

Portraits of people with dementia: three case studies of creating portraits

ABSTRACT

Communication difficulties associated with late-stage dementia can make it difficult for care staff in residential environments to get to know people with dementia. This lack of knowledge can have a negative effect on the social environment of residential facilities which can have a detrimental effect on the health and well-being of the residents and the job satisfaction of the staff. In this paper we discuss the creation of *Portraits* of people with dementia to aid care staff in understanding the individual. The major findings of these case studies include that it is possible for families to create *Portraits* of their relatives within a relatively short period of time, families found the process enjoyable and a good trigger for reminiscence.

Author Keywords: Dementia, Multimedia, Portraits

INTRODUCTION

The social environment in residential homes is essential to the quality of care and quality of life for residents (Ward *et al.* 2005, Ward *et al.* 2008, Caris-Verhallen *et al.* 1997, Burgio *et al.* 2001, Armstrong-Esther *et al.* 1994, Nolan *et al.* 1995, Vasse *et al.* 2010). In many instances interaction with the care staff will be the only social contact for many residents. Despite this, there is considerable evidence showing that there is a severe lack of staff-resident interaction. The issue of staff-resident interaction has been investigated since the 1970s (Vasse *et al.* 2010, Ward *et al.* 2008), but current studies (Ward *et al.* 2008) show that the levels of interaction are still the same despite 30 years of research. Residents with dementia spend an average of just 10% of the day in direct communication with others and 2.5% of the average day is direct contact with care workers (Ward *et al.* 2008). Of all carer-initiated interactions 77% are task-based encounters and only one-third of contact between staff and residents in care homes involves verbal exchanges (Ward *et al.* 2008). As Ward *et al.* (2008 p635) note *“Thus, silence is the dominant mode of caring encounters.”* Armstrong-Esther, *et al.* (1994) found that patients with dementia spent 45% of their time engaged in solitary activities, and Ward (2005) reports that verbal input from residents was often not encouraged and rarely required. Furthermore, Caris-Verhallen, *et al.* (1997) state that the different agendas of staff and residents affects social interaction; residents want to continue the interaction with social talk as opposed to the nurses' need to hurry up because they have work to do. Edberg, *et al.* (1995) mention the fact that, in some cases, it seems the patient continued their vocal interaction with the nurses even though the nurses had left (unpublished observation). Despite this clear lack of social interaction Armstrong-Esther, *et al.* (1994) found that nurses of various grades ranked talking to elderly patients as enjoyable, important, rewarding and an objective for themselves.

Ward, *et al.* (2005) discuss the fact that there is an identifiable structure to most resident-staff interactions: an opening, signal of intent, accomplishment of task and closing. There is no social interaction involved during these interactions with many being carried out non-verbally. Research suggests this standardised format of interaction and communication is due to the experience of completing certain tasks on such a regular basis that this leads to the accompanying communication becoming part of the standard routine also. What is important to note is that this type of communication or interaction is structured around specific care tasks determined by the needs of the individual and the schedule/routines set out by the care environment. If social or informal discussions happen during the formal interactions it is serendipitous rather than an integral and expected component.

In this paper we will present a system called *Portrait*. The overall goal of *Portrait* is to help care staff get to know a person with dementia as a person given the limited time in their work schedules achieving this goal requires families to populate this data. However, before care staff can actually use the system, it must be populated with content foreseen as being created by family members or the person him/herself. This paper reports a study examining the creation of content for *Portrait*. Earlier work has reported on usability testing and feedback from care home managers (Webster, Fels, Gowans & Alm, 2010; Webster, Fels, Gowans, & Hanson, 2011). Here we report case studies conducted with families of people with dementia who live in care home environments by examining the processes involved in populating *Portrait*.

BACKGROUND

Person-centred care is a term widely used within the community of dementia care. Kitwood was the first person to use the term ‘person-centred’ in relation to the care of people with dementia (Brooker, 2004). Kitwood (1997) said that he used the term ‘person-centred’ to bring together ways of working with

people with dementia, to emphasise communication and relationships. While the umbrella term, person-centred care, can mean a number of different subtle ways of working with people with dementia, the critical and common element is that there needs to be an individualised approach to the care of each person with dementia (Brooker, 2004).

Healthcare professionals have increasingly been encouraged to move away from traditional task-oriented models of care to person-centred care which emphasises the patient's perspective, experiences and needs (Timothy, 2003). The term person-centred care has also become synonymous with good quality dementia care with any new approach having to 'claim to be p.c. (person-centred) in order to be p.c. (politically correct)' (Brooker, 2004).

Kitwood (1997) presents a person with dementia as a person in the fullest sense: he or she is still an agent, one who can make things happen in the world, a sentient, relational and historical being. Staff caring for people with dementia can face an impossible job, trying to provide a positive environment, with low staffing levels and large groups common practice in care homes. Staff can struggle to balance the social needs of an individual with that of the person's physical needs and the group as a whole. Marshall (2001) discusses the difficulty involved in providing good quality dementia care with residents because there can be communication and interaction difficulties, high levels of incontinence, problems with eating and impaired abilities. These difficulties plus the fact that staff often do not have the time, or the energy, to provide more than the basic physical needs, means "*It is all too easy to blame the dementia for the extent to which patients spend their time sleeping or sitting apathetically around the walls of the communal areas. In a sense dementia lets staff at all levels and those responsible for quality of care, off the hook.*" (Marshall, 2001, p.2). What is needed then is ways to enable staff to add the

informal elements into their communication strategies that are comfortable and interesting too all involved.

CURRENT TRENDS IN DEMENTIA CARE

Current practices that attempt to promote the person-centred approach to dementia care include reminiscence work, care plans, life stories and memory boxes.

Reminiscence is the act of remembering or recalling past experiences and is an activity that is commonly undertaken in care homes. It takes advantage of the fact that the long-term memory of a person with dementia may be relatively intact even when their short-term memory is severely affected (Alm, *et al.*, 2004). Reminiscence can take many different forms. It can be carried out as a group activity with objects, photography or music to stimulate discussions about past events, traditions or places within the group. It can also involve life review stimulation and oral history (Bender *et al.* 1999, Davis *et al.* 2010). Regardless of how it is implemented, Bender, *et al.*, 1999 showed that reminiscence can have positive effects for the person with dementia and the care staff.

Life stories, memory books, and scrap books are all documents that are produced with photos and stories relevant to the life of a person with dementia for the purpose of reminiscence. Life story books are filled with a person's experiences, achievements and life history. They can be used to help the person with dementia remember past events, to aid conversation with relatives and carers, to involve families in the care of a person with dementia in a positive way and to remind carers that the person had a full life before entering a home. Past life experiences and a person's history can help care staff to better understand current patterns of behaviour, to encourage interaction between care staff and residents and to help care staff see beyond the disease (Kennard, 2006). There is a limited amount of research

investigating care staff-family relationships in long-term care settings (Duncan & Morgan, 1994, Haesler, Bauer, & Nay, 2006) despite family involvement having a strong positive effect on resident's well-being (Haesler *et al.*, 2006). For family involvement to be successful within the care environment Duncan & Morgan (1994) state that the family's efforts must be integrated within care staffs formal routines.

Care plans or Personal plans tend to hold little information on the service user's personality or life, focusing instead on the physical care of a service user as opposed to their social needs. They are legally required documents created for each person who is entering a care home (The Social Care and Social Work Improvement Scotland (Requirements for Care Services) Regulations, 2011). The care plan contains information about medical history, hospital history, risk assessment (for lifting and handling, health and safety, infection control etc.), weight charts, fluid charts, blood pressure charts and daily nursing plans. These plans focus on actions designed to solve or minimise existing problems. They describe systematic processes to meet all the needs of the service user.

To date most work on tools for dementia has focused on solutions for the person with dementia, not on solutions for the caregiver. For example The *Computer Interactive and Conversation Aid (CIRCA)* software (Alm *et al.* 2004, Alm *et al.* 2007) and *Multimedia Biographies* (Smith *et al.* 2009, Damianakis *et al.* 2009, Baecker *et al.* 2006) allow people with short-term memory loss associated with dementia to draw on reminiscences to converse with relatives and carers. *Biography Theatre* is an in-home ambient display designed to be placed in the home of a person with Alzheimer's disease. It shows the person's digital life history in the form of music, photographs, movies, and narratives (Massimi, *et al.*, 2008). All of this work is focused on communication or reminiscent support for people with dementia rather than by care staff to understand important social or personal information about the individual with dementia.

None of these projects specifically focused on looking at the processes involved in gathering the information for such *Portraits* or how families identify which information to include.

FAMILY CASE STUDIES

The *Portrait* system consists of a multimedia portrait for individuals with dementia who live in a care environment. It is intended to be used by the care staff in that environment to gain an initial understanding of that person's life prior to entering care and to learn more personal information about their needs and habits. The *Portrait* system contains important but limited personal and social information about the people with dementia for their care staff to access. Specifically, each portrait contains information about the person's key life events, family, important things to know, preferences, and hobbies and interests. The portraits are presented on a combination touch screen/computer system and are designed to be used for about three to five minutes (see Webster *et al.*, 2010; 2011 for further description and images). However, it was uncertain as to whether persons with Alzheimer's and their families would be willing to complete portraits. Further, we wanted to understand the effort and resources required to populate a portrait in order to determine the feasibility of implementing the *Portrait* system as a stand-alone entity and any training materials for families or individuals that might be necessary.

A study with families of people with dementia who live in a care environment was thus carried out to examine:

- a) How would the information required for populating the *Portrait* system be collected?

- b) Who would be involved in this collection process?
- c) How time consuming and difficult is populating *Portrait*?
- d) What information would be included in the *Portrait*?
- e) Is it possible for family's to create *Portrait's* of their relative?

Participant families for the study were recruited from the population of residents in two care homes belonging to the same care group. The study was approved by the University of Dundee ethics committee which was acceptable to the care group operators.

As people with late-stage dementia can have communication difficulties and due to ethical issues, the researchers recruited the families to take part in the study rather than the people with dementia. To ensure there was no disruption to the person with dementia's daily activities or health care the researchers only interacted with the families.

As *Portrait* is for people with late-stage dementia living in care environments it is likely that in many (perhaps most) of the cases the *Portrait* of the person will be created not by them, but by a family member. While it could be hoped that the family's information about the person accurately represents the person's life and preferences, it can be imagined that if the person were writing their own portrait some of the information would be different. In this respect, future research should seek to have persons newly diagnosed with dementia involved, to begin capturing important information about their lives.

METHOD

Participants were recruited through their relative's respective care home through a 'Relative's Meeting' held at each care home. In this meeting the *Portrait* system was introduced in a demonstration and then families were shown the '*Portrait* Creation Pack' which consisted of 6 forms to complete to help guide families while gathering the information required for the *Portraits*. The *Portrait* system was positively received by the families with many expressing an interest in the study.

In the first care home (Care Home P) visited, one family was recruited. Two families were recruited in the second care home (Care Home B). Once families were recruited a meeting was arranged with each family to review how the *Portrait* system worked, answer questions and to provide them with access to it for as long as they wished. Once all questions were answered by the researchers, the families were given a verbal explanation of the study along with an information sheet and were asked for informed consent in compliance with the University of Dundee's ethical guidelines.

Data were collected using a pre-study questionnaire and observations. The pre-study questionnaire consisted of 13 questions and collected demographic data such as age, relationship to the person with dementia and time in care environment. The pre-study questionnaire also gathered information about participant's opinion of how long it would take to gather the *Portrait* information, who they anticipated would help and how they would collect the information.

During the process of gathering the information for the portraits, the researchers maintained contact with the families by having regular meetings to answer any questions and assist the families when needed. As one of the aims of this study was to see what type of information would be selected for inclusion in *Portrait*, the researchers did not assist with identifying the content to include.

Once the families had gathered all the content for the *Portraits* the researchers manually entered the information into the *Portrait* system. When completed, the final *Portrait* was shown to the families and any changes requested by the families were made. At this point the *Portrait* of their family member was considered complete.

RESULTS

PARTICIPANT 1

At the time of the study, Miss E was an 83-year-old Scottish female and had been living in the specialist dementia unit of Care Home P for 4 years. This was Miss E's only care environment. Miss E had been diagnosed with dementia for over 5 years. Her family described her as having late-stage dementia, stating that she no longer spoke, and rarely said random words.

Miss E's niece-in-law (V) consented to participate in the portrait creation and was the researcher's only contact from the family during the study. Miss E was never married and had no children but had been very involved in her two nephew's families. Her nephews and their wives were her main family carers and oversaw her care.

V was a retired female over the age of 60. She intended to complete the information for the *Portrait* in two or three sittings over a one week period with the help of other family members.

Portrait Creation Process

The researchers visited V a total of 4 times during the process of gathering the information that lasted two months. V provided the *Portrait* information in sections, completing one section completely before starting another. Two of the meetings with V lasted over an hour (first and final) and two were very brief lasting only ten minutes when the researchers collected the completed information.

V took over two months to complete the *Portrait*. V's family withdrew her from the care facility which translated into V being withdrawn from study. For this reason the completed *Portrait* was not able to be included in the Care Home Study. V stated that she found gathering the information enjoyable but spent a long time waiting for other family members to provide her with the photographs she wanted.

PARTICIPANT 2

Mrs. MM was an 86-year-old Scottish female and had been living in Care Home B for 3 years. This was the only care environment Mrs. MM had lived in. Prior to entry she was living with her husband at home. Mrs. MM had been diagnosed with dementia for over 5 years. Her family stated that she sustained two strokes seven years ago, when she was 78. This was followed by the onset of dementia and the loss of mobility. Mrs. MM's family visit her every other day, taking her out of the care home for the afternoon to go for a drive, picnic or dinner.

Mrs. MM's son (D) consented to participate and was the researcher's only contact from the family during the study. Mrs. MM was married and has two sons. D lived locally and visited every other day. Her other son visited regularly.

D was a male between the ages of 50-59. He was an author who worked from home. D intended to complete the information for the *Portrait* in sections and within two weeks. He did not intend to involve other family members.

Portrait Creation Process

The researchers visited D three times throughout the *Portrait* creation process, two before he began the *Portrait* creation process and then at the end when he had completed it. D preferred to contact the researchers through email.

D delayed working on the *Portrait* for about one month due to other commitments/priorities. D stated that once he made the decision to make gathering the *Portrait* information his top priority he was able to complete it easily within one day. He then emailed the entire package to the researchers.

D found gathering the information quite an easy task as Mrs. MM had been exceptionally organised. She kept diaries and sorted all of her photographs into albums with details of where the photographs were taken, when and with whom. For this reason D thought that identifying what events/topics to include was easy and was very confident that the information he provided was accurate. As a result of the quantity and quality of the information for Mrs. MM, a very full and detailed *Portrait* of Mrs. MM's life was created.

PARTICIPANT 3

Mrs. Ma was a 95-year-old Scottish female who had been living in the Care Home B for five years. This was Mrs. Ma's only care environment. Prior to entry Mrs. Ma was living on her own at home. Mrs. Ma did not have dementia but her family thought that helping care staff to learn more information about any resident was a good idea.

Mrs. Ma's granddaughter (T) consented to participate and was the researcher's only contact from the family during the study. Mrs. Ma had a large family with frequent visitors. Mrs. Ma was married but her husband had passed away; she had 4 children, 10 grandchildren and 15 great-grandchildren.

T was a female between the ages of 30-39 and was working away from home Monday to Friday. T intended to complete the required information for the *Portrait* a section at a time by identifying photographs first, in between 1 and 2 weeks, with the help of her Mother (Mrs. Ma's Daughter) and Mrs. Ma herself.

Portrait Creation Process

The researchers visited T only three times throughout the *Portrait* creation process (Relative's meeting, once at home and once for the final demonstration). T preferred to communicate with the researchers via email.

T took two weeks to complete the process and emailed all of the required content as one large file. When viewing her completed *Portrait* T stated that she went through family photographs and identified the key points she wanted in the *Portrait*. Once these points were identified she discussed them with her mother and Mrs. Ma to confirm the information was desired and accurate.

T found collecting the information was an easy task and was able to collate all of the information at one time. Having the assistance of T's Parents and Mrs. Ma herself made the process of gathering the information simple and quick. T said that she found the process enjoyable as it allowed her family to remember many happy memories. T would strongly recommend making a *Portrait* to other families.

DISCUSSION

A main finding from these case studies is that it seems possible for families to create *Portraits* of their relatives within a relatively short period of time.

The information required for populating *Portrait* was gathered in different ways by each family with some selecting photographs and matching information and others identifying topics and matching photographs. The *Portrait* creation pack seemed to provide sufficient guidelines and support for collecting and collating materials that could be contained in a *Portrait*.

However, providing more immediate feedback as to how the information would be displayed in a *Portrait* was suggested to assist family member's motivation and identifying what is missing once the process begins. We noticed that every family had provided additional or 'spare' photographs or information during the creation process. If the family was able to create the *Portrait* on the computer directly while gathering the information they would have instant feedback and not need to collect extra, unnecessary materials. This is a step towards a simplified process and further studies are required to investigate the possible development of a method. The impact of *Portrait* on care workers has been investigated and reported elsewhere (Webster *et al.*, 2010; 2011).

Previous studies such as *Multimedia Biographies* and *Biography Theatre* that involved the families of people with dementia in the process of gathering information found similar results (Massimi *et al.* 2008; Smith *et al.* 2009; Damianakis *et al.* 2009; Baecker *et al.* 2006). These studies reported that families found the process enjoyable, and a good opportunity to reminisce about past memories. They also suggested that it was feasible for families to develop a portrait of their relative's life. Gathering information for the *Portrait* system did not seem as lengthy as reported in previous studies. Other studies have reported a typical time was between one and two months (Massimi *et al.* 2008 and Smith *et*

al. 2009). One reason why there is a difference in duration for gathering data between *Portrait* and the *Multimedia Biographies* system is that *Portrait* only required a limited quantity of information and detail, while *Multimedia Biographies* and *Biography Theatre* projects required more detailed information and targeted a different audience (Massimi *et al.* 2008 and Smith *et al.* 2009). Also, the *Portrait* system in general did not actively involve the person with dementia as it was targeted at people with late-stage dementia who ethically could not consent to participate. As a result, family members were responsible for collecting and filtering the information; the issue of fatigue during the process for the person with dementia postponing the collection until another session was not a factor (Smith, *et al.*, 2009). It is uncertain as to how specific advantages and disadvantages of each system compare and would affect care practices in the long term. One future research direction would be to systematically compare the acceptance, use and impact of each type of system on family involvement in the care process, care worker procedures, processes, and attitudes.

Who would be involved in the collection process will depend fully on the family and person with dementia's current situation and structure. The information included in the *Portraits* was all very different and unique in some topics, for example 'Please Note' contained preferences for some people and important family information for another. There was a similarity among participants for other topics, such as 'My Life Events' where childhood, working life and family was often discussed. Further research with families would possibly begin to identify more common patterns as to the type of information contained in the *Portrait* system.

How time consuming and difficult families find populating *Portrait* again depends on the situation of each individual family. Families with access to organised photo albums or diaries can identify the information easily and quickly. Whereas families who have "a box full of photographs" may find it

more time consuming to sort through. Although there was a large variation in the time taken by each participant to gather the information for the *Portrait*, none of the participants stated that they found it a particularly difficult process. Waiting for information from other family members or having other duties and activities such as work, had the largest effect on how long the gathering of the *Portrait* information took, rather than families finding it a difficult or time consuming process.

LIMITATIONS OF THE RESEARCH

The small number of participants in this research is a clear limitation and we recommend further case studies involving families of people with dementia are required to create generalised processes that could be followed to help families when gathering the information for the portraits. The results, while suggestive, cannot therefore be considered representative of the entire industry. However, the case studies with families did provide initial indications of the potential benefit of the *Portrait* system and technology in care environments.

Also it is likely that all of the cases reported in this paper, the *Portrait* of a person with dementia was created by a family member, and we suggest that this would likely be the situation in future cases. We assumed that that the family's information about the person accurately represents his or her life and preferences, it could be that if the person were writing his or her own portrait some of the information would be different. In this respect, processes that seek to have persons newly diagnosed with dementia begin capturing important information about their lives could assist in mitigating this limitation and rely less on the family's input. It would also transfer responsibility for the content to the affected individual rather than delegating it to family members. Further research is required to examine how *Portraits* would change and how people with dementia would react to the task of creating a self-*Portrait*. *Portrait* is not designed to be a static system but to be a dynamic system that can change with the person with

dementia. *Portraits* effect as a person's identity possibly changes was not addressed in this study and needs to be investigated in detail with families and people with dementia.

CONCLUSION

Through in-depth investigations with three families it was found to be possible for people to create *Portraits* of their relative's lives using specific topics such as key life events, preferences and hobbies or interests.

We found that families used different strategies for gathering information to populate *Portrait*. However, all three participant families were able to complete the process in about one month. The family that took two months had holiday in the middle of the process demonstrating it is possible to leave the process and come back to complete.. None of the families thought that the process was a difficult or time consuming, but balancing *Portrait* creation with other life events resulted in the one month average completion time. Families found the process enjoyable and a trigger for reminiscing.

Further case studies involving families of people with dementia are required to better understand the processes they use and whether there are any common patterns that could be used to make the process/system more efficient and provide generalised guidelines for families.

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