers**. Table 2 shows the structure of the coded information. The structure comprises of the most robust elements across 30 messages. These were themes that each had more than 10% of the total client-specific codes.

### How Care Messages Were Used

The messages showed that volunteers were **leveraging previous information in order to inform their own approach**. In Table 3 (Example A), where the previous information agreed with their own impressions, they would often affirm the previous information with words like “*really is*” or “*actually*”. This was often accompanied by elaboration. In this case, “*easy-going*” was followed up with “*willing to cooperate*”.

#### Example A

R0: He is very chatty, very alert and speaks fluent Tamil, a little English. He likes to talk about his past and God. He is a very happy, peace loving person. He enjoys the Xylophone, jackpot 777, animal sound, milking and matching cards games. After every game, chat with him. Give him lots of encouragement.

R1: He is a really easy-going person and willing to cooperate with me with playing any kind of games. We had a little of language barrier but he does understand a fair amount of English. Tip: Do actions and sounds. He is very expressive! Let him play games with challenges because he picks up really quick and is smart! He likes puzzle-games, matching cards, animals game and maybe some sport games!

#### Example B

R0: The client doesn't talk much. Try not to repeat the same games over and over again as there will not be any surprising element anymore.

R1: She really doesn't say anything. Please do not feel discouraged. Client is very introverted and prefer games with visual and music.

R2: The client really doesn't talk much, in fact she didn't talk to me at all. However she can understand Mandarin and Hokkien when I spoke to her. It is not true that she doesn't like to play the same over and over again. In fact for the almost one hour session I had with her today, she is only interested to play the same polar bear striking bowling pins game. She is able to manage the tablet's stylus pen which was being given to her to help her pull the trigger for the polar bear to the bowling pins. I can observe that she felt very motivated whenever I gave her verbal encouragement words when she was able to strike down almost all the bowling pins.

**Table 3: Successive care messages with affirmation (A) and elaboration (B) of previous content. Volunteers underlined useful sentences.**

In situations where previous information highlighted a problem, volunteers responded by changing their own behaviour. In Example B, the R1 volunteer underlined one line of advice of the previous volunteer as the most useful (above). Her reason for highlighting this text was “*Because I did not know that the client has a preference to keep to her own,*” meaning she was withdrawn. In her own message (R1), she reports on an alternative route to communicate with the client, using games and visually stimulating games. In turn, the R2 volunteer marked this statement as useful too, saying that it helped her to “*mentally prepare*” and “*know that it's normal for [the client] not to answer questions*”. In her own message, she elaborates on one particular game that had good visual elements and applause sound effects.

Where successive volunteers had more divergent experiences, we observed that **volunteers attempted new interaction strategies until something worked**. In Table 4

(Example C) volunteer R0 indicates that the client “*is not interested in the activity.*” R1 disagrees and points out the exact game that did engage the client. R2 not only finds another game that works, she also explains the specific strategies that helped her to engage the client.

#### Example C

R0: Even though one of her languages is Mandarin, it'll be best to speak with her in Hokkien instead. Most of the time she's not interested in the activity and would prefer interactions in Hokkien. As she is not interested in the activity, she will tell you that she wants to leave. It'll be best not to ignore her, and reassure her that the session is ending, as she is going to repeat her message until you reply her...

R1: She is quite engaging with the tablet. She can play the games quite well. Especially the bowling game. When playing the game, she does not speak much. I think most of her attention is on the game...

R2: [Client] loves the firework display as well. When viewing the fireworks, allow her to explore other ways of displaying her fireworks by guiding her to use her other fingers and hands. It makes it more fun for her! She is quite friendly so if you can, you can engage her in conversations in Hokkien. I believe she will be lovely to talk to! Hold her hand and guide her thru the games. She was very engaged in the games and she didn't get bored which is great!

**Table 4: Successive care messages with corrections being explained by new volunteers. Volunteers underlined useful sentences.**

**Volunteers were occasionally incorrect.** In 30 messages, we coded 5 sentences that may have shown misinterpretation of the client's behaviour. In one case, the volunteer found the client was particularly responsive, in contrast to previous volunteers' reports. She wrote, “*It is not true that she is not interested in the games.*” When the therapists later viewed this text, they attributed the positive report to “mood”, explaining that the client was less responsive on most days.

In another case about a client who had curled fingers of the dominant hand due to stroke, one volunteer wrote: “*These games must also not be too challenging as she is quite restricted in her hand movement.*” This advice was not consistent with our experience with the client, as she had only a mild cognitive impairment, and often preferred the more complex games. In all, the volunteers' lack of daily overview and expert insight contributed to these misinterpretations of client behaviour.

However, we do not consider misattribution a major concern. The previously described mechanism of correction between volunteers seemed to be able to correct major differences in opinion. In the cases mentioned here, based on what we have seen in other messages, it is highly likely that future volunteers will be able to correct the misattributions.

Of greater concern might be the actual changes in client behaviour due to the progressive decline in dementia. When this happens, previously recorded content would appear

wrong to new volunteers. We address this issue in the “Design Considerations” segment of this paper.

#### Harvesting Caregiving Knowledge

In all, the process of affirmation, elaboration, and correction led us to characterize the volunteers' interaction with the care messages as a dynamic activity of harvesting caregiving knowledge. When presented with a record of previous interactions, volunteers scanned the information for incidents of success. If their replication of the behavior was successful, they would affirm it, and share the anecdote to be passed on to future volunteers. If these replicated interactions were unsuccessful, volunteers would attempt new or different strategies. Volunteers used the system as an asynchronous platform for learning volunteer-appropriate behaviour with clients, and for collaborating towards finding effective, non-obvious strategies. This harvesting mechanism helped explain how the presence of care messages had a real impact on the clients' level of engagement in the activity. The quantitative results of impact indicated that just one message was enough to have a strong effect (Effect size was 1.4 times the pooled standard deviation.) However, the mechanism by which such effects happen argues that even incremental increases can be valuable. It is possible that successive rounds of volunteers can further improve their performance, assuming that the attendant scale issues of the volume of information are addressed.

#### Types of Caregiving Knowledge

We draw on Stokes' holistic model of dementia [32] to categorize the relevant types of caregiving knowledge. Two types of knowledge were predominantly represented in this content - psychogenic and neuropathological. Psychogenic information formed the bulk of the content (Table 2).

Volunteers attempted to describe some neuropathological information (information on disability), but the language used reflected their lack of professional insight and training. Still, **the use of lay language and first-person narrative had the advantage of immediate applicability and relevance.** For example, we previously observed that volunteers are often hesitant to instruct older adults and initiate handholding, for fear of overstepping their bounds and appearing disrespectful. However, active guiding and handholding is often a necessary component of engaging clients [24]. Hence, one R1 volunteer wrote: “*Although she is uncooperative, you need to be patient and assure her that she can play the games. After demoing the game and explaining how to play it you can try encouraging her to play along with you. Hold her hand and lead her on how to play...*” This information that hand-guiding has occurred, and that it was acceptable and even common behaviour when interacting with these clients seemed to reassure volunteers. The R2 volunteer marked this text as useful, explaining “*She is willing to try the games when you encourage and tell her what to do.*”

### Biographical Information with Privacy Concerns

We had just two instances where volunteers recorded biographical information shared by the client. The lack of such information from our participant group (residents with dementia) is unsurprising since the erosion of the clients' long-term memory leaves an information gap.

However, **the sharing of volunteer-provided biographical information raised the issue of client privacy.** For example, one client (female, 82) shared with her R0 volunteer about her experience working as a singer, performing for Navy audiences. This type of sharing is normally regarded as a positive, unproblematic development, indicating a connection formed between client and care staff, or client and family. However, in our case of using volunteers in dementia care, it becomes a problematic situation. The R0 Volunteer reported these stories in great detail, sharing it with all volunteers in the successive sessions. Information that the client felt comfortable sharing with one volunteer was shared with the next volunteer without her express knowledge. Additionally, sometimes people with dementia are not able to differentiate lived memories from experiences from other sources [16], so there was no guarantee that this was accurate information. We sought clarification from the therapists who were familiar with the client, but nobody could validate it.

We have not seen research on caregiving information systems raise privacy concerns as a problem. Based on previous target groups of family and care staff, it is understandable why it has never been raised. However, as the need for volunteers to fill in caregiving gaps increases, this issue raises the important question of how to promote social intimacy between volunteers and clients, as well as sharing between volunteers, while ensuring that private, personal information about the client is not indiscriminately shared and published.

### 3. THERAPIST ASSESSMENT OF RELATIVE VALUE OF VOLUNTEER KNOWLEDGE

Having established the value of the content to volunteers and the mechanism by which it is valuable, we turn now to the research question of what this means in the greater caregiving context.

To do this, we asked the therapy team at our partner care home to review and discuss the messages. We recruited 4 therapy assistants (Therapists 1-4, all female). In total, these therapists had 15 years' experience in geriatric care. All therapists had supported the logistics of the care messages study, but at the time of the review, had not been briefed about the goals and purpose of the study. Additionally, during the discussion segment, we included the input of the head of therapy team (more than 8 years' experience in geriatric care).

Each of the therapists was given a folder containing 9 collected care messages, for 3 randomly chosen clients.

After reading each client's care messages, each therapist was asked to rate all the statements for this client on the same set of criteria as for the volunteers - similarity, usefulness and importance.

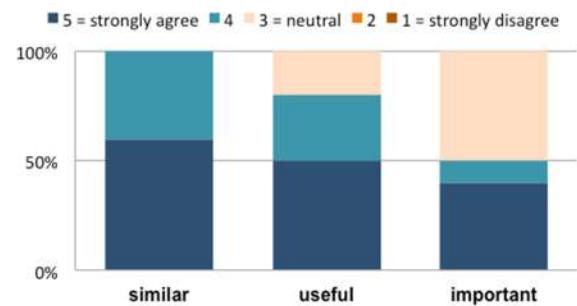


Figure 5: Therapist ratings of the content after reading each client's care messages

Figure 5 shows the therapists' *similarity*, *usefulness* and *importance* ratings of the messages on 10 clients. Therapists unanimously agreed (100%) that the information was similar to their own experiences. However, the agreement was somewhat weaker (80%) with regard to usefulness. About 50% thought the information was important to their work. This last rating was about 30% lower than the volunteers' assessments of message importance. We now turn the therapists' review of the messages to explain these findings, and to expand on how these messages are valuable to the work of caregiving.

**Firstly, volunteer-provided knowledge could help therapists familiarize themselves with the client because the volunteer-client dyad engaged in conversations at a depth that the therapists may never be able to achieve.**

This was particularly true for clients who may be new to their care, or who spoke no English. As with many aging nations that import care staff, these foreign workers often struggle to overcome cultural and linguistic barriers to care. Due to shared languages or serendipitous personality matches, some volunteers achieve a level of closeness to the client that none of the therapists can. The conversational intimacy achieved by clients and volunteers speaking the same language allowed therapists to obtain new information regarding old clients. This type of information can be useful to therapists because it helps them to craft new engagement activities for their clients.

However, this value did not extend to all care workers. There was a new therapist who happened to be present at the review. At the time, she was just ending her first week on the job. She read the texts and found that she could get very little information out of it: *"I couldn't understand the information because I have no idea of the client, don't know anything about them, or even who it is."* It seemed that some level of existing previous experience with the client was needed before the volunteer-provided information could be effectively processed and digested for therapy work.

Secondly, **volunteer-provided information helped the therapists to circumvent the limitations of professional distance.** The therapists explained that they avoided interacting with clients outside of the therapeutic activities. The reasons were to avoid giving false hope if there was nothing they could do to help and also feeling under-equipped to deal with personal matters. They gave examples such as clients’ rivalry with other clients, or clients’ family problems. When encountering such issues during a normal workday, they often referred these matters to the social workers. According to Therapist 3, some clients also maintained a certain distance from the therapists: *“They sometimes are more willing to share information with volunteers who are ‘outsiders’, not people like us, who they see every day.”*

The care messages circumvented these distances - it gave the therapists access to personal information about the client, without the felt burden of needing to respond to it. In effect, they were given the opportunity to gain previously fraught information about the clients, which could be potentially helpful in guiding their own interactions with the client.

Thirdly, the therapists explained that **volunteer-provided information had chronological value.** Reviewed over time, the therapists found that in one or two instances they could see change over time in the way the client responded. Our study spanned almost 2 months, from R0 to R2. The head therapist indicated that the reporting of behaviour over time could be useful to therapists as an additional source of information for tracking client progress/decline over time. This could help them see previously undiscovered interests of the client. However, the value of this last function is dependent on the degree of specificity required of the information.

**The main drawback of volunteer-provided information was the lack of detailed, therapeutically useful information.** Therapists reported scanning the messages for information about physical functional status or signs of cognitive difficulty - information they could use to inform their work. Compared to their regular sources of information (therapy logs, medical records and transfer records from social workers) volunteer-provided information was too sparse in directly usable information. Nevertheless, this therapist review hints that even novice insight can help report previously unknown knowledge gaps to health experts. Related work on volunteer information elicitation [29] suggests that this can be achieved with the help of additional, creative elicitation mechanisms.

Secondly, as mentioned earlier, the lack of experience led to some **misattributions within volunteer-provided information.** What one volunteer reported as an improvement in response due to a different approach strategy, was simply attributed to changes in the client’s mood, indicating that this client was only exhibiting

temporary cooperativeness. Volunteers lack contextual and historical overview, and this weakens the value of their input.

**Summary of Relative Value**

Caregiving Content	Volunteers as Source:	To Use Volunteers:
<b>Neuro-pathological</b>	<b>Least Likely</b> Offers layman terms Small subset of knowledge Lacks expert insight Lacks overview	Requires comprehensive elicitation methods and support via additional tools to provide insight
<b>Biographical</b>	<b>Likely</b> Content may be difficult to verify Privacy and sharing in tension	Requires carefully managing biographical content so that private content is not indiscriminately shared
<b>Personality and preferences</b>	<b>Most Likely</b> Even non-kin, non-expert caregivers can fill this gap effectively, with recency, variety, layman language and efficacy.	Requires platform to bring asynchronous, distributed volunteers to share knowledge  Requires ongoing participation to maximise useful attributes of variety and recency

**Figure 6: Summarized therapist review, showing how it can be used in the caregiving context.**

On the whole, the therapists’ show that the key value from volunteer-provided information about the client was the specificity of the information to each unique client, and the richer psychosocial information from face-to-face interactions between volunteers and clients with languages or cultures in common. This information also had the value of recency, permitting insight on the client response to activities over time. However, without further scaffolding to improve specificity, or guidance to improve the input quality, the information was not yet useful enough for therapists. They deprioritized volunteer-provided information against existing medical and therapeutic case information.

**DISCUSSION**

Our driving research question was: “How can we elicit useful information from transient volunteers in dementia care so that future volunteers can interact more effectively with clients?”

We found evidence that volunteer-provided caregiving knowledge can be effectively transferred between current and future volunteers. The basic approach of having volunteers write care messages to give tips to future volunteers for interacting with clients was sufficiently useful to boost future volunteers’ performance. Specifically, future volunteers perceived the client-specific tips as helpful and leveraged the information to engage the clients more effectively.

The content was not just useful for other volunteers. The therapists’ review affirmed the validity of the reported content, but indicated the particular conditions for volunteer-provided content to be useful (Fig. 6). To these experts, the strongest value of the content was in its recency, specificity to the client (not generalized information) and how it helped them to bridge professional, language and cultural gaps.



This was because volunteer-provided content predominantly consisted of psychogenic information about each client's interests, preferences, responses to specific activity and methods to motivate the client. Additionally, the content was written in lay language, had the advantage of being easily interpretable by other volunteers.

### DESIGN CONSIDERATIONS

We now consider how the results motivate the design of systems that integrate non-expert, transient volunteer information in dementia care. To this end, we offer three design considerations.

#### 1. Volunteer-provided content can be a source of recent, rich, effective psychogenic information about each client.

Volunteers provided content about the clients' unique preferences and abilities. The degree of specificity and customization we saw in these care messages is difficult to achieve using traditional training materials. Dementia caregiver training usually must cover a large number of possible challenges, since dementia has a large variety of manifestations, which change over time [25]. Caregivers consuming such materials have the extra work of filtering instructions to determine which response is applicable to each care recipient. In contrast, volunteer-provided care messages transfer known-to-be effective, client-specific strategies to future volunteers. This specificity of information aligns with other research on peer-sourced, non-expert information. A study of online, peer-sourced pregnancy information found that participants benefited from receiving specific, development and condition-matching information [18]. Similarly, an evaluation of a peer-annotated learning system for student nurses showed that peer-annotation helped reduce information overload by filtering objects by each new learner's ability and relevance [5].

Hence, future volunteer-facing systems can utilize this volunteer-provided input to supply updated, personalized information on the client. One possibility is to use volunteers to create personal profiles of people living with dementia, which have been shown to be helpful to person-centred care [33,34]. Our findings suggest that personal profile material that is used to introduce personality of the client does not need to be only sourced from family or care staff. This usage is particularly relevant for older adults who are the so-called elder orphans (people who are single in their old age) for whom no reliable informants are available to supply holistic profile information. Both volunteers and expert staff may find this information useful, and it saves primary caregivers the effort of maintaining the content.

However, one important footnote in the use volunteer-provided psychogenic information is that sharing the biographic components should be carefully balanced against the need to protect the privacy of the care recipient.

If online systems are used, content distribution should be carefully regulated. A health information sharing study between cancer patients, family, and formal caregivers identified a similar need to manage privacy in multiple caregiver contexts. One solution the authors suggested is to consider tracking the use of shared information and increasing the transparency of use [21]. To this we add that non-primary caregivers should not easily retain such information once they leave the facility, as might be the case with content delivered on volunteers' mobile phones.

#### 2. To maximize the value of the content, it is critical to ensure that new volunteers contribute information, regardless of the completeness and effectiveness of currently collected knowledge.

Our study showed that volunteers rely on previous volunteers' information to indicate good strategies. Volunteers were leveraging the content to either repeat strategies for interaction or to find new ones if the current set was not working. This reliance was central to the transient volunteers' ability to innovate new strategies for client interaction.

However, the progressive nature of dementia creates a need for caregivers to constantly adapt existing strategies for interaction. A strategy for interaction that may have worked for a client before, (e.g. verbal instructions), may cease to be effective as the client's executive functions decline. Caregivers may need to change strategies and resort to manual guiding. New behaviours such as repeated questions can also emerge with increasing impairment, and caregivers have to develop new strategies to adapt without distressing the client.

Our data showed that ongoing collaboration between successive rounds was effective in reducing misattributions. It improved the accuracy of the content, without any intervention needed from primary caregivers.

Therefore, caregiving knowledge systems that use volunteer-provided content for dementia care should place priority on freshly gathered knowledge, over previously affirmed and validated content. Thus, a critical feature of future systems is an explicit focus on encouraging volunteers to provide new content, even when the previous content appears complete, effective or comprehensive.

#### 3. To elicit volunteer-caregiver knowledge, focus on the minimum set of 4 themes - likes/dislikes, how to interact with client, how to communicate with the client, and how the client behaves.

Table 2 listed the structure of the most recurring volunteer content that was derived from the thematic analysis. These four themes represented 89.5% of the coded content. We removed *client background* from this recommendation, as its inclusion is dependent on privacy constraints within the context of use (Fig. 6).

We used these codes to create a structured version of the care messages prototype. We recalled participants from R2 (n=10) and asked them to use both the first (care message) interface and the structured interface to enter their previous messages again. Participants were very positive about this more streamlined, 4 item interface (instead of 1 narrative block). They preferred it to the unstructured format, and rated it highly on encouraging thoughtfulness during input, helping to highlight useful content, being memorable, and supporting their ability to improve client engagement.

Past research suggests many ways to elicit and structure content for engaging persons with dementia. Certainly, content for reminiscence activities (where people with dementia recall past life events) benefit from family members and care staff providing accounts of personal life anecdotes, family trees and personal memorabilia [7,8,16]. However, our study suggests that volunteers are **not** a reliable source of this type of information.

Instead, we recommend this 4-item structure for systems that elicit volunteer caregiver knowledge, because its limited coverage has the advantage of being focused on what volunteers can *provide*, and focusing volunteers on what they can *use*. Our recommended structure cannot elicit material for biographic and reminiscence activities, but we have evidence that what it does provide is sufficient to support future caregivers interactions with clients for other engagement activities.

#### LIMITATIONS

An unexamined concern in our study and a clear limitation is the lack of longer-term data on the interactions of volunteers with a system for harvesting caregiving knowledge. Hence, there was no opportunity to understand the impact of large quantities of input on the quality of information and retrieval of quality content. With this data, we could have further investigated the participants' behaviour with regard to the need to focus on recency of content over previously validated content.

A larger sample size of volunteers and clients would allow generalization and provide further evidence for the statistical validity of these results. This study chooses to use the realism of a field context and ecologically valid activity, which restricted numbers. This meant we had to balance more heterogeneity against controlling for group composition between rounds. Future work should consider how other volunteer populations such as older adults or repeat visit volunteers may contribute content differently.

We used volunteers to rate client engagement. Despite validating the results with therapist scores and using a non-expert friendly scale, there may have been some loss of acuity from using volunteer-sourced scores. Therapist scoring would have been unfeasible with a large group of clients as each client needed a unique score. Using video for later therapist review was utilized in the pilot study, but was discontinued for the main study when we noticed that

the presence of video cameras during the pilot study made some of the clients anxious. Ideally future work will be able to leverage the methods detailed in this study to investigate the impact of care messages using more objective outcomes for clients and collect additional behavioural measures.

The goal of this paper is not to specify all the features of a final implementation for eliciting and sharing caregiving knowledge. Each version of a system to support the gathering of volunteer caregiver knowledge would have features that depend on additional constraints of the context such as volunteer characteristics, primary caregiver involvement, or development budgets. For example, volunteer literacy levels will change the preference for text towards other input methods such as voice or video. Development budgets will influence the resources available for more sophisticated content processing as might be enabled by incorporating natural language processing.

#### FUTURE WORK

One unexplored avenue in our study is that future elicitation strategies could include additional instrumentation to support volunteer insight. Previous work on qualitative constraints for curating family photos [28], and constraint-based crowdsourcing for crowdsourcing journey planning [35] shows that untrained crowds can be aided in providing subjective content. Our findings add evidence to the idea that large numbers of untrained workers can be utilized in various stages toward finding appropriate, non-objective solutions for health care [1]. It remains to be seen if dementia care volunteers in larger numbers can act as crowdsourcing input for further improvements in customized client information.

#### CONCLUSION

In this paper, we describe volunteer-provided content in terms of its structure and mechanisms for iterative improvement of content quality. Despite using the insights of inexperienced, untrained volunteers, we show that the collaborative sharing of such content provides sufficient knowledge for successive volunteers to be more effective when interacting with people with dementia. Additionally, we developed a sense of the relative value of non-expert, non-kin input within the dementia care context. We offered design considerations for further optimizing the contribution of volunteer-provided content to dementia care.

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