Designing Conversations: Using Life Stories to Improve Dementia Care

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Abstract

Dementia is a long-term condition that impacts on various aspects of a person's functioning. The person-centred care approach has been shown to be integral to quality of life however the communication challenges facing people with dementia makes understanding the needs of the person difficult. Our research shows that this is a big issue for people with dementia and their families and carers and can be compounded as they navigate different elements of the care. This paper explores the role of design in the context of creating tools to support communication with people living with dementia and personalise their care, with a particular focus on the use of co-design methods for drawing out and sharing people's life experiences and stories. Two case studies are presented which describe how designers and design educators in Australia and Canada have approached this topic.

Keywords

Dementia · Design · Person-centred care

1 Background

Dementia is a term used to describe a group of syndromes, including Alzheimer's Disease, which are characterized by deterioration in cognitive functioning. Dementia affects memory, mood, comprehension and communication and has been identified by the World Health Organization (WHO) [1] as one of the major causes of disability worldwide, impacting on both the person and their caregivers and families.

At present it is estimated that 50 million people have dementia worldwide, and every year a further 7.7 million individuals are diagnosed with the condition [2]. The total estimated worldwide costs of dementia were US$818 billion in 2016 and in 2018 it became a trillion-dollar disease [3] This increase will have an enormous impact on health care and social services globally. For instance, Alzheimer's Australia and the National Centre for Social and Economic Modelling estimated that in 2017 over 400,000 Australians were living with dementia, a cost of $9 billion per annum [4]. By 2056 these numbers are expected to increase to over 1 million individuals, with direct costs rising to over

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$24 billion. In Canada similar figures exist with recent estimates suggesting that the total cost of dementia in Canada is $12 billion CAD per annum [5].

There are over 200 subtypes of dementia and whilst epidemiological studies continue to offer new insights into the disease, to date there is no cure. Emphasis has therefore been placed on the development of approaches and interventions that focus on quality of life and strategies to equip individuals to cope with the challenges that living with this long-term condition brings. However, whilst approaches to caring for people with dementia have changed dramatically over the last few decades, stereotypes and false beliefs are still too prevalent [6]. Lack of awareness and understanding often leads to stigmatisation, reduced quality of life and barriers to quality care. Unfortunately, many people, professionals included, have difficulty seeing the person (and not just the patient), behind the symptoms.

Many of these stereotypes and preconceptions need to be challenged. Despite the cognitive decline in dementia, there is evidence to suggest that aspects of self-identity are not lost in the person, that a person's identify is intact and perhaps just concealed [7–9]. Person-centred care is an approach to care that acknowledges the importance of self and identity—regardless of cognitive ability [9]. In his pioneering work on the theoretical perspective of person-centred care, Kitwood defined this notion of identity as personhood; "a status or standing bestowed upon one human being, by others, in the context of social relationship and social being. It implies recognition, respect and trust" [10, p. 8]. Some attempts have also been made to incorporate person-centred care into patient files with documents such as Dementia UK's Life Story Template [11] and the This is Me leaflet from the Royal College of Nursing and the Alzheimer's Society [12]. These documents are "intended to provide professionals with information about the person with dementia as an individual" [12, p. 4], thereby enhancing care and support in an unfamiliar environment. Unfortunately, the research reported here found that these types of documents are not effective and/or not used effectively.

Kitwood's work has made a significant impact on dementia care [13], particularly around the introduction of non-pharmacological tools used in care environments. Based on various perspectives and methodologies, non-pharmacological approaches address loneliness and boredom, encourage social interaction and increase quality of life [14]. These approaches focus on the needs of the person and recognise that behaviours are influenced by social and emotional needs as well as past experiences and life histories. Assisted-living caregivers using person-centred knowledge such as life histories were able to anticipate the needs of individuals and customize their care [15]. The ability of staff to provide higher quality care improved the quality of life for people in care, and in turn, increased staff job satisfaction. While there is no consensus as to which interventions are most effective, creative approaches such as art therapy, music, and life story work have developed significantly [16]. Research continually points to the potential of such psychosocial interventions at improving self-esteem, enhancing cognition and physical capability, and reducing behavioural problems [17–20].

Person-centred care has featured heavily in healthcare literature for some time. However, there is a growing recognition of the challenges to the implementation of such an approach. In part this is because the medically modelled healthcare industry has largely ignored the role of personal histories and social contexts in dementia care [21]. Caregivers noted that, rather than being included as a part of their training, person-centred knowledge came from experience, where information was passed from long-term staff to new caregivers [15]. A British study by Popham and Orrell [22] found that in residential facilities, person-centred care was seen as an "ideal rather than realistic goal" [p. 185].

While there is evidence to suggest an increased recognition of person-centred approaches across the broader healthcare industry [23] actual day-to-day implementation remains challenging and inconsistent [24]. Some tools, such as Dementia Care Mapping (DCM) [25], have been criticised as being expensive, time consuming and somewhat out of reach for the basic grassroots level of care [26, 27]. Significantly, in their critical comparative review of published tools measuring person-centred care, Edvardsson and Innes [27] concluded that the voice of the person with dementia is still largely absent in the available tools, and that further work is required on tools designed to incorporate the knowledge of people with dementia.

This to some degree is not surprising. This lack of understanding is not without good reason as there are significant methodological challenges in relation to capturing the voices of people living with dementia. Communication has been cited as possibly the most difficult obstacle to overcome when trying to capture the voices of people living with dementia [28]. Dementia impacts communication. Dysphasia is a condition that occurs as a consequence of the neurological changes occurring in the brain and this impacts comprehension and expression of the written and spoken word [29]. Dysarthria, again resulting from neurological damage, can also affect the mechanisms and subsequently the quality of speech. For individuals with cognitive impairment and dementia, additional challenges can include word finding problems, understanding abstract concepts and memory recall [30]. These challenges can be compounded by general age-related changes in sensory acuity. For instance, one study by [31] found that half of people in nursing homes did not communicate with others in the setting because of hearing and speech problems.

Communication problems can pose a significant barrier to understanding the views of people with dementia, although it is very important to continue trying as it is possible to elicit their views [32]. This becomes even more pressing in the context of people living with dementia since individuals can find themselves in numerous care environments. Poor co-operation and communication between different levels of care and from different services affects the quality of care for people with dementia.

2 Transitions

The decision to place a loved one in full time care is perhaps one of the most difficult phases of dementia and can cause overwhelming stress for caregivers. Carers report experiencing conflicting emotions such as sadness and resentment alongside relief and comfort [33]. There is a common sense of becoming homeless during the transition to long-term care. Even for people without significant cognitive impairment this change requires extensive negotiation of the new surroundings; they need to fit in, learn the rules and create a place for themselves [34]. For new people living in long-term care with dementia there is often a feeling of abandonment and a sense that perhaps they have done something wrong; they cannot understand why their loved ones come to visit but refuse to take them home [10].

Heliker and Scholler-Jaquish's study [34] demonstrated that sharing of personal stories and lived experiences helped people in care illustrate what is meaningful and important to them. People used stories to provide context for their lives, "to preserve their history and culture, to validate their self-identity, and to form bonds with others" [34, p. 41]. As a result of their study, story sharing is a strategy being developed and encouraged during the transition process. From admission, transitional care teams including the people living in care, their family members, healthcare professionals, other appropriate personnel, participate in story sharing activities with the intention of getting to know the individual and helping them integrate into the new facility.

Reuss et al. [33] presented a model of seven individual factors that contribute to, and are necessary for, positive transitions to full time care. The authors emphasise the need for transparency in decision making to avoid feelings of the process being 'expert-driven'. Their detailed model builds on previous work exploring the process of navigating transitions in care. It demonstrates the value and importance of including the family in the overall process, and further highlights the critical role of strong, open communication between staff, families and advocates for “pre-placement education programs” [33, p. 38]. However, nowhere in this extensive and thorough model is the inclusion of the individuals’ life history or personal stories.

3 A Design Approach

Although professional and personal caregivers recognize that having person-centred knowledge such as life histories increased their ability to provide quality care, the use of such knowledge is seen as ideal rather than standard practice. Current methods of collecting and using this information are inconsistent and ineffective—challenges only compounded by the communication difficulties experienced by people living with dementia. With this in mind, our research employed design approaches and methods aimed at improving the collection and use of person-centred knowledge in order to improve communication and personalization in dementia care.

Co-design methods are intended to draw out latent and tacit knowledge through creative, hands-on activities, often referred to as “make tools”. By using creative methods of engagement and actively involving people, or users, in the design process, these tools and methods are similarly useful at drawing out people’s stories and experiences. Co-design activities typically take the form of word/image association, quizzes, games, or hands on design or making in the moment [35], such as painting, drawing and construction activities, all with an added storytelling element. Such methods elicit deeper forms of expression and encourage people to share their experiences, thoughts and ideas [36].

This paper now describes two case studies, one from Australia, one from Canada, which developed approaches to sharing and recording the stories of those entering and living in aged care facilities. Both studies demonstrate the value of design methods; both emphasise the value of personal life histories, storytelling, and *knowing the person*, to the delivery of quality in dementia care.

4 Case Study 1—Knowing the Person

In Case Study 1 we present research that sought to understand the application of person-centred care, and person-centred knowledge in particular, in the various environments that a person with dementia would experience across the care system. The research illustrates the types of knowledge used both by professional and family caregivers; how and where this knowledge is used, and where it is not; as well as opportunities to improve the use of person-centred knowledge in dementia care.

4.1 Method

Case study 1 was based in South-East Queensland, Australia, however, data were collected from both local and international sources. The research, approved by the QUT Human Research Ethics Committee as part of the curriculum, was conducted in three phases—(1) expert interviews; (2) online content analysis, and (3) unobtrusive observations.

In Stage 1, four interviews were conducted with health-care professionals. Participants were approached from within the researchers personal network and selected to represent various environments and experiences of the care spectrum and service delivery: two experts in dementia care (email interview with a Director of Assisted Living and Memory Care at a continuing care facility in the United States; a Manager from Alzheimer’s Australia’s Dementia Behaviour Management Advisory Service) and two front-line staff in the health care industry: a Nurse Unit Manager (NUM) of an emergency ward at a Brisbane hospital and a paramedic with the Queensland Ambulance Service. Audio recordings of the three face-to-face interviews were transcribed verbatim; in the case of the email interview, the written correspondence was used in place of a transcript.

In Stage 2, content analysis was carried out on an online community discussion forum supported by the Alzheimer's Society [37]. The forum represents both people with dementia and their caregivers. At the time of the review the site had over twenty thousand members. As of 2020 it had grown to over sixty thousand members. The researcher introduced herself and the project to the site's administrators before any analysis was carried out. This method sought to understand the experiences of carers and people living with dementia first-hand. Our intention though, was on generating a broad, higher-level understanding and we did not record any personal details of the forum's members and do not report on members' individual situations.

In Stage 3, unobtrusive observations were carried out on five separate occasions at a nursing home facility in South-East Queensland in Australia as part of a pre-existing volunteer program. The home, an older facility that was later closed, had 120 residents in four interconnected units: two residential units, one secure dementia unit and one secure mental health unit. Results from each stage are presented below.

4.2 Results

Stage 1: Interviews. Interviews focused on the characteristics and challenges within dementia care. As described by Saldana [38, 39], analysis of interviews was undertaken by following an iterative and inductive coding process to identify recurring themes of consistent meaning and context. Table 1 outlines the categorization of findings into six topics and includes sub-themes to clarify the definition of each. All six topics are briefly discussed here, including quotes from participants.

Topic 1. Needs recognition; this includes emotional, environmental and daily activity needs of people with dementia, the staff and the caregivers. Both experts suggested that understanding individual resident needs proved beneficial in personalizing care and that past life experience had a major influence on how the person coped with the disease.

[Director]: "Everyone with dementia is not the same - 70–80 years of past life plays a huge role in how the individual handles the disease."

Topic 2. The importance of knowledge & knowledge transfer in care environments includes the knowledge staff have about dementia in general and about the person with dementia specifically. Echoing the results presented by [15], participants noted that personal patient information was useful in accomplishing daily work activities and contributed to increased job satisfaction.

[NUM]: "[what's] really good is when you get the photocopy from the nursing home of the drugs that they're on… they write at the top, 'Betty likes her tablets to be crushed, and given with green jelly'… some of them write that, and if I didn't know that I would be trying to shove a massive tablet into Betty's mouth and she would be spitting it in my face".

While no specific reference was made to person-centred care by the researcher during interviews, all participants referred to its use, and to the value of such information when dealing with things such as behavioural issues.

[Paramedic]: "Some dementia patients just want to talk about fish… and next thing you know you have a person that's fighting and screaming and saying they don't want to go anywhere and then you say 'oh, you should have seen this fish that I caught the other day' and they'll stop… 'was it this?, was it this?' and then they'll follow you…".

Knowledge transfer in dementia care occurs at many levels and it can be represented by various types of knowledge. For instance, it may be about sharing knowledge about dementia at a broader societal level in order to reduce the stigma, or it may be detailed personal information about one person with dementia. This knowledge transfer is present from research to industry, from families to facilities, between facilities, and between individual carers and staff within facilitates.

The Manager cited transitions to permanent care as one of the most difficult times for the person with dementia and their family. She stressed that behavioural issues occurring as a

Table 1 Key themes from interview data

	Topic	Sub-topic
1	Need recognition (person, staff, and caregiver)	Emotional: security, familiarity, freedom, preferences Environmental: familiarity, visual cues/triggers, personalisation, engagement Activities of Daily Living: bathing, feeding, dressing, mobility, communication, medications Family/Caregiver need/Staff need/Professionals Emergency situations (immediate needs)
2	Importance of knowledge & knowledge transfer	*Knowledge* Staff knowledge about disease and person Staff attitudes: task oriented vs. person-centred Collecting personal information Availability, storage & accessibility, documentation, formatting, presentation, admission *Knowledge Transfer* Handovers: between facilities, staff to staff, Family to facility, Family to Emergency staff Sharing, teaching, educating Research to industry Cultural/attitude shift—stigmas
3	Influence and suitability of environment	Physical & social environment Treatments, Programs & Activities Policy & Legislation—Health & safety
4	Impact of dementia on caring	Different stages becoming difficult to manage, indicating need for higher care accommodation Reverting back to instincts Different stages as an indication of physical ability, communication and care needs Impact & Identification of Behaviours (physical/emotional) Physical: wandering, aggression, violence, spitting, biting Emotional: agitation, depression, boredom, anxiety
5	Recurring problems restricting quality care	Restriction of Finances & Time: Cost, Affordability, "Big business" Not enough time Staff change over, Temporary staff Lack of necessary information, Lack of knowledge/training
6	Provision of Medical Information	Documentation, medical history, medication, allergies, abilities, cognitive state, mobility, DOB, next of kin, drug

result of this change could be better managed if appropriate information was gathered beforehand.

[Manager]: "It's really the relationship between the facility and the family. That relationship needs to be so healthy for the whole journey within residential care, and it starts before admission."

In exploring knowledge transfer during transitions, participants had high opinions of nursing homes that were able to provide extensive patient and, in the case of emergency response, incident information.

[NUM]: "…and really good nursing homes, they bring a copy of: 'Gertrude likes classical music, she used to have a dog, she needs everything doing when she has her wash, but she likes to brush her own hair', like the really good ones send all of that… the sh*t ones you get nothing, not even an allergy…".

However, while the sharing of detailed patient information is highly regarded and useful, participants of this study noted the size of the files and disorganized nature of documentation was difficult to manage effectively.

[Paramedic]: "…sometime its [personal patient information] documented if you can flick through the 25 pages of scribbled hand writing, photocopied-multiple-times-paper that's handed to you."

Topic 3. The influence and suitability of environments reflects both physical and social environments, from legislation and design, to programs and activities. Interestingly, the results reflect the nature and role of each participant. For example, the paramedic made mention of the impact physical features of facilities had on being able to access and extract the patient in emergency response situation. The director and the manager, both with extensive experience in residential facilities, had holistic perspectives on environments, seeing them as vital to overall quality of care.

[Director]: "Environment plays a HUGE role in the care of someone with dementia…So what has to happen is provide the right environment where they feel like they are home and there are activities that keep them engaged, this redirects them from their fears. The best environments are those that allow freedom to wander within safe limits."

Topic 4. The impact of dementia on caring addresses the identification and impact of both physical and emotional behaviours expressed by the person with dementia; from wandering and spitting, to depression and anxiety. The Director explained that there was no standard for navigating different stages of care and that changes often happened in crisis situations.

[Director]: "The spouse who is the caregiver often becomes ill and is hospitalized, therefore the person with dementia ends up in a care facility in an emergency situation, unless children take over the care. Or, the spouse dies, resulting in admission. Often the spouse caregiver has been covering up and children don't realize how far the dementia has progressed, until they have to take care of mum or dad. If there is no spouse and children are the responsible parties, they tend to be more willing to place mum or dad in a facility."

Topic 5. Recurring problems addresses barriers to providing quality care, fundamental challenges such as financial issues, the affordability of care, and the unfortunate notion of 'get what you pay for'. Participants of this study indicated that the use of temporary and agency staff in nursing homes further impaired the provision of quality care as temporary staff have minimal knowledge about their residents,

[NUM]: "…you have other nursing homes where they just can't keep staff, so the staff are brand new every day, or they're agency every day, and they just don't know the patients, so they just don't know anything about them…".

Other barriers included time constraints and high workloads in care environments, a lack of information, or poor management of information, and a general lack of dementia-specific training across the wider healthcare industry.

Researcher to Paramedic: Do you get any dementia training?

[Paramedic]: "We get a vulnerable clients training, which is pretty piss weak really, it's a chalk and talk… they stand up in front of you for two hours…. blah blah blah… there's no going out to an actual dementia wing and spending time there…".

In line with the literature, staff expressed feelings of frustration and inadequacy at not being able to deliver quality, personalized care.

[NUM]: "… most of them[nurses], go into it because they want to help people, and if they could spend an hour with each one they'd love that because, they'd go home and feel like they'd done their job properly and that's why they went into nursing and I think a lot of nurses go home at the end of the day and feel like they didn't do what they wanted to do…".

Topic 6. The provision of medical information, fundamental documentation such as DOB, allergies, next of kin, etc. Information that is sometimes provided, but often not.

[Paramedic]: "there should be a list for every patient, in their room on their wall…here's their medical history, date of birth, allergies, the medications they're on, that's it… that would then open up a whole different scope of practice for what I can do for that patient…".

The analysis of interview data highlighted the issues of communication that people with dementia face, particularly in relation to their past lives and sense of self. Analysis also pointed to the valuable role that this knowledge of past life may play in communication and personalizing care. The following section presents results from Stage 2, thematic analysis carried out on an online community discussion forum.

Stage 2: Online Forum. The online investigation was conducted in the most popular discussion thread on the website of the Alzheimer's Society [37], which at the time had 23,000 threads and over 280,000 posts compared with an average of 530 threads in other fora within this section. Each page displayed 25 threads and six consecutive pages were reviewed on three separate occasions, totaling 450 threads. To simplify the process, only the initial post of each thread was reviewed to identify key words that would help determine the general topic and the intention of the post.

Most posts were related to sharing experiences and seeking the advice of people in similar situations, including the process of diagnosis and dealing with behavioural and personality changes. In a process similar to the analysis of interview transcripts in stage 1, and with consideration of the themes identified in that data (Table 1), recurring topics were grouped according to similar meaning and context. Eight key topics were identified: (1) Facilities; (2) Diagnosis; (3) Seeking Support; (4) Caring at home; (5) Behaviours; (6) General Sharing; (7) Medication; and (8) Venting.

Analysis illustrated a consistent pattern across the 450 threads reviewed (Fig. 1), of those, 25% (112/450 threads) related to experiences with Facilities and transitions through various stages of care. This topic often generated a substantial response from other members of the forum, was the most prominent in all three separate reviews and will be the focus of the remainder of the research presented here.

Posts about experiences with facilities related to the search for suitable facilities, transitioning a loved one into permanent care and the difficulties experienced by carers during this time. Other notable topics included: a fear of hospitals; a general lack of knowledge, guidance and structure within systems of care; and a recognition that the use of personal information had a positive impact on the care of the person living with dementia.

Family members were often the primary source of care. Care within the home was generally relinquished as a result of the situation becoming unmanageable, where injury had occurred or was a serious risk. Carers seemed unprepared for this point in care and were often asking for "some advice asap". They were confused by the process, which often involved a stay in a hospital or assessment centre while determining what type of facility would be most suitable.

Reflecting the literature [33], the process of transition to permanent care was recognized as one of the hardest parts of the dementia journey. People described being "a nervous wreck" and "panicked" waiting for the call from the hospital to say that their loved one had left for the care home, often realizing that they "had no choice". Forum members expressed an overwhelming sense of responsibility and a mixed sense of guilt and relief when placing their loved one in permanent care. Some felt "awful, sick". One went so far as to say, "at this moment I wish I were dead". Interestingly, within the search for suitable care homes, design features were not discussed as regularly as the attitudes of staff and their interactions with the people living there.

People appreciated staff that were kind, patient, and placed great emphasis on meeting the needs of the individual. Whether in hospitals or nursing homes, carers were aware that personal knowledge about their loved ones had a positive impact on their care and had high opinions of facilities that recognized individual needs. Carers expressed a desire to be consulted about their loved one's care and were keen to provide information that may assist in the personalization of their care. However, they were frustrated that even when personal information was provided, it was not given proper attention, lost or "just thrown away".

Trips to hospital were frequently portrayed as negative experiences, where issues of time and workload within such structured care

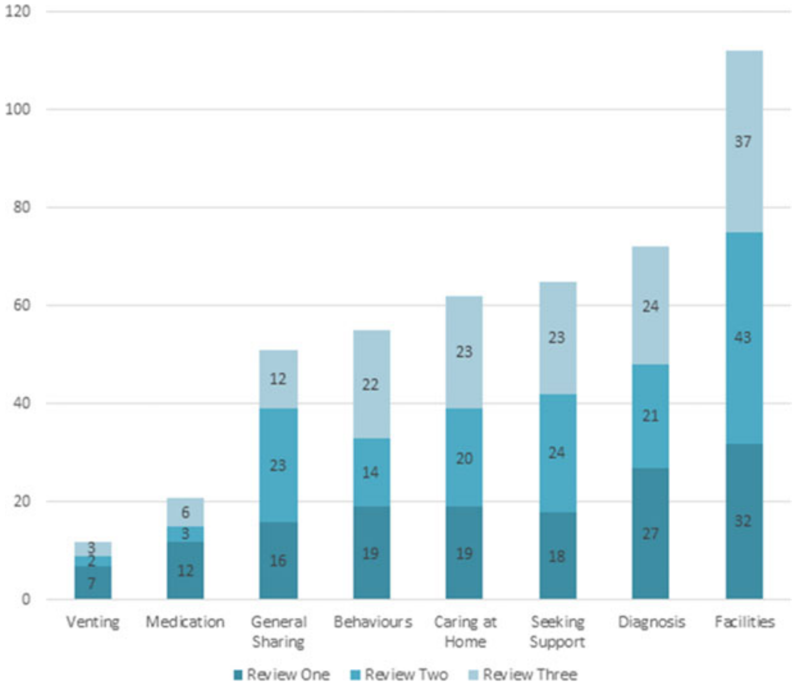

Fig. 1 Frequency of themes in online data

environments appeared to limit interactions and the use of personal information. Many people wanted hospital staff to find out about the person with dementia, not just medical needs but social needs, habits etc. A few minutes to uncover this information from family or carers on admission could make a lot of difference. Comparable with results in Stage 1 (Topic 5) members expressed frustration that staff in both residential and acute care environments did not have even basic training in Dementia care.

Thematic analysis of the online data suggests the journey through care with someone with dementia is worsened by a general lack of knowledge, guidance and structure within systems of care. Similar to the information provided by the Director in Study 1, transfers to permanent, long-term care often came at the last minute, as a result of rapid deterioration, a crisis, or where care at home was no longer manageable.

Given the overwhelming popularity such of forums it seems the information and support carers are seeking is not readily available to them elsewhere. Seeking information and advice from such an avenue also suggests that caregivers are more likely to trust the opinions of those that have had firsthand experience in caring for a loved one with dementia. The next section presents analysis from the final study of this project, unobtrusive observations at a residential nursing home.

Stage 3: Unobtrusive Observations. As part of a pre-existing volunteer program, unobtrusive observations were carried out on five separate occasions at one residential nursing home. The visits occurred on Sunday mornings between 9 and 11 am, and were the only activity scheduled over the weekend. This timeslot may have reflected a general lack of activity within the facility. It should be noted that this was an older facility and the unit visited most was providing higher-level residential care. Residents had very limited independent mobility and most were experiencing mild to moderate cognitive decline. There was some interaction with residents in the communal activity/dining room, however, most residents were visited individually in their rooms and all, apart from one, were in bed. During an orientation to the facility, the facility's volunteer and activity coordinators identified which residents to approach and which were best avoided. The coordinators discussed a plan to collate some basic information about residents that they would then supply to the volunteers; however, this did not eventuate.

Contrary to advice from the Director in Study 1 (Topic 3) and [40], that facilities should strive to feel like a home, most rooms visited by the researcher had minimal personalization, with staff suggesting it was the responsibility of the family. Some residents' names appeared on the doors or walls outside of their rooms, but not all, and some were incorrect. The staff did possess a wealth of information about their residents, however.

Staff facilitated introductions to residents and were able to provide information on each resident that was used to initiate conversations, "Eric used to live on a farm" or, "Hazel had dogs growing up". When this personal history information was gained by the researcher, either through conversations with staff or by artefacts in residents' rooms, it was effective in helping stimulate conversations with residents. In several instances, residents would become much more lucid, animated and conversational when asked personal questions.

Where a resident's speech was difficult or limited, staff were able to 'translate' some of the conversation during these visits. Staff were also able to recognize when a resident was uncomfortable and shift their position, even though the resident was not verbally able to communicate this discomfort.

Unfortunately, however, without staff on hand, life history information of residents was not provided or readily available. Staff suggested this lack of information was often due to the acute nature of transitions in dementia care. Ultimately, most families were not prepared. Staff expressed disappointment, even sadness, at the fact that some residents did not have any family to help create this personal space.

Over the course of five visits it became apparent that the physical appearance of the old building played far less a role in the care of the residents when compared to the knowledge used by the staff during interactions with residents. The staff were aware of residents' preferences, interests and backgrounds; they showed sensitivity to their needs, desires and physical comfort. They encouraged interaction but also recognized when it was not appropriate. It was clear staff had the welfare of their residents as a priority. Unfortunately, however, successful volunteer interactions would not have been possible without the staff escort. This suggests that current methods of collecting and sharing this vital information are not effective.

4.3 Summary of Findings

Overall, the findings of Study 1 agree with the extant literature. Issues surrounding experiences in different care environments featured repeatedly in all the data. Changes from independent living to a permanent care facility, or from a facility into an acute care environment, are challenging and painful experiences for both the person with dementia and their carers.

There was overlap in the identified themes across the data and although it was difficult to distinguish areas of priority, the findings were developed into three overarching themes: (1) Communication and Engagement; (2) Recognition and Awareness; and (3) Knowledge and Compassion. Communication and Engagement emphasizes the need for improved communication between care providers, and increased engagement with the person and their family during transitions to and within care. Recognition and Awareness is about recognizing the impact that an individual's life history has on their needs and behaviours. Knowledge and Compassion is the need for increased understanding about dementia in general across all care providers.

Limitations are recognized regarding the data presented. Given that the online analysis was conducted on consecutive pages, one particular thread may have influenced the appearance of similar discussion topics and future studies might consider a review of more than one forum. Observations were only conducted on Sunday mornings within one high-care nursing facility where residents had limited communication and mobility. It is suggested observations within a facility where residents have more independence and awareness may have provided a more balanced view. Lastly, data for Study 1 has been collected from three continents. It is recognized that issues and processes of one care system may not apply to that of another. However, the general context of poor communication, a lack of training and knowledge, and attention to individual needs appeared in all data regardless of origin.

The next section describes a product concept based on the outcomes of the research in case study 1. With the aim of improving the availability of personal information about people living with dementia for care providers and services, and promote a person-centred approach to dementia care, the concept aims to create a more coordinated system of communication, focused on the individual.

4.4 Person-Centred Design Development of a Reminiscence and Conversation Kit

In considering design solutions the concept presented here specifically sought to improve the process of collecting the life history information in the first place. Given the progressive nature of dementia, a system focused on information collection would need to be provided to the person with dementia in the early stages of the disease, while communication is still possible and they are able to consent to sharing their stories.

ReCollect (Fig. 2) is a personal reminiscence and conversation kit that is intended to be given to the person on diagnosis. Designed to reflect core family leisure activities and stimulate conversation, the concept provides for the collection, storage and display of small objects of significance. Most importantly, a set of cards provides ten themes with which to begin exploring a person's life history (Fig. 3).

Each card has a question on the front and space for answers on the back. The aim of the cards is to stimulate conversation and quality interaction between the person, their family and close friends in the early stages of the disease, and before significant cognitive decline.

In later stages and after permanent placement in care, the cards provide valuable information that can be easily and quickly accessed by carers and nursing home staff (Fig. 4). This information provides starting points for conversation and learning over time.

The questions and themes of each of the cards (Table 2) were derived from several sources; the essential information included in documents such

Fig. 2 The recollect concept


Becoming an Adult

What advice would you share about marriage?

The little things

Find an object of significance that you have kept - perhaps a memento or souvenir. Why is it valuable to you? Is there a story behind it?

Your life now

What is something you have always wanted to try but haven't had the chance yet?

Family

What were your parents' names? Do you know anything about how they met?

Love

Do you remember your 1st kiss?

Entertainment & events

Are there any significant world events that you particularly remember? How old were you? Can you describe the feeling at the time?

Fig. 3 Examples of the cards

as Dementia UK’s Life Story Template [11]; the Alzheimer’s Society’s This is Me leaflet [12]; and our earlier findings outlined in Table 1 such as emotional needs and familiarity, environmental preferences, as well as daily activities and routines. Importantly, as a low-cost and accessible concept, the cards also address some of the challenges identified in Table 1, particularly around financial restrictions and knowledge sharing across the care system.

To elicit some of those needs, the card themes and questions have been guided by autobiographical interviews [41–44]. Autobiographical memory is related to both episodic memory—information at a specific time and space, and semantic knowledge of the self—like knowing where and when you were born [43]. Finally, inspiration was taken from examples in published articles by Svoboda [43] and Concordia University [45], as well as the Smithsonian Institution’s Folklife and Oral History Interviewing Guide [46].

The purpose of ReCollect is to encourage families to document the life of the person with dementia in order to improve the quality of their long-term care. Feedback from initial trials of the cards has been positive. One family offered the following comments, “…thought you might like to know that we have all been using the cards for Granny and they are proving quite distracting! Once she starts to think about an answer, it leads her onto something else and thus another topic of conversation. Can easily pass half to three quarters of an hour! Some of the questions are quite emotive so we have to be a bit selective at times! - depending on her mood… I think they are an excellent tool for those with Alzheimer’s or dementia” (A. Baron. personal communication. June 2012). Future work within this concept should revise and refine the topics and questions included in the first iteration, especially a more in-depth understanding of the specifics of health care documentation.

Building on, and applying, the importance of life histories and of knowing the resident demonstrated by Case Study 1, Case Study 2 presents a codesign method as a way of engaging people living in care homes in the creation of artefacts to communicate their life experiences.

5 Case Study 2—Perspectives

Perspectives is an intergenerational teaching program that brings together art and design students with people in long-term care to co-design and co-create outcomes that reflect both the participants’ life experience and the shared

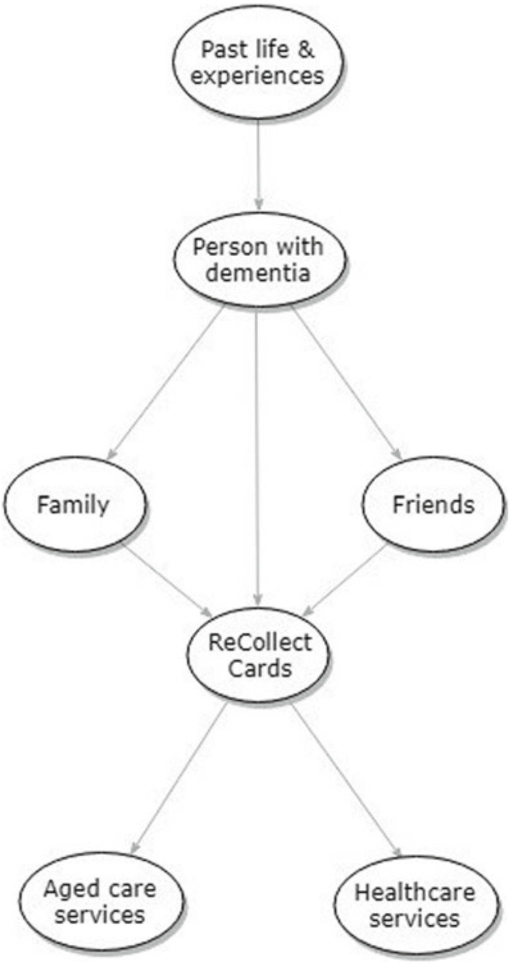

Fig. 4 Card interactions

experience of the intergenerational exchange between two groups of people at different stages in their lives.

Developed at Emily Carr University, Vancouver, Perspectives, formerly called Zeitgeist, takes place over the course of twelve weeks and sees students and people living in care form small groups to undertake a series of co-creational activities, designed by the students, that emphasise the importance of storytelling and sharing [47]. The materials generated during these sessions form the basis of the program's outcomes, with these outcomes typically taking the form of high quality, printed publications that are then shared between participants, their families and care home staff at a storytelling and sharing session at the end of the program.

5.1 Relationship Building & Identity

In many local care homes a 'Getting to Know Me' form (similar to This is Me leaflet from the Alzheimer's Society) is the main tool used to capture a person's history and character upon entering a long-term care home plays a large role in determining the care they will receive. The form is poorly designed from both a visual design and user experience perspective, which could easily leave someone feeling like their life experience has been edited down to a few fields of text. Little care is given to opportunities for personalisation and it is not possible to differentiate the form to accommodate different life experiences. Many people entering long-term care are doing so because they have been diagnosed with dementia, and it is not uncommon for these people to already have low self-esteem and to feel like they have a reduced role in society following their diagnosis [48]. Further, this form is often used upon transition into a home and is therefore collected and used at a single point in time.

To prepare communication design students to lead co-design activities with participants living in long-term care (a context which is usually unfamiliar to students), we begin with a small introductory assignment which asks students to re-design the 'Getting to Know Me' form.

The students are first asked to put themselves in the position of someone entering a care home and complete the form with one of their peers. This quickly leads to frustration, boredom due to the repetitive nature of the form and an overwhelming sense of empathy from the student as to the challenge someone faces in this situation. The act of completing the form often triggers conversations around what it takes to truly get to know somebody, touching on themes of trust, respect and divulging personal information to people who we do not know. The students are challenged to reimagine the experience of getting

Table 2 Card themes, topics and example questions

	Card theme	Topics & questions
1	Growing up	School/teachers Childhood food/toys/books/games/pets Complete the following sentence: The words that would best describe me as a child are…
2	Becoming an adult	How old were you when you left home? Describe the different types of jobs you have had over the years… What advice would you share about marriage?
3	Family	Do you have any favourite family occasions /traditions? How would you describe your parents? Are there any family heirlooms, recipes, or other things that have been passed down in you family?
4	Sports	Do you have a single greatest sporting event of all time? Do you have a favourite sport to watch? Did you play any sport
5	Entertainment & events	Moments in life/traveling… Describe your perfect party Are there any significant world events that you remember?
6	Faith	Values & beliefs How have your beliefs changed or remained the same over the years? Describe your faith.
7	Love	Do you remember your first kiss? What does love mean to you?
8	Your Life Now	Routines/habits/activities Do you have a morning routine? Can you walk us through it? Do you collect anything? Complete the following sentence: On the weekends I like to…
9	The Little Things	Personality/idiosyncrasies Is there anything you are afraid of? What is your life are you grateful for? Is there something that brings you comfort?
10	If…	Imagination/fantasy If you could have dinner with anyone, who would it be? If you could have stayed one age forever, what would it be? If you could have been at any event in history, what one would you go to?

to know someone and propose alternative solutions to the form and the experience of a care worker getting to know someone. They typically start by restructuring the form from a visual perspective, but this leads to broader conversations of what may be more appropriate ways of approaching this task.

The completion of this assignment coincides with the first meeting of students and care home participants. In the first meeting groups of 2–3 students and 2–3 care home participants are formed—groups which they will remain in over the course of 6 visits, in order to gather, document and share stories by ultimately co-designing a publication. In the first visit, the process of getting to know each other begins with a small icebreaker led by the care home recreation therapist (Fig. 5).

5.2 Co-creation & Personalization

Having met the people in their groups once, and started rapport building, students are asked to

Fig. 5 Students and care home participants (and Elvis) engage in ice-breaker activities

design a series of activities that will engage them in a process of story-telling and story-sharing with the ultimate goal of creating a publication together that features these stories. Students must creatively design participatory activities that are personalized to the interests and experience of the people living in care, while accommodating individual abilities, allowing for maximum participation where possible. It soon becomes apparent that although many of the participants may have lost a degree of cognitive ability or have physical limitations, their personality and personhood remain intact [49]. There is an emphasis on designing activities that are focused on an individual's abilities rather than disabilities, agreeing on a shared language and discussing goals and objectives together to, where possible, create a valuable experience for all participants [50].

This personalized focus is often the key to the unique aspect of the group outcomes, as individual character traits and interests become the focal point of the exploration. Through the process of making, participants can express preferences, feelings and thoughts that would have been difficult for them to verbally express, with co-design methods drawing on more tacit knowledge than traditional approaches. These personalized 'things' allow for them to construct their own unique creative language with which to express themselves, enabling people living in care to act as designers, while also helping to level the power imbalance that can exist when 'jargon' is used by the students. This staged and personalized co-design approach also allows participants to see their contribution as the project develops and trace their input back to the beginning [51].

For example, one group of students created a large set of dice to play with to accommodate the visual impairment of one of their group members. Rolling the die then corresponded with a question that was to be answered by the roller. In this game both the people living in care and the students participated in sharing stories about themselves by rolling and answering questions; it was not a one-way interview. The simple act of creating larger dice for the game was met with great enthusiasm by one participant who excitedly exclaimed that she could see the numbers! This customization enabled the individual to participate fully by recognizing her abilities.

In another group, several of the members had expressed an interest in bowling as a pastime in the home. This led students to develop an activity that took the form of a bowling competition, with different storytelling questions associated with different scores (Fig. 6).

Students are instructed to "scaffold" activities to aid participation and discuss how the materials

Fig. 6 An interactive bowling game is used as a game to get to know each other

generated will be used following the sessions [52]. This ongoing collaboration is an important factor, as students are asked to leave activities "open" and prototypical in nature, allowing for quick customization following feedback and therefore personalization by individuals in the home [53] (Fig. 7). The participatory nature of this assignment allows people living in care homes to become actors in the design process and not just passive observers [54] (Fig. 8) Through these storytelling activities participants find common ground, often through shared histories of places, cultural backgrounds and preferences for art, music or sports [55].

In this context student interactions with people living in care differ from typical staff interactions, engaging creatively with the explicit goal of drawing out their story, and as a result students are often are able to uncover new stories and information about the people living there that staff had not previously known, even from individuals who had been living in homes for long periods of time already.

Fig. 7 A collage activity is used to support storytelling

Fig. 8 Students and people in care review publication content

5.3 Storytelling & Validation

Materials generated through the co-design activity sessions are then collated and refined by students into publications that can be returned to participants and shared with their families and care home staff (Figs. 9, 10, and 11). This typically sees the groups telling stories together and participants expressing a sense of pride in what they have created. There is often a performative aspect of the storytelling session, with live readings from people living in care and even instances of individuals singing songs and performing to all groups. Dementia often means a person goes through "biographical destruction", seeing their identity and image restricted [56]. This celebration of individual stories allows participants to celebrate their experience and identity, providing a great sense of pride, and also allows them to actively contribute to solving their own problems surrounding identity and self-expression [57].

Having run the project four times, there have been opportunities for some people living in care to repeat the program multiple times. One participant even returned for a third time and proudly displayed her two previous program outcomes in the first session with her new group. In this instance she became the expert designer, using her previous experience to inform students on how to best proceed with their co-creational activities [58]. This also demonstrates that getting to know someone takes time and is never complete. Filling out a 'Getting to Know Me' form at the point of transitioning into a care home will not sufficiently enable to staff to know a person. Opportunities for ongoing story-sharing can be valuable.

5.4 The Research Study

A qualitative research study was conducted with ethics approval by Emily Carr University (Research ethics #: 100246) and the University of British Columbia (UBC; research ethics #: H18-01781), seeking to explore the impact of the Perspectives program for the participants.

5.5 Method

The study consisted of interviews with long-term care participants, a pre- and post-survey with students, and an observational study during the program. The observational study involved making detailed notes regarding engagement and interactions within the sessions. Care home staff were also involved in mid and post program interviews, during which they were asked about

Fig. 9 Example of a group's finished publication in the form of a comic book

David likes traveling, went to Alaska, California, Las Vegas, San Francisco, Vancouver Island by driving. Been to Thailand, Bali.

Fig. 10 Example of a group's finished publication

their feelings about the project and the perceived benefit for care home participants.

5.6 Findings

The findings of the research study highlighted many benefits to personhood for care home participants. Notably, staff remarked that they learned things about the people lving there that they did not know before and the final publications also allowed for staff outside of the program to learn more about the participants as well. By utilizing a group format that brought together multiple people living in care and students together, participants also learned things about each other and made new connections and friends within the home—addressing some of the

Chasing Sunsets

Lois-Anne's thrilling teenage years dawned new adventures, meeting the man that would make her the happiest, Wayne. With sleek black hair, brown eyes and a maroon Harley-Davidson, this man was the definition of cool. They were a spectacle at Templeton Secondary, beginning right from the moment Wayne would roll in to pick her up after class on the motorcycle, and then loudly roar off. From there, they could be seen at the PNE or lighting up at parties every week. They would often be found dancing and talking while chasing that teenage dream. Whether at a house party or the beach, her time spent with Wayne truly resembled how it felt to ride into the sunset.

Fig. 11 Example of a group's finished publication

isolation challenges often facing individuals when they transition into a new care home.

Families also learned new things about their loved ones, and were able to have their stories documented in a publication they could keep. Unlike the 'Getting to Know Me' form, the information wasn't simply biographical, covering their lives before entering the home, with many of the publications containing new works. When staff were asked the impact, they believed the program to be having on care home participants one responded:

> Not everybody is going to remember that experience or what happened in the moment, but this document or publication is going to allow them to share with other people, so the lasting experience will go beyond just meeting in the group. Many of our residents have short-term memory loss, but have long-term memory intact. They are able to remember the stories, but they are going to forget they did these group sessions. Family members and fellow residents are going to be able to recall and share this publication with them and enjoy it with others and that keeps the whole emotional experience alive.

When asked how they think this program will benefit or impact care home participants, one responded:

> You also have the staff relationship. The staff will know more about the resident so it's a much easier way to connect. Much like a resident-to-resident. There is no more of a difference but to know someone more and provide meaningful care and honour their personhood and knowing that as staff that this is their person then it goes a long way to affect the way we provide care to them.

When asked how they think the program will impact their knowledge of the people living in care, one staff member responded:

> Absolutely. It will impact the knowledge of our residents… I really want to see how engaged everyone of our community is in this opportunity. It reminds us that we are in a village and everyone has a role and often the elders are the storytellers and they teach us history, they teach us lessons and they give us the experience we need to learn from. Yes we are an institution, yes we provide care in a formalized setting, through the government and all that, but at the end of the day, the care home is a village and it's giving it back to the elders and giving them back and saying you are the storytellers, the shamans and the wise men of the village and so we want to empower them…

5.7 Next Steps

Following four successful incarnations of the program at two different care homes, a How to Guide has been developed to allow other institutions to introduce the program within their curriculum (www.perspectivesprogram.ca). The program has also led to conversations about how to further enable these stories to be shared beyond the program itself—such as adding the publications to the care home library, sharing them during staff meetings and creating pub nights for story sharing.

6 Discussion

Dementia care is big business and growing. To ensure the effective delivery of future services, the current system of care needs immediate attention. There appears to be a gap between the wealth of research in the field of dementia care—and person-centred care more specifically, and the application of this knowledge at a grassroots level of care. Our case studies illustrate the importance of a person's life history and identity for people with dementia—both to their sense of self and in the creation of quality long-term care. Understanding a person's history, their likes and dislikes, their interests and sensitivities can have an immediate positive impact on care within all environments and can help to support the experience of transitioning into a new home, and a new community. The information gathered about each individual can inform the approach to their care and can be transferred between different care providers to maintain quality care at all stages and within all environments. The important challenge that our case studies address, however, is the development of creative and accessible methods for collecting and documenting these histories.

The Design + Storytelling framework is a way of better understanding people through storytelling [59]. The framework advocates the use of storytelling as a research methodology, as storytelling reveals more social context than a typical interview style of investigation. Storytelling is naturally a collaborative activity, with a story being created not just by the person telling the story, but also by the person listening to the story and responding to it. Stories expressed by people living in care during the activity sessions in Case Study 2 undergo a process of narrative analysis to identify the key themes that are important to the participants, and they then become the focus of further exploration and future activities.

The ReCollect system (Case Study 1) and Perspectives Program (Case Study 2) enables the residents to translate information into a permanent record through the power of storytelling. Going through this process in the early stages of dementia helps to reinforce the person's sense of self and identity [9] The activity brings families to a deeper level of understanding, and by asking specific questions, it begins to prepare them for the later stages and the potential move to permanent care. In the long-term, when the person with dementia begins to experience memory loss or they have difficulty communicating for themselves, this collection of valuable information provides starting points for conversation and interaction with others. Additionally, the process of reflection and reminiscence [60] may also provide a welcome distraction from the everyday worry of dealing with dementia. These storytelling approaches have a lot of potential as a better ways to get to know people living in care homes. We have shown just two ways in which this can be done, but there are likely to be many more.

Our findings reflect Kitwood's notion of person-centred care [9], where observations and personal accounts from carers indicate that this perspective, and the use of user-specific information, deserve priority. Non-pharmacological interventions, recognising individual needs and the benefits of person-centred care, are increasingly being used and trialled in care environments worldwide. However, many outdated work cultures do not give this perspective priority.

The challenges we see with these concepts that future iterations will need to address are threefold: (1) strategies to manage sensitivities around emotionally charged experiences and the recollection of potentially painful memories; (2) the timing of activities to coincide with early stages of the illness to accommodate communication and informed consent; and (3) managing the personal information once the person with dementia is no longer able to give informed consent, or indeed, after they have passed away. While we see a significant benefit in such information being able to communicate aspects of a person's life story to new and 'unknown' caregivers, challenges remain on maintaining truth and respect to the voice of the person. Further, in both cases, consideration for how these design approaches can be utilized and integrated by staff within the context of their duties is required.

7 Conclusion and Future Work

True understanding comes from conscious listening in conversations. Design methods provide accessible ways to encourage and engage older people and their caregivers in a process of reflection and reminiscence that brings a deeper level of understanding. Such methods also provide opportunities to explore respectful, creative and effective ways to collect and share valuable life stories and experiences so that they may contribute to genuine quality, personalised care for people with dementia. Future research and practice should consider a greater emphasis on the use of personal life history information in dementia care. A challenge we are currently facing is how to recontextualize the work we do for a post-pandemic landscape that restricts access to long-term care homes in a time when connection to people and community is more essential than ever.

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