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Enabling Self, Intimacy and a Sense of Home in Dementia: An Enquiry into Design in a Hospital Setting

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ABSTRACT

Design and digital technologies to support a sense of self and human relationships for people living with dementia are both urgently needed. We present an enquiry into design for dementia facilitated by a public art commission for an adult mental health unit in a hospital in the UK. The interactive art piece was informed by the notion of personhood in dementia that foregrounds the person's social being and interpersonal relationships as sites where self is maintained and constructed. How clients, clients' family members and staff used the piece is reported and insights related to the notions of home, intimacy, possessions and self are presented. The art piece served as window on both dementia and the institution leading to a number of insights and implications for design.

Author Keywords

Dementia; intimacy; self; home; empathy; dignity; design.

ACM Classification Keywords

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

General Terms

Design, Human Factors.

INTRODUCTION

Dementia and the context of life for people living with dementia has become an increasingly important topic in HCI and Design over recent years [cf., 25]. Dementia has a profound effect globally and on each individual living with the condition. Globally, there are estimated to be 35.6 million people with dementia and this is expected to rise to 115.4 million by 2050. In fact, about one-quarter of all hospital patients aged 65 and older are people with Alzheimer's disease and other dementias [2]. Despite this, it is the focus of little research in the field of HCI, with efforts primarily being directed towards supporting ageing in place [cf., 23]. Likewise, research that foregrounds the role of design in dementia is still under-explored [14].

This paper describes an interactive art piece (*Tales of I*) that was commissioned for a hospital in the UK specialized on the assessment and treatment of older adults with severe dementia. The development of *Tales of I* enabled us to engage with staff in the unit and gain an in depth understanding of the care environment and the routines of hospital life. This revealed certain complexities and a set of particular design challenges. Furthermore the art piece served as a window on dementia and the institution itself. We detail the design of *Tales of I* and the design rationale, which has been informed by the concept of personhood [16] in the philosophy of dementia care. The piece was motivated by the desire to create a valuable resource for clients and staff that centered on a notion of home and offered connections to a number of themes which were suggested by staff through workshops.

Through interviews with staff, we were able to gain insights into nuanced complexities of their practice when engaging with people with dementia and from these propose a number of implications for design. We also unpacked key dynamics occurring around clients' interactions with the piece. These related to intimacy, home, sense of self and possessions. Our account is not intended as an evaluation of an art piece and its design. Rather, we describe how the art piece can serve as a lens onto this care environment and the people within it in the spirit of Gaver et al.'s *Prayer Companion* [12]. As a tool of enquiry it revealed valuable spaces for design in dementia that have wider implications for interaction design.

This paper centers on understanding users in the extreme context of severe dementia within a hospital setting. We highlight dynamics and challenges in the hospital setting that were revealed through the use of the art piece, which help us to understand severe dementia and staff-client exchanges more holistically. We reveal nuanced and multi-textured aspects of what it means to have severe dementia and the themes of personhood, intimacy, sense of self and home are shown to enable a rich understanding of this context and how this can help us to design in this environment. We highlight spaces for design to make a positive difference and show how understanding users can inform sensitive empathic design. We suggest that a

designer should step back from constraints emphasizing the institutional environment or cognitive impairment and instead focus on enabling the full person.

THE PUBLIC ART COMMISSION

The art piece *Tales of I* came into being through a public art commission for a specific care and treatment unit (which we will refer to as Francis Place) in a new annex of a hospital in the UK. Francis Place is a secure unit for up to 16 clients with psychiatric disorders (predominantly severe dementia) and mainly accommodates male clients. The unit specializes in the assessment and treatment of these clients, who are usually transferred from care homes following extreme changes in their presentation or displays of anti-social behavior. A client's stay in the unit ranges typically from 2-4 weeks depending on diagnosis and treatment plan.

Francis Place was a newly constructed facility, predominantly white and unornamented, with a wide corridor that meandered through the whole unit around a series of courtyards. There were a number of spacious dayrooms, individual bedrooms for clients, a dining room, and a few much smaller rooms.

Workshops with Staff

We ran two workshops with staff from the hospital. The informal brief for the art commission indicated that pieces should reflect the care conditions and context of the unit. On our part we wanted to use the opportunity to build on our previous projects with people living with dementia [31] and create an interactive art piece that enhanced the lives of clients and staff within the unit.

The All About Me Books

From the workshops we learnt about staff practice, the kinds of activities that clients' engage in at Francis Place, general context of clients' experiences within the unit and gained insights into clients' behaviors (without any identification of specific clients). Staff members' work with clients included: support of their moods, engagement in acts of reminiscence by using photographs of objects to promote recognition and conversation. They work to de-escalate feelings of distress through the use of gentle hand holding, walking together and calm conversation about things that were meaningful to clients. This last point was enriched by the use of *All About Me* books, which staff members produce for each client. These A4 paper books detail a client's life story, likes and dislikes and include personal photographs. Family members supply much of this content, and photographs are scanned and printed for the book by staff. The simple premise of the *All About Me* books underplays their value in the unit. The books offer family members a way to contribute to the wellbeing and care of their relative both in the supply of information and in the use of the book during visits. Moreover, the books enable staff to get to know a client and see him or her as a multi-faceted person; someone who has had a life's worth of experiences and achievements; an individual.

Exchanging Existing Practice

The workshops and subsequent visits to the unit enabled us to spend time with staff fulfilling different roles including occupational therapists, qualified nurses and auxiliary staff. We were able to show staff previous projects that had involved a sustained and meaningful engagement with people with dementia in the research process [31] and that typified our person-centered design practice [24, 30, 35]. This prior experience allowed us to engage in rich and creative conversations with staff about what the art piece could be. Our commission was the last to be developed for the site; therefore, we were able to see the other pieces of art in situ in the unit. These included wall based sculptures, each with tactile qualities. A variety of material and color has been used and the pieces were made by a number of different artists. In each case the forms were abstract. However, staff explained that these pieces were rarely acknowledged, touched or interacted with by the clients.

THE ART PIECE

Influences & Insights from Previous Projects

As noted the Francis Place art piece was informed by a previous project in which we had engaged with Gillian, a woman living with dementia, and John, her husband, through a co-creative and design-led enquiry [31]. Within this enquiry the notion of *Personhood* had central importance to us. Arising from the philosophy of dementia care, the concept of *Personhood* [15, 16] counteracts many of the damaging effects that traditional accounts of dementia have on common assumptions of self and identity for someone living with dementia. Early accounts present the view that "individuals with dementia experience a steady erosion of selfhood to the point at which no person remains" [17], or in the extreme that dementia causes the "death of self" [9]. In contrast *Personhood* regards self as something not solely constructed internally, but created, nurtured and sustained by an individual's relationships with other people. For Kitwood "personhood is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" [15]. As such, *Personhood* provides a valuable extension to the notion of self. Drawing from this perspective we can understand that, in order to support personhood in dementia, we need to see the person as far more than the sum of his or her cognitive ability. We need to support the 'social being' of an individual, which relates to his or her relationships to things, events and experiences which strengthen connections to the many facets of who the person is. We therefore need to nurture and support an individual's relationships with other people as this is where the person's self is most sustained. Hughes et al. [13] suggest that the people closest to an individual with dementia become guardians of their personhood.

Through our engagement with Gillian and John in the Personhood project we were able to gain a rich understanding of what life was like for them, how dementia had changed their lives and enact the notion of personhood



Figure 1. From left to right: The wall cabinet containing themed globes, the television cabinet with the *Nature* globe and *Nature* film playing, detail of *Holiday* globe with its specific color (top) and detail of the room locating the art piece (bottom).

within the design process to make pieces that were both social and relational. We were able to see how artifacts and digital technologies could play valuable roles for them. We saw how they used the artifacts we made (including a digital locket holding Gillian's photographs, a digital jewelry box through which they could record memories to different jewelry objects) as tools for self reflection, for reminiscence, for comfort, reassurance and as receptacles of aspects of identity to be passed on to their children. It is key to mention that this engagement deeply informed our approach at Francis Place.

Elements of the Art Piece

Tales of I comprises two pieces of furniture: a wall cabinet and a television cabinet (see Figure 1). The sculpted casing of the wall cabinet has colorful vinyl graphics on its surface and a thick, transparent acrylic door that locks. The interior of the cabinet is made from walnut inlaid with resin in various colors and houses a series of globes. Each globe is made from clear cast resin of optical quality to reduce discoloration over time and each encases objects that relate to a different theme: *Holiday*, *Football*, *Nature*, *Local*, *Objects* and *Making*. Beneath each globe is a wooden drawer containing tactile materials that relate to the particular theme (for example velvets, feathers and spiky textured objects accompany the *Nature* globe). The base of each has a resin inlay of a specific color that corresponds to the recess in which it sits (see Figure 1). In its aesthetics and materials the television cabinet echoes the wall cabinet and has a colorful vinyl graphic of a doily with a central circular recess that a globe fits into. The screen is fronted with a thick sheet of clear acrylic and the cabinet has a prominent volume control dial to the top right hand of the screen. Hidden behind a sliding door is an on/off button and a USB port.

The television cabinet houses a computer, a screen, an RFID reader and a USB hub. Once a globe is selected from

the wall cabinet and placed onto the television cabinet a film begins to play. Radio frequency identification or RFID tags in the base of each globe connect with an RFID reader positioned under the top surface of the television cabinet, which triggers the correct film to play. Each bespoke film is between ten and fifteen minutes long and relates to the theme of that globe. Films were made from a combination of footage that we took ourselves on location, footage shot of domestic and popular culture artifacts from the archives of a local museum dating from the 1930s to present day, footage from a local creative film archive and footage from the archives of the particular football club of the area. Films loop if a globe remains in place on top of the television cabinet and a new film begins once a different globe is placed on the cabinet. Different films have different qualities and tempos. For example, the *Holiday* film has a lively cadence with much color, the *Nature* film has a much calmer, slower feel to it and the *Football* film has a more reportage nature using old television coverage of matches, which have commentary running over the top of them along with audio tracks of crowds from matches running over the top of film footage from the stadium over the years and images of different players from the team.

Finally there are in addition a large number of USB memory sticks that accompany the piece. Each memory stick is associated with a client, onto which staff can place any personally meaningful images and film clips supplied by a client's relatives and friends. Once a client's memory stick is plugged into the television a slideshow of this content plays. The software of the cabinet is set up to play files in alphabetical and alphanumerical order; images stay on screen for ten seconds before moving onto the next image and the full sequence loops once it reaches its end.

Design Rationale

Through the workshops we developed ideas that were grounded in both daily life in the unit and staff practice. We

were motivated by several dynamics. Firstly, the *All About Me* books, which were clearly a valuable resource, used for many purposes and supported creative interaction with clients. Secondly, as a newly built unit Francis Place did not offer many vibrant spaces or any stimuli that a client would recognize from the outside world. The unit, although clean and bright, looked and felt like a medical institution. Other than a client's bedroom there were few spaces that felt private or cozy, which motivated us to create a home-like space.

A Home-Like Space

A couple of rooms within the unit had signage describing spaces as *quiet rooms*, but we learned that they were rarely used and had yet to be given a purpose. We developed the art piece for one of these rooms with the aim of both enlivening the space and creating a welcoming but private space – akin to a living room – that family members might sit in with their relative to watch the *Tales of I* films together, and talk about the different stimuli that the films presented. Likewise, staff would be able to use art pieces here for reminiscence activities, to de-escalate someone's anxious behavior and to build on current practice, to enhance an individual's sense of wellbeing, through discussion of things that were meaningful to the client and the use of stimuli that a client found visually and aesthetically pleasing.

The Role of Aesthetics and Beauty

By placing the cabinet just outside the quiet room we hoped that clients would naturally see it during the many hours they spend walking in the corridors, be attracted to it, and want to interact with its contents. To this end a sweetshop window and a cabinet of curiosities inspired the design with a view to engaging interest and fostering a sense that something 'good' was inside. We were aware that clients had little interest in the abstract sculptures that made up other art pieces in the unit. As such our use of color, variety of materials and detailed colorful scenes that were captured in resin globes were all intended to catch the eye and provoke curiosity and fascination. The detail inside each globe was intended to hold someone's attention and interest on closer examination as he or she drew closer to it. We used walnut with an expressive grain and the vinyl graphics and resin inlays were added with precision. It was important to us that the piece was well made, interesting and beautiful as we wanted to convey to clients that they were valued and deserved beautiful things. The value of beauty and aesthetics in attracting people to artifacts is a well-documented phenomenon, but particularly well articulated in Killick and Craig's work [14], in the field of occupational therapy, who emphasize the value of creativity and beautiful artifacts for people with dementia.

The value of Recognition and Familiarity

The television cabinet referenced 1950-60s furniture; something that would be *known* by clients from their youth and that suggested *sitting* and *watching*. The piece was intended to be suggestive of a home environment, and staff

helped to provide curtains, a lamp, comfortable chairs and a sofa. In doing these things we were able to start to shape the room into something that offered an intimate space. In this way the art piece became connected to the room, and the room reflected a home-like space. *Tales of I* offered a tailored experience with a variety of film content that spanned very general subject matter, as well as local identity and very personal things.

We hoped that we had provided an informal space where families could behave in more natural ways than the rest of the unit afforded. It was also important to us that we provided the means through the art piece for family members to be able to make connections with their relative through the use of the films and various artifacts of the piece and so aid more positive visits.

Themes

The themes of the globes arose through conversation with staff in the unit, who made specific requests relating to content that would hold relevance for their clients. Each globe encases a scene or a series of small objects. For example *Nature* holds butterflies that are local to the area and *Football* encases images of well-known footballers from the local team over past decades. The globes were made to be light and easily held or cradled in the hand. Tangible interaction with the globes by clients was an important design consideration and we hoped that they would be touched and explored. To add to this drawers beneath each globe held a mixture of tactile materials to allow a multi-sensory experience when watching the films. Through the films we aimed to draw on the local identity of the area, which we hoped would resonate on a personal level for many of the clients as almost all had lived in the area all of their lives. This allowed us to involve close detail of the local character, culture and industry of the region.

Another of our goals was to build on the practice of using *All About Me* books and create a way that personal imagery and video from a client's life could be made into a short film that could be played for them on the television cabinet. Staff had already invested time scanning in photographs brought in by clients' relatives for the books; these images could now also be used as part of a personal film for a client and be supplemented by short film clips provided by relatives. The dynamics of the display of films (timings and cut effects) were discussed with staff in the unit using demos in situ as the piece developed. We hoped that these films would enable a truly personal experience for the client, that they would supplement the varied uses of the *All About Me* books and would give family members a greater opportunity to contribute to the care of their relative and communicate with them during visits. However, at the point in time of our evaluation the 'All about me' memory sticks had not been deployed (due to staff changes on this unit).

FINDINGS & IMPLICATIONS

As part of a service evaluation for the art piece, we conducted semi-structured interviews with members of staff

in the unit, including 2 ward managers, 1 occupational therapist, 1 auxiliary and 7 qualified staff nurses. Interviews were conducted on the day of installation, and in months 1 and 3, lasted on average 30 minutes and were audio recorded, transcribed and analyzed in-depth by following Braun and Clarke's thematic analysis approach [6]. We asked staff about their experiences and observations of using the piece with clients and adopted the most ethical approach that we could in this context: one that added no additional burden for clients. Clients in the unit have extremely challenging and complex behaviors and the staff group, who have a very person-centred form of care working one-to-one with clients were perfectly positioned to act as client advocates to give us feedback over the prolonged period of use that formed our evaluation.

General Engagement with the Piece

The log data for 143 days of deployment indicate that globes were placed on the cabinet to trigger a video on 308 occasions. On 57 days no interaction was logged. However, these non-interaction days are evenly distributed over time (see Figure 2).

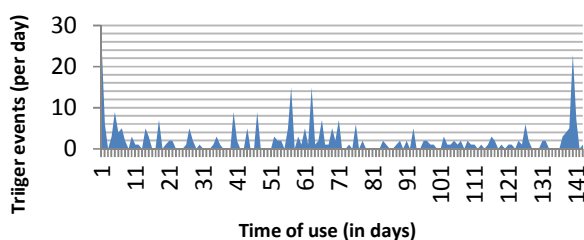


Figure 2. Number of video events triggered per day.

On average, videos were triggered 5 times per day (*modal value*), with a maximum of 27 interactions on one day alone. The *Football* and the *Holiday* globes were used most commonly (73 times each); *Objects* (54 times); *Nature* (35 times); *Local* (28 times); and *Sewing* (23 times).

Our interviews with members of staff revealed that the piece has been appropriated for different purposes: for individual reminiscence practices; to calm, relax and engage clients who were exhibiting challenging behaviors; to assess a client's memory span and life history; and to assess and improve the communication skills of trainees learning to work with dementia clients. The room became several different spaces within the hospital environment.

Space for Relaxation for both Clients and Staff

The room had been used to calm clients down, when their behavior escalated or when they felt anxious or agitated, and was also found to be relaxing space, where staff could sit with a client quietly. Here, clients could be distracted from experiencing distress and become more settled in their presentation. Interestingly, the room was also used to calm down members of staff. For example after a serious assault by a client. *Nature* was described as being particularly good

for relaxing clients and easing conversation. Expanding on this, one ward manager (Amy) explained:

"The other thing we're exploring is, you know the nature one? If we've got somebody that we want to do relaxation with, we want to engage with them, it's to put them on. It's the ambience it creates with the music and the pictures. If you're sitting there and you've got long, silent periods, there is something for them to focus on and it doesn't make them feel uncomfortable."

Beyond providing a calming and relaxing atmosphere, the *Tales of I* provided activities that had different characteristics to the more functional activities of care in a hospital environment (e.g. taking medication, being washed or fed). It allowed clients to take part in a personally meaningful activity, something that they could focus their attention on. Clients were generally very restless and tended to wander around the corridors for long periods of time each day. They also had only a short attention and memory span making it difficult for them to concentrate or to focus their attention. Getting the client to sit down in the room, to engage with the piece and watch one of the films, even if only for a short period of time, was described by staff as remarkable. Amy described an event relating to a client:

"And actually their dad [the client] actually sat for ten minutes which was really good because normally he would walk round and round. He would sit for his meal because his meal was in front of him but then he'd get up and he'd continuously walk. And he used to get into a lot of altercations with people. (...) She [the nurse] put it on for him and he sat there. It was [the] football one again. But he sat there and he sat for ten minutes."

A space for Intimacy

Issues of intimacy arose from people's engagements with the art piece and the room in which it was located. It also brought the client's desire for interactions and conversations with other people to the forefront, and the need to have an appropriate space to be intimate and private with somebody within the formal setting of a hospital.

Inter-Personal Communication

Staff described how interactions with the art piece enabled and stimulated conversations about things that were central to the film, but also about a wider scope of topic as this quote describes:

Clare: "...for a particular patient say it's football they might play football or you can talk about when they were younger playing, if they had children or...So it does bring things out.. And then they would talk about like the old football boots..."

This functioning of the piece was as expected and confirms that it was facilitating the kinds of conversations that it was designed to support. Interestingly the piece also created situations whereby the client was the expert about a particular topic shown in the films.

Amy: "[the piece] is also there for educational purposes. You'd be amazed, some of the staff don't even know what half the objects are. (...) prompting them "Well, what's that?" gives some leverage to the client and to instigate conversation."

Staff described this dynamic as exceedingly unusual in the unit and that an occurrence whereby a member of staff

learned something from a client was extremely rare. This dynamic is bolstered further through description of how the art piece functioned when staff, who had not grown up in the area or country used the piece with clients.

Amy: *"Our ethnic minority staff. You know the one [globe] for industry? One of the auxiliaries, (...) he was fascinated to find out why ships were painted half red under the water, and one of our clients was able to tell him."*

This dynamic was one that the ward manager prized about the piece. She described how as a result she encourages staff to use the piece to ask the client questions about things that they genuinely don't know about, rather than merely asking about the known aspects of the film in an effort to engage the client.

Amy: *"That's something else; you've got to get students and staff to say (...) If you don't know where it is, ask. The patient will remember and if they don't you can say 'Well, maybe we can go and find out'...Why can't you go and find out?"*

Moreover staff expressed how such interactions with the art pieces had enabled a more balanced communication with clients than is often possible; staff commented that the interactions were *"proper conversations, even if only for a short time"*, *"encourage[d] two-way conversation"* and were *"more equal"*. Engagement with the piece was perceived as *"an activity where no one's in control of it"*. Normally, the professional relationship between staff and clients does not allow for a reciprocal exchange of personal information. Clampitt [8] describes inter-personal communication as a dance, where partners have to coordinate their movements in order to both understand where they are going. Within the dance he suggests that there are rules and skills, but there are also flexibilities whereby dancers can interject their own styles into the movement. If we consider this analogy within Francis Place it seems that there are a number of common 'dances' that typically occur, where staff predominantly take the lead. What staff were describing around the use of the piece suggests that a few more dance styles and tempos have been enabled in the unit, that the client has been able to take the lead or to change the movement and that this has been enjoyable for the client and staff.

Paula: *"They [the clients] actually, they're toe tapping and some of them have been dancing. The thing is the staff do it as well you know and it's getting to the point where it's a more natural setting."*

As noted earlier we drew heavily on local references and culture for the creation of the films and staff described how these aspects often acted as very strong memory triggers for clients. Staff were encouraged to build an active rather than a passive engagement with the piece. If content in the film was unknown they were motivated to find out about the meanings either from a client or from a different source. The ward manager saw this as a dynamic that had developed because of the piece that created interesting and new opportunities for connection between staff and clients and also between staff and the unit itself.

Staff described how the piece has often stimulated clients who usually didn't talk very much to instigate or be part of a conversation and how this could then lead on to the client continuing this conversation with other clients when he or she left the room and went back into the main unit.

Anna: *"Even with patients who normally wouldn't chat you know? It would just be like constant observation and just wondering around in their own world – we got them in here and then we were able to discuss something."*

The desire staff had to find ways in to a client becomes acute when he or she has limited ability to articulate something. We were told about a client who only used one term to describe whatever she wanted to say. Working with her became about trying to pick up on nuances of her behavior, gestures and intonations to try to understand what she wanted to communicate. This would clearly frustrate her at times, as she would repeatedly say the term in increasing efforts to communicate. Equally, staff would want to understand her and help her and in some situations this would become extremely difficult for them. Staff described how they were able to use *Tales of I* with her to connect with her in new ways, for example through her gestures towards certain aspects of different films or through words that she would say stimulated by the films.

Need for Self-Disclosure, Intimacy & Relationships to Others
This, and other examples outlined earlier, demonstrate clients' need to communicate and self-disclose information to others [19]. In unfolding their inner life by disclosing personal or private information, the client communicates something about her or himself (e.g. personal experiences, meanings attached to events, fact's about their life). The sharing of information with others can increase mutual knowledge and understanding and allows people to better meet each other's needs [28]. As such, self-disclosure supports the development of closeness with others, can increase interpersonal liking and trust, and offers opportunities for sympathetic and supportive responses [19]. Thus, communication in this context should not only be understood as the interpersonal exchange of information on a content level (e.g. a person's memories or feelings), but incorporates what Watzlawik et al. [32] termed the 'relational level' of communication, whereby the relationship between the people is defined through the exchange itself (e.g. as a caring relationship).

The desire to communicate with others and to feel close to them, describes the very fundamental human need of belonging [4, p.497] suggesting that "human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships". Thus, to fully satisfy this need, individuals have to have frequent interactions with other people which should be perceived as providing an interpersonal bond marked by stability, continuation and affective concerns (e.g. that one cares about one another).

In this regard, intimacy is a valuable aspect of interpersonal relationships as it enables the experience of warmth, closeness, commonality and caring [28]. However, establishing a clear and specific definition of the concept is rather difficult. Moss and Schwebel [22] identified five key components describing intimacy as a mutual exchange between people, that is characterized by the receipt and expression of affect (e.g. feelings of compassion, validation of a person's worth, providence of assistance), cognitions (e.g. information about beliefs, values or experiences), physical closeness and commitment. This human need for intimacy, for touch, hugs and kisses and the desire to feel connected to others does not diminish with age. Yet, aspects of closeness, intimacy or even sexuality are often overlooked in discussions about the well-being of clients with dementia in hospital or care settings [11, 18]. People with dementia have the same psychosocial needs as other individuals: "They need stimulation and companionship, they need to feel secure, to feel they are unique and valued individuals, and to feel a sense of self-esteem" [3]. According to Kuhn [18, p.165], enabling them to "maintain their social skills and sense of self in close relationships is essential to enhancing their quality of life".

The Relationship to Staff

Having more natural and equal conversations between members of staff and clients, in which both parties disclose and exchange pieces of information about themselves, facilitates the building of a relationship. Against the backdrop of the fundamental human need to belong to others [4], clients may benefit from the opportunity to develop a relationship with the nurse [33]. They also have the need for closeness in a relationship. Buckland [7, p.33] describes, "the insecurity and loneliness of a dementing illness can make the interpersonal relationship the most important aspect of care". This suggests identifying new ways for members of staff to support residents in their desire for closeness and social engagement with others [18].

In the past, the role of the nurse was characterized by a professional detachment from clients, meaning that the nurse could appreciate the client's situation but was emotionally detached and distant to them. This definition was driven by the idea of a desexualizing of the nurse-client-relationship, where the nurse stays in control over any interaction with the client [cf., 33].

With the redefinition of nursing care as 'The New Nursing' [26], the emphasis of care was extended to include both the caring *for* and caring *about* clients, which includes emotional involvement and commitment to the patient. In this context, closeness or intimacy between nurse and client does not mean having an intimate relationship which is characterized by a deep emotional and personal attachment to the client, which could be an example of over-involvement increasing the vulnerability of the nurse. Instead, intimacy in nursing can simply mean to spend time with clients, to demonstrate appreciation of their

experiences, to self-disclose personal information to facilitate mutual understanding and acceptance in order to build a confiding relationship as a base for an empathic engagement with one another [cf., 33].

Relationship to Family and Friends – Creating a Visit

Clients usually perceive the transition from their home to the hospital as a 'reality shock' [1], and also their relatives can experience emotional distress about their loved one being institutionalized [29]. Involving family and friends in the care of the person with dementia, and facilitating a sense of purpose beyond the 'visit', can be of great benefit to both parties [10]. Family engagements in care are generally valued for "empowering the client and protecting against feelings of helplessness, improving compliance and supporting early hospital discharge" [1, pp.150-151]. They can best fulfill the more intimate and affective needs of clients, but they often feel disempowered to contribute in a hospital setting, and at times do not know how to engage with a person living with severe dementia. *Tales of I* had so far only been used a few times by family members, but was found to settle the client and to help them in visiting their relative Amy described:

"We had a relative (...) use it. They were concerned about their mother. They were struggling when they were visiting, so this was more of an aid for them than anything else, and what the staff were doing was taking them through and leaving them with the key [to the globes], going back for them later."

As such, the room and the engagement with the piece may provide family and friends with an avenue into involvement and care for their relative, without invading the workspace and care practices of members of staff [cf.,1,29].

The Room and the Art Piece

As staff talked about the room and the art piece it was clear that they had become one and the same thing within the unit. The room was described repeatedly by different staff as "cozy" and the intimate setting of the room and what this enabled were reflected upon by the ward manager in terms of privacy and dignity. She described how important it was to give clients and family members privacy during visits. Intimate gestures such as holding hands and having cuddles are needed by both clients and relatives, and staff did their best to give people the space to be intimate.

"We encourage people to visit in the bed areas, as well as the day areas, but we encourage especially couples to visit in the bed areas, because people like privacy and they like to be intimate in the sense of holding hands, having cuddles, pecks on the cheek"

Tales of I had now provided an additional space in the unit for couples to be alone. One point worth noting here is that because the room is accessible to everyone and is located along the meandering corridor people can walk into it not knowing what kinds of conversations are already happening inside, which may feel intrusive. So whilst the room has successfully enabled people to feel that it is a cozy space where intimacy can be displayed it highlights the challenges to the design of such spaces within this extreme context and shared environment.

Sense of Self

The triggering of memories and past experiences had deep implications for care in terms of the sense of self of someone with dementia. The role of familiarity, possessions and home were all key factors in the re-connecting with self that occurred in interactions with the piece.

Value of the Act of Remembering

As described, clients were reconnected to past memories through their interactions with the piece. A key example of this is worth sharing as it demonstrates how important the act of remembering something can sometimes be to someone and how powerful this can be.

Amy: *"This gentleman, (...) he watched the football one, stimulated when he remembered that when he was young his dad had gone to [a famous footballer's] house. His dad had been a friend of [the famous footballer] and he'd sat on his knee. Now, he remembered that, not in the full format of what he remembered at the time. This was before breakfast, about 8 o'clock in the morning. At 3 o'clock in the afternoon he was still talking about sitting on [the famous footballer's] knee. That was fixed, it was there and he was going round engaging with people, telling them."*

This was an exceptional occurrence for this particular client who would typically walk around the unit for hours each day, only stopping to eat meals. Staff were able to get him to sit for ten minutes to watch the football film, which in itself was remarkable. And as the quotes describe he connected with a past personal experience powerfully and moreover this memory stayed with him for hours. Staff described how this had given them something to work with for this client. They used football related imagery and conversation as well as the globe and the football film to connect with the client and build on the sense of wellbeing that he experienced from watching the film.

Furthermore the powerful connection that the client had with the film about his football club suggests that aspects of his identity were bound up with being an avid football fan. Belk [5] states that people define themselves through their possessions by which he is referring to more than artifacts. Personal skills, how someone relates to other people, places and groups all factor in this way. Such 'possessions' Belk asserts contribute and reflect a person's identity and as such are an important component of their sense of self.

As such we can posit that in the case of this client the football film offered him a connection to a piece of himself kept within signifiers of his football club. The film itself contained a piece of him and he was a part of it. This sense of rich connection is a form of ownership. Through this example we can see how even for people who will stay in an environment such as Francis Place only fleetingly it is possible to offer connections to things that resonate with self on a deep level. This example was not an isolated occurrence and staff described other similar accounts. Again, as previously noted, a connection to things that are local and from the local community where an individual is from enable relatively general referents to strike a rich

chord. As Belk [5, p.152] describes: "we exist not only as individuals, but also as collectivities."

Ways in such as the football club for this client are things that staff used to develop a richer understanding of a client's life history. The value of narratives and telling your life story are things that staff frequently mentioned. We tell our life stories to disclose who we are to others, but also to reflect on a personal sense of self and to understand self more. In Francis Place the enabling of clients to tell their life stories is regarded as good care for this reason. Furthermore as part of the assessment process staff are searching to connect a client's current presentation to events from their pasts in order to gain an understanding of why they are behaving as they are.

Amy: *"On the organic side we link it to the life history and what we do is we're trying to find out can we link somewhere in the person's past the presentation we're seeing now."*

Amy: *"You know is what they're displaying to us anything from there or around there and can we work with it."*

Gaining knowledge about an individual's life story was described by the ward manager as a way for staff behavior to be appropriate for a client, which she describes as staff conforming to a client rather than the reverse occurring:

"You know and if you keep people's identity (...) you working with them so even though we have our standard environment (...) we are conforming to them they're not conforming to us."

Transitory Space and Possessions

Francis Place, as already noted, is an assessment and treatment unit. Thus, clients are there for a relatively short period of time. Like most hospitals it is a transitory space. This makes it challenging for staff to get to know clients and to engage them in personal care when the emphasis is often on functional aspects of assessment and daily routine.

Designs that help change a client's perception of the environment from a 'place-less' space to something more recognizably relaxing and homely aids the personal care that staff are able to give. The new build construction of Francis Place meant that, as an environment, there was little or nothing that was old. There were subsequently no other referents of anything 'old' for the clients to relate to or have memories triggered by. Many of the films and objects like the old coins and badges in one of the globes provided a resource for nostalgia. Davis [1979, p.31 as cited in 5] notes the relevance of such longing to the self:

"nostalgia (like long-term memory, like reminiscence, like daydreaming) is deeply implicated in our sense of who we are, what we are about (...). In short, nostalgia is (...) a readily accessible psychological lens (...) for the never ending work of constructing, maintaining, and reconstructing our identities."

You could posit that in the relatively unadorned, new environment of the unit there were few objects that could tell a story and therefore few objects that could fundamentally connect clients to things outside of the unit; to their own lives or to different times from their pasts. Belk [5] and McCracken [21] relate environments in which

people are denied their personal objects or objects that connect them more generally to things that are meaningful in their lives to a dehumanizing of the person. Although within the unit it clearly was not staff practice to dehumanize clients the severity of the clients' dementia meant that they would often unintentionally damage or break any personal possessions. As such each client would commonly own only a few personal artifacts. Therefore Belk's perspective that a lack of personal possessions leads to a "traumatic lessening of the individual's sense of self" [5, p.142] is very relevant in the context of any environment where people with severe dementia live without the evidence of many of their life experiences referenced through artifacts around them. To regard this more generally we could argue that environments in which residents are treated as the same and have the same clothing, the same rooms and the same artifacts is a form of standardization that Belk relates to an elimination of uniqueness and again to a lessening of a sense of self. Furthermore such standardization often relates to an institutional identity being the dominant voice in such situations.

The contexts of *home* and *neighborhood* are argued by Belk to counteract such lack of personal sense of self:

"As with more personal possessions, home and neighborhood have been hypothesized to contribute to sense of self to the degree that a person feels control over them" [5, p.143].

This hypothesis resonates with the work of many anthropologists such as Miller [21, p.1] who stated that:

"We live today in a world of ever more stuff (...) We tend to assume that this has two results: that we are more superficial, and that we are more materialistic, our relationships to things coming at the expense of our relationships to people (...) in many ways, the opposite is true; that possessions often remain profound and usually the closer our relationships are with objects, the closer our relationships are with people."

Tales of I offered a different space in the unit; somewhere where objects *do* feature and objects that reference different aspects of the past at that and staff still had plans to decorate the room further:

Sara: *"what I would plan to do is put some pictures and things on the wall and put some cushions and things in here."*

Jess: *"we still need to get the furniture and things, put in here, to make it look a bit more homely. And a few soft furnishings."*

Possessions can be instrumental to maintaining a concept of self for individuals [5]. Through possessions we create and preserve our own sense of who we are; acts that in themselves contribute towards a healthy identity. For people who have severe dementia possessions clearly have a powerful potential in this respect. Through possessions an individual can reconnect to past identities, to skills once possessed and to the knowledge that he or she has been loved and has commanded respect.

Along with possessions, the role of home equally cannot be underestimated in a care or hospital context. As we have

noted 'home' can engender calm, enable intimacy between individuals and support a sense of self through a connection to things that are known and have a deep meaning. The ward manager also described how the room could act as a form of security and reassurance for clients.

"It's like, some people when you're driving down the street, and you start seeing sign posts that you know, you become more familiar "Well, I'm getting closer to home now, this is now my home." You go down your drive, in your house. Patients on the organic side, they miss them triggers. It could be that they're in a room full of colors or maybe an object, or it even be an individual. Wherever that individual is, they're there with them, that could be their security blanket. They're their signpost."

The environment of the hospital can feel very alien and things that denote a sense of home for someone can act like recognizable and reassuring triggers within these unknown places. For someone with severe dementia who has a very short memory span ways of regularly triggering and retriggering a sense of reassurance and a connection to a personal sense of home has extremely high value.

CONCLUSION

Through *Tales of I* we were able to explore the environment of a hospital unit to draw out implications for design in dementia. The piece became a window on dementia and the institution itself. The ways that the piece was used and experienced by clients, staff and relatives revealed many rich insights.

Home was shown to be an intensely important concept. Home-like spaces can function as a retreat, a space for relaxation and a natural setting to help de-escalate anxiety and challenging behaviors. Home is something familiar, that is recognizable and that a client can relate to. Unlike the hospital environment referents that speak of home reflect the person, aspects of their identity and life history with all its achievements and experiences. By connecting with a client's past staff were able to 'meet them there'.

Possessions, in their widest sense, for instance artifacts, places, groups or local culture can hold parts of a person; they can define and extend a person's sense of self. Therefore preserving parts of the person's self means that possessions play a crucial role in dementia. To design for the support of self we need to value the client's dignity and acknowledge the potential of possessions and of beauty.

When a person reconnects with aspects of self that are triggered by these things staff are able to see them more as a full person. Supporting these re-connections to self enables staff to find ways *in* to a client. Design needs to promote more reciprocal conversations in which clients can contribute their knowledge and share their expertise with staff. Through self-disclosure of personal information a client opens the space for staff to give an empathic response and value the person for who they are. This also fulfills the fundamental human need to connect to others and to be emotionally close to them. Our findings show that there was an urgent need for privacy and intimacy in the hospital

setting. This is often neglected in design for these contexts. In short design should empower the person with dementia. To this end a designer should step back from constraints that emphasize the institutional environment or cognitive impairment and instead focus on enabling the person.

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REFERENCES

1. Allan, D. Negotiating the role of expert carers on an adult hospital ward. *Sociology of Health & Illness*, 22(2), 2000, 149-171.
2. Alzheimer's Disease Facts and Figures report 2011, p.36, from www.alz.org/downloads/Facts_Figures_2011.pdf
3. Alzheimer Society of Canada. Guidelines for Care. Toronto: ASC; 1992, p.3.
4. Baumeister, R.F., and Leary, M.R., The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117(3), 1995, 497-529.
5. Belk, R.W. Possessions and the extended self. *Journal of Consumer Research*, 15(2), 1988, 139-168.
6. Braun, V., and Clarke, V. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 2006, 77-101.
7. Buckland, S. Well-being, personality and residential care. In: Kitwood T, Benson S, eds. *The New Culture of Dementia Care*. Hawker Publications, 1997, 30-34.
8. Clappitt, P.G. *Communicating for managerial effectiveness*. Sage, 1996.
9. Cohen, D. and Eisdorfer, C. *The loss of self: A family resource for the care of Alzheimer's disease and related disorders*. Norton, 1986.
10. Davies, S. 'Making the move': relatives' experience of the transition into a care home. *Health and Social care in the Community*, 12(6), 2004, 517-526.
11. Ehrenfeld, M., Bronner, G., Tabak, N., Alpert, R., and Bergman, R. Sexuality among institutionalized elderly patients with dementia. *Nursing Ethics*, 6, 1999, 144-149.
12. Gaver, W., Blythe, M., Boucher, A., Jarvis, N., Bowers, J. and Wright, P. The Prayer Companion: Openness and Specificity, Materiality and Spirituality. In *Proc. CHI 2010*, ACM Press (2010), 2055-2064.
13. Hughes, J.C., Louw, S.J., and Sabat, S.R. *Dementia: mind, meaning, and the person*. Oxford Medical Publication, 2006.
14. Killick, J. and Craig, C. *Creativity and Communication in Persons with Dementia: A Practical Guide Jessica*, Kingsley Publishers, 2011.
15. Kitwood, T. *Dementia reconsidered: The person comes first*. Open University Press, 1997.
16. Kitwood, T., and Bredin, K. Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12, 1992, 269-287.
17. Kontos, P. C. Embodied selfhood in Alzheimer's disease – Rethinking person-centred care. *Dementia*, 4, 2005, 553-570.
18. Kuhn, D. Intimacy, Sexuality, and Residents with Dementia. *Alzheimer's Care Quarterly*, 3(2), 2002, 165-176.
19. Larson, J.H., Hammond, C.H., and Harper, J.M. Perceived equity and intimacy in marriage. *Journal of Marital and Family Therapy*, 24, 1998, 487-506.
20. McCracken, G. Culture and consumption among the elderly: Three research objectives in an emerging field. *Ageing and Society*, 7(2), 1987, 203-224.
21. Miller, D. *The comfort of things*. Polity Press, 2008.
22. Moss, B.F., and Schwebel, A.I. Defining intimacy in romantic relationships. *Family Relations*, 42, 1993, 31-37.
23. Mynatt, E.D., Melenhorst, A.-S., Fisk, A.D., and Rogers, W.A. Aware Technologies for Aging in Place: Understanding User Needs and Attitudes, *IEEE Pervasive Computing*, 3(2), 2004, 36-41.
24. Olivier, P., and Wallace, J. Digital technologies and the emotional family. *International Journal of Human Computer Studies*, 67(2), 2009, 204 - 214.
25. Orpwood, R. et al. Designing technology to support quality of life of people with dementia. *Technology and Disability*, 19, 2007, 103-112.
26. Salvage, J. The theory and practice of the 'New Nursing'. *Nursing Times*, 86, 1990, 42-45.
27. Schaefer, M.T., and Olson, D.H. Assessing intimacy: the pair inventory. *Journal of Marital and Family Therapy*, 7(1), 1981, 47-60.
28. Thieme, A., et al. Lover's box: Designing for reflection within romantic relationships. *International Journal of Human Computer Studies*, 69(5), 2011, 283-297.
29. Tornatore, J.B., and Grant, L.A. Burden among family caregivers of persons with Alzheimer's disease in nursing homes. *The Gerontologist*, 42(4), 2002, 497-506.
30. Wallace, J., Dearden, A., and Fischer, T. The significant other: the value of jewellery in the conception, design and experience of body focused digital devices. *AI & Soc*, 22, 2007, 53-62.
31. Wallace, J., McCarthy, J., Wright, P. and Olivier, P. Beyond reminiscing: Looking back to look forward in dementia. *CHI 2011 Workshop on Bridging Practices to Support Reminiscence*. http://www.cs.cornell.edu/~danco/remchiwork/papers/Wallace_CHI2011_wkshp.pdf
32. Watzlawik, P., Beavin, J.H., and Jackson, D.D., *Menschliche Kommunikation: Formen, Störungen, Paradoxien*. Hans Huber, Vol. 10. 2003, 1-170.
33. Williams, A. A literature review on the concept of intimacy in nursing. *Journal of Advanced Nursing*, 33(5), 2001, 660-667.
34. Wimo, A. and Prince, M., *World Alzheimer Report: The Global Economic Impact of Dementia*, Alzheimer's Disease International (ADI), London, 2010.
35. Wright, P., Wallace, J. and McCarthy, J. Aesthetics and experience-centred design. *ACM Trans. Computer-Human Interactions*, 15 (4), 2008, 1 - 21.