Imagined futures: designing future environments for the care of older people.

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Imagined futures: designing future environments for the care of older people.

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Abstract: This paper contributes to understanding the role of design in promoting quality of life for older people living in care homes. The study described employed photographic methods to understand the life-world of older people in three care homes in the north of England. Individuals were provided with cameras and invited to record aspects of the home and the environment that reflected what was important to them. These images formed the basis of interviews, the content of which was analysed using an interpretative phenomenological method. Participants described the multiple transitions they faced and the challenges of simultaneously navigating this new environment whilst also making sense of the 'alien' body they now inhabited. The life world of the older person was one conceptualized as betwixt and between place and space, between hope and despair. This paper discusses the potential contribution of design in creating future environments for the care of older people.

Keywords: Design, care homes, life-world, older people, photo-elicitation

1. Introduction

Globally the population is ageing and the fastest growing demographic are individuals who are aged eighty-five and over (World Health Organisation 2015). These individuals, described by the literature as the frail elderly represent a significant proportion of the 431,500 older people who currently live in care homes in the United Kingdom (LaingBuisson, 2013). As such, this area requires the due consideration of designers and researchers interested in understanding and promoting the quality of life of older people living in these settings.

A growing literature highlights the potential of the design of the environment to promote wellbeing. This relationship is not new. As early as 1863 Florence Nightingale identified that "variety of form and brilliancy of colour in objects presented to patients are actual means of recovery" (Nightingale 1863).

More recently Ulrich et al (2008) have written of the role of the physical environment and the healing process citing evidence to demonstrate the direct link between design and patient health outcomes.

The design of many hospitals and health buildings now recognize that the quality of the patient and staff environment is a main driver for efficiency in terms of health outcomes, staff performance and integrated service delivery (Commission for Architecture and the Built Environment 2009). Evidence relating to design in the context of quality of life and older people continues to grow. For instance a systematic review of the literature undertaken by Marquardt et al (2014) interrogated 169 studies pertaining to environmental design in the context of older people with dementia and concluded that specific design interventions are beneficial to the outcomes of people with the condition.

Whilst much attention has been given to researching the design of hospital buildings less has been given to the design of care home environments. Yet care homes offer support to individuals living with some of the most complex needs of society (Office of Fair Trading 2005).

Within the United Kingdom care homes occupy an interesting space. A care home is defined as an establishment that "provides accommodation together with nursing or personal care for [individuals who] are or have been ill" (Department of Health 2000, p.3). This perspective places these environments firmly in the health and social care literature and regards the care home as fulfilling the function previously performed by long-term hospital settings.

Against this categorization of the care home as an institution, an alternative picture of the care home as home has emerged. The Minister of State for Care Services in England stated in 2013 that:

"The care home has a future. At its heart the care home of the future will be the idea of 'home'. A place where relationships matter. A place open and outward looking, part of the community not closed, isolated and institutionalizing" (ILCUK, 2013).

The conceptualizations of the care home as hospital and the care home as home can conflict. Davies and Brown-Wilson (2007) for instance challenged the appropriateness of naming long term care settings as home when "home is usually associated with family, shared memories and comfortable familiarities" (p. 65). Their concerns relate to how such associations can raise the expectations of older people in terms of what to expect, leading to confusion and, on occasion, disappointment.

Research undertaken by Nakrem et al. (2012) has further highlighted these tensions and the ambiguities that can exist as older people seek to make sense of living in a place that is called home whilst being required to adapt to and engage with institutional routines. The resultant 'identity crisis' described by Vladeck (1980) arises as care homes try to balance their dual role of attending to the technical dimensions of care whilst still ensuring that they create a home-like environment (Steinhauser, 1998). This provides an added dimension to their study particularly since these conceptualizations will potentially shape and affect the way that living and working in such an environment is experienced by residents and staff.

When thinking about design of the next in relation to the care of frail older people the care home seems to be a valuable focus.

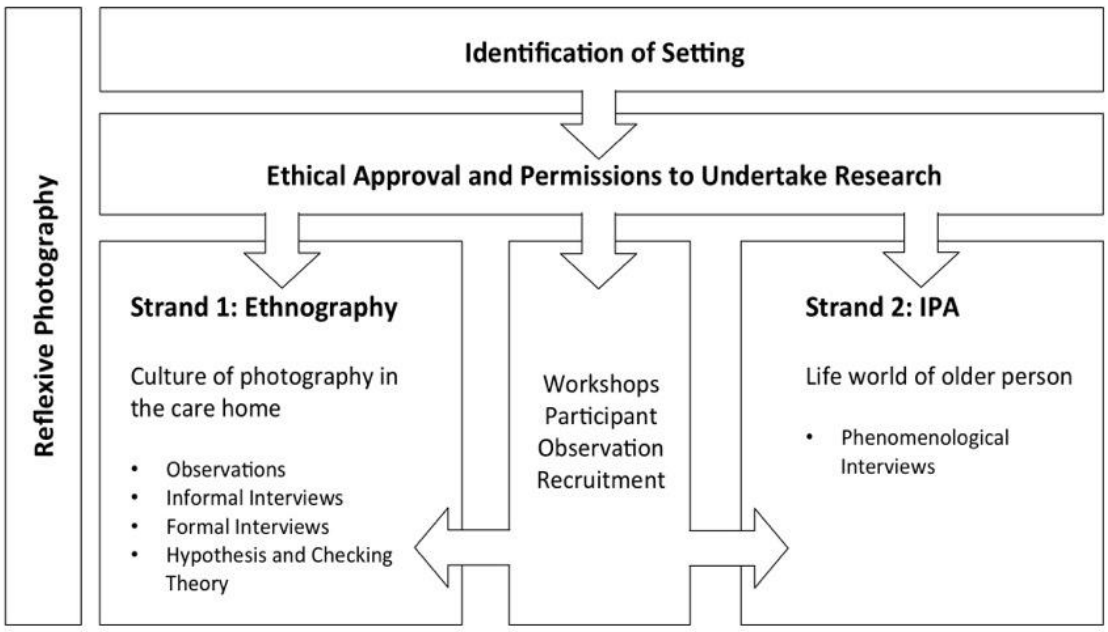
2. Description of the present study

The present study sought to understand the experiences of older people living in care home settings in the United Kingdom. Emphasis was placed on methodological approaches to access the views of individuals directly. This was important as to date few studies have sought to capture the experiences of older people. This is not without good reason since the physical (age-related changes in sensory acuity) and cognitive challenges (increased incidence of long-term neurological conditions) facing many individuals living in care homes make it difficult (Care Quality Commission 2012; Johnson et al 2010).

Photography was chosen as a method to elicit the views of older people living in 3 care home settings in the North of England. Photo-elicitation is the broader term given to the use of photographs as a stimulus during the research interview (Collier 1986). Its overall aim is “to trigger responses and memories and unveil participants' attitudes, views, beliefs and meanings or to investigate group dynamics” (Meo, 2010, p.150). An increasing number of studies support the view that using photographs within interviews can help to overcome some of the communication challenges people face when confronted by complicated interview schedules (Clark, 1999). In part this is because photographs are tangible objects that can be physically held, offering a point of reference as they are looked at, described, explored and discussed. These qualities have been found to promote engagement and act as visual prompts, offering a way to initiate conversation, stimulate memory and structure discussion. This approach is effective in studies that include participants with memory problems or individuals who have difficulties in verbal expression. For instance in one study by Levin et al (2007) it was found that individuals with stroke aphasia could participate more fully because the inclusion of photographs within the research interview helped to overcome the communication difficulties they faced. In light of these strengths photography was felt to be an appropriate method in the context of researching the experiences of older people living in care homes.

3. Methodology and methods used

Philosophically this study was positioned within a constructionist epistemology and embraced an interpretivist paradigm the central tenet of which is that “individuals are constantly involved in interpreting their ever changing world” (Lipu, Williamson and Lloyd 2006 p.2-3). The study design comprised of two distinct but related parts illustrated by the following diagram.



Strand one comprised of an ethnographic study which aimed to build understanding of the broader culture of the care home and strand two utilized interpretative phenomenological analysis to build understanding of how older people described and made sense of their experience of living in the home. It is on this second strand that this paper will focus.

Ethical approval for the study was obtained and three care home settings in the north of England were identified. All were privately owned. Four photography workshops were held in each of the homes. This acted as a mechanism through which residents could build confidence in using the camera and was a way to ensure that if people wanted to participate in the second strand of the study that they were able to make more of an informed decision.

Individuals attending the photography workshops were invited to participate in strand two of the study. Purposive sampling was chosen. Inclusion criteria were that the person had lived in the home for a period of less than eight months (to ensure that they were close to the phenomenon under investigation) and that they had mental capacity to give informed consent. Once individuals had expressed an interest in taking part of the research they were visited at a mutually agreed time in order to provide further information about the study. The information was provided in both written and pictorial form and each person has the opportunity for questions. If an individual chose to take part they spoke with the activity co-ordinator in the home who contacted the researcher. Once written, consent had been obtained from the person a follow up visit was undertaken.

Individuals were invited to take photographs that captured their day-to-day life and these formed the basis of an interview with the person. At a mutually convenient time the person was then invited to an interview based around these photographs. The interviews took place in the person's own room where a level of privacy could be observed and they were invited to select and to talk about each photograph in turn. An order was not imposed (based on the chronology of when they had been taken or what the person considered to be most important) but the decision was left to the person. Just two questions were used to prompt discussion. These were: Please tell me about the photograph and Can you say a bit about why you chose to take this picture?

Consent was sought to tape record the interviews and these were then transcribed and analysed using an interpretative phenomenological method as described by Smith, Flowers and Larkin (Smith et al 2012)

4. Findings and discussion

The themes identified through this analysis are illustrated in the following diagram. These themes were clustered around: lived body, lived time, lived relationship and lived space. The life-world of the older person in this study was conceptualized as one betwixt and between: between place and space, being in time and out of time and between hope and despair. In each of these themes design potentially had an important role to play.

4.1 Lived body: the body and environment as barrier

Participants were not only coming to terms with living in an alien environment they were also coming to terms with the physical changes and the medical conditions that had directly contributed to the decision to move into the care home. The sense of being betrayed by the physical self and the body as barrier were strong themes that emerged through the analysis. However rather than compensating for the physical limitations they experienced the care home environment contributed to these feelings.

All participants had significantly reduced mobility and the majority was dependent on wheelchairs yet the care homes where the study took place were all built over multiple floors. This posed significant challenges to the residents who participated in the study. One person articulated this through the following image:

> “You see when you get into your 90s you...can’t walk about anymore. I can stand up just a bit but I can’t without that (points to frame) – it’s old age you know, it wears you out.”

For another resident, the physical limitations he faced as a result of his stroke were compounded by the design of the environment. He described the frustrations of not being able to even enter his own room without help. Health and safety regulations meant that the door needed to close automatically but the weight of the door meant that he was unable to open this himself. On numerous occasions he had been forced to sit in his wheelchair outside the door to his room until a member of staff opened it for him. He articulated his feelings of helplessness through the following photograph and words,

> "I was younger I swam down the Suez canal...since the stroke, well that's finished. Even now this thing they put outside your door. To push the button to get in...I can't do that so I take this [walking stick]. I have to use my walking stick to push the thing so I can get into my room…Sometimes it'll work… it does work… most of the times it doesn't. So I've had to wait until someone comes past and I say 'can you open the door'".

These feelings of helplessness were not only the consequence of the building design but also in the design of much of the furniture in the home. For instance, the height of tables made it difficult to accommodate wheelchairs. Wardrobes and drawers were designed in such a way that it was impossible for residents who used wheelchairs to access and choose their clothing independently, increasing reliance on staff, chairs were positioned around the outside of the room making it difficult for individuals with hearing problems to interact with each other. This was further compounded by the constant sound of alarms. In the words of one of the individuals interviewed,

> "This is not a relaxing place to be. The constant sound of the alarms makes me feel so depressed."

And as another person expressed, "evenings are the longest because you don't feel like going out and there's always someone shouting."

4.2 Lived time: Lack of stimulation

The design of the environment did not only impact on levels of dependency it also impacted on the types of activities individuals were able to engage in. Boredom and lack of stimulation was a theme that ran throughout the interviews. As a consequence time passed very slowly. The following comments were typical of those of many participants,

> "There's not much to do here...I get right bored sometimes... I can't walk. I just get bored. I've got some of those things you put in the telly (DVDs). You can watch them for so long but then you've had enough."
>
> "All you are doing is taking pills, going for a smoke, watching the telly and that's about it."

In one of the care homes lack of access to outside space was problematic. Residents described the challenges of living in an environment without access to everyday physical stimulation. In the words of one participant,

> "You stop being able to feel, 'everyday, everything here is the same.' Everyday is warm, no cold, no rain."

4.3 Lived relationship

Without opportunities to engage in meaningful activities, individuals' life-roles and sense of self were significantly eroded. The physical layout of the environment, the loss of connectivity with family and the locality reinforced a loss of identity and the overwhelming experience described by participants throughout the study was a sense of loneliness. The care home effectively offered communal living but ironically individuals described how the level of disconnect they felt between themselves and others living in the home simply served to reinforce feelings of isolation. In part this was because of the range of needs experienced by individuals in the care setting. For residents who had never met a person with dementia this could be frightening. One participant described this in the following way;

> "It's quite lonely really. Some of them can answer you but a lot don't bother. It can be difficult...we've a lady who tears up her pads so we've been giving her newspaper to tear up instead...and they don't always know what time it is...they sit for hour and hour in that lounge with the blaring out of the television...some of them have got dementia."

As a consequence some of the residents chose to isolate themselves spending time in their rooms rather than sitting in the communal lounge:

> "Mostly they watch television out there and talking and falling out and I think I can go up and watch my own television without all this going on because if it is anything interesting you miss it because you can't hear it properly."

4.4 Lived space

The most significant theme that arose during analysis was the sense of being betwixt place and space. The physical environment was extremely confusing. Individuals struggled to navigate a place that was called home but which resembled more of a hospital.

Individuals in the study used different coping mechanisms to try to make sense of this environment which was very much designed to look like a home but in reality presented as a hybrid space between hospital and the home environment. One participant for instance separated out different parts of the home deeming some as public and some private. She described the entrance and the reception area of the care home in the following way;

> "Downstairs…it feels like you are going somewhere else. It's where we go for hairdressing and they have staff meetings there. You know it's where staff go to those things like that."

For another person it was impossible to make sense the design of the care home compounded feelings of confusion,

> "It's an unusual place in that it's home but its not home. Sometimes I think it's a trick and it's just another hospital. I don't know what is happening…It's like a game where no-one tells you the rules, like finding your way through a labyrinth... I don't know, I don't know what it feels like. It doesn't feel like there's no warmth. I don't know. I can't explain it."

To others the care home had qualities of both a prison and a hotel. This created tensions and some residents resisted the notion that it could ever be a home. For instance one resident described how not having photographs in his room was one of the ways he coped being there. The act of putting photographs in the space would have been tantamount to accepting that the space was home which to this individual it was not. "Why would I have photographs here?", he asked "It's not home is it?" He was not the only participant who struggled to reconcile notions of home and the care home. Another resident described how initially she had felt 'lost'. The care home held no connection for her. She described it as a 'feeling-less' hotel that 'held no attachment' and initially she had been homesick for the environment she knew as her home.

5. Conclusion

The role of design in promoting quality of life of older people living in care homes is an area that warrants further research. This present study describes the lived experience of older people resident in three care home settings in the United Kingdom and whilst it does not for one moment claim to be the story of every older person in a care home if these accounts are juxtaposed and read inter-

textually there is the offer of new insights into the experiences of these older people with the potential of design to impact on each element of lived body, lived time, lived other and lived place.

The most striking finding within the study was the magnitude of the upheaval and the multiple transitions residents were attempting to navigate. Previous studies have described the challenges facing individuals in adapting to life in the home (Sussman and Dupuis, 2014; Reuss, Dupuis and Whitfield, 2005; Davies and Nolan, 2003). However the negotiation of the physical space occurred as participants were simultaneously attempting to adapt to and manage a range of physical changes and life events that had in some way precipitated the decision to move there. Potential support networks provided by family and friends were, for reasons of geography, compromised and existing routines were disrupted or subsumed by the rhythm of the home. As a consequence the move to the care home represented a significant threat to identity. Questions relating to the nature of the care home and the meaning of the space individuals now inhabited were linked to the more fundamental question of who they were within this space. The sense of being 'betwixt and between' related as much to an understanding of the self as it did to the care home environment.

The potential of design in this study moved far beyond providing older people with the opportunity to gain physical access to and around the building. Design acted both as an enabler and a barrier to developing and maintaining relationships with others in the home, to engaging in valued activities and to building a sense of self at a time when identity was most under threat. Objects were regarded as being of particular value in enabling older people to navigate transition.

Older people who participated in the research did not regard the physical environment of the care home as their 'home' and if the definition of home used by Gifford (2007) is used, this is not surprising,

> "A house is not a home. A house...is a physical structure. Home is the rich set of evolving cultural, demographic and psychological meanings we attach to that physical structure. Thus, despite real estate advertisements to the contrary, you cannot buy a home. You can buy (or rent) a residence and, with luck, time and effort, turn it into a home" (Gifford, 2007, p.194).

Home was rather defined by residents according to the level of control they could exert over their surroundings, the quality of relationships there and the emotional warmth they experienced. The notion of home as a physical space was frequently rejected and replaced by a definition that located home in the embodiment of named individuals, usually spouses or family members.

At present within the United Kingdom care home design places emphasis on incorporating generic features into the environment that seeks to convey feelings of homeliness (fire-places and décor emulating living room furniture). However as this study has highlighted these very elements, which seek to offer support, can add to the confusion a person experiences as they seek to navigate the multiple transitions that moving to a care home entails.

Care homes are in many ways contested spaces seeking to fulfill both the role of hospital and home. Rather than contributing to this blurring of boundaries design must continue to highlight and grapple with the complexity and the challenges these spaces present.

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