Ethics and Risk. Doing Design Research with People in Care Homes

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Abstract: Drawing on doctoral research that is currently in progress within two care homes for older adults, this paper makes an argument for participatory approaches to design research and explores how a situated and social understanding of risk is required to develop an ethical approach to design research in this field. Within this it is argued that researchers working with marginalised groups should not only be aware of the risks that group might face but be sensitive to potentially competing perspectives on risk. Secondary literature encompassing design as well as health and social care is used to frame some of the issues arising in the fieldwork before moving on to develop insights about the potential for design to provide an ‘ethic of care’ that can respond to tensions around risk and potentially recast these as a creative and constructive opportunities.

Keywords: care home, ethics, risk, participation, older people

1. Introduction

This paper responds to the title ‘A healthy attitude to risk’ by exploring what risk means in the context of research within care homes for older people. As John Tulloch and Deborah Lupton write, “the concept of risk pervades everyday life” (Tulloch & Lupton 2003, p. 1) leading both to the claim that we live in “risk society” (Ulrich Beck, 1992) and to a growth of interest in risk across a wide range of academic fields and social policy, not least of which is that of health and social care (see for example, Heyman, 1998). Drawing on current doctoral research set within two care homes, the paper explores the way in which normative concepts of risk run through the very subject of the research as well as the ways in which a social and cultural understanding of risk might be used to frame the way in which research is conducted and what role ethics play in this theoretical adoption. The doctoral research on which the paper is based explores how the discipline of design can support older adults to maintain a robust sense of self and place attachment as they move into and adjust to life in residential care. Within this, it is specifically concerned with the role that personal possessions play in relation to maintaining self and social identity alongside meaningful place attachment. The study examines the relationship care home residents have with their things and their experience of transitioning into a care home, with a view to informing potential design strategies that will support this process. After setting out the context for the research, the paper is divided into three parts: the first looks at the ways in which risk is conceived in relation to care homes and their residents; the
second explores how risk shapes the research process and what specific ‘risks’ arise from researching with participants in care homes; and the third concluding part sets out how design methods informed by an ‘ethic of care’ might be used to respond to the limitations of formal ethical protocols.

2. Context

The project is set against the national debate in health and social care about the quality of care home provision for people in the later stages of life. On 31st March 2017 there were 31,223 long stay residents in care homes for older people in Scotland (Scottish Care Home Census, 2018) but according to a government report published in 2016 the number of older care home residents across the UK is set to rise by 49% between 2015 and 2035 (Government Office for Science, 2016, p. 77). Within this context the design of care homes has come under increasing scrutiny and in 2018 the Care Inspectorate published new guidelines (Reid, 2018) that responded to the revised Health and Social Care Standards implemented in the same year (Scottish Government, 2017). Alongside, spatial requirements, these new Standards include a person’s right to: “decide on the decoration, furnishing and layout of my bedroom, including bringing my own furniture and fittings where possible” (The Scottish Government, 2017, standard 5.13).

This policy builds on a strong body of research within gerontology and its associated disciplines that establishes the importance of home and home possessions to a strong sense of self and mental wellbeing (for example see Oswal & Wahl, 2005; Rowles and Chaudhury, 2005; Rubinstein, 1987). It is also builds upon the National Institute for Clinical Excellence’s (NICE) earlier recommendations that noted the important role that valued personal possessions play in supporting a person’s sense of self (NICE 2013, p. 20) and the need to “maintain and develop their personal identity during and after their move to a care home” since this promotes “dignity and has a positive impact on their sense of identity and mental wellbeing” (NICE 2013, p. 21). However, while there has been a surge of interest in the role that valued possessions play in reminiscing and place making both within gerontology and more recently within design (see for example, Bowen and Petrelli, 2011; Hoven, 2014; Lazar, Thompson and Demiris, 2014; Lindley and Wallace, 2015; Nord, 2013; Wallace et al., 2013) less research has been conducted on the process of transition itself and how residents then engage with their own belongings – both mundane and valued - once they are settled into their new ‘home’.

The focus of the doctoral research is therefore to explore how people’s possessions are managed through the transition process and whether residents are then supported to continue engaging with their things and finally whether there is a role for designers to assist in developing better supports for these processes. The research is based on ethnographic research in two care homes with a small sample of residents within each home. So far three residents in each care homes are participating but the recruitment process is ongoing. The initial research findings will then be used to structure co-design workshops which will include invited designers and the participating residents. Throughout these phases the participants will be involved in the discussion and assessment of provisional research findings; the identification of issues that arise out of these; and the development of potential applications. This involvement of the participants in the research process is informed both by critical ethnography’s principles of intervention to improve a social situation (Maddison, 2005), Tim Ingold’s concept of anthropology as employed by designers such as Ann Light (2015) and the democratising principles of participatory design that developed in Scandinavia in the 1970s that sought to give voice to marginalised groups and draw on a plurality of knowledge systems (Aldridge, 2015; Nind 2011). However, it should perhaps be stated that the research cannot strictly be classed as participatory research or co-research since the residents that I am working with do not have an equal role in setting the research questions or agenda and only play a partial role in conducting the
research, both of which are identified as key components of participatory or co-research (Bergold and Thomas, 2012; Heron, 1996).

It is also perhaps worth noting here the distinction between ‘participatory research’ where these principles are strongly advocated and ‘participatory design’ (PD) where these criteria have also informed practice but in a less stringent manner. Thus, participatory design is often used to describe design research that engages with participants at various points and in ways that are more embedded than user-centered design would imply or public consultation but which would not meet the more robust requirements of participatory research or PAR. As Ann Light also notes, in recent years participatory design has also expanded to encompass design research that moves away from the initial emancipatory imperative of Scandinavian PD to a more “expedient” application in pursuit of improving “’fit[ness] for use’ with no analysis of cultural contexts or desire to change them” (Light, 2015, p. 85). To this extent it is worth adding the qualification that my work aligns with what Light calls “democratic participatory design” which itself can be situated within a broader conception of design that is concerned with effecting ethical change (Findeli, 2001; Heller and Vienne, 2003; Felton, Zelenko and Vaughan, 2012; Ehn, Nilsson and Topgaard, 2014; Resnick, 2016). The aspiration for social improvement has structured design in the UK to varying degrees since at least the design reform movement of 19th century. However, what marks out the more recent reconsideration of ethics by design and particularly democratic participatory design is its concern with process and power: who is involved in the design process; what methods of enquiry are most suitable; who decides what the problem is; how is this decided etc. Ethics within this paper is therefore understood as more than a procedural requirement for managing risk but a driving force behind the motivation and methods of design research.

This critique of process and power and the resultant shift of participatory approaches towards the mainstream is not limited to the field of design. In 1996 the National Institute for Health Research, established INVOLVE, a government funded advisory group set up to encourage and support “active public involvement in NHS, public health and social care research” (INVOLVE, 2018). It is also interesting to note that the research ethics guidelines to which researchers are directed by the City of Edinburgh Council state that “Public involvement in research is increasingly encouraged by funders” (http://www.ethicsguidebook.ac.uk/Research-led-by-service-users-196). This shift may still be in process but it does reflect a fundamental change in the way in which ‘service users’, and here more specifically older people, are regarded within the NHS and social care. At the heart of this change is a paradigmatic shift away from a purely bio-medical understanding of older age to social understanding that emphasise the ways in which society and social processes construct what older age is as well as shape how older age is experienced by individuals (for an overview of these theoretical frameworks see Bengtson, Silverstein, Putney & Gans, 2009). This recognition of the differing experiences of older age and the impact of social factors and processes on health and wellbeing has not only led to the development of more person-centered approaches to care (see Kitwood, 1997, for example) but also to the concomitant argument that the voices of older people should inform policy development (see Wilkinson, 2002, pp. 9-24).

Clarke and Keady trace this shift in policy development from the introduction of the Community Care Act (Department of Health 1990) in 1990 which placed an emphasis on “user consultation” for the first time to negotiate “a mutually agreed package of care” (Clarke and Keady, 2002, p. 27), through to the development of the first National Standard of Care for Health and Social Services in 2001. This they state was underpinned by older people (including those with dementia) and their carers “being afforded considerable attention in the development of the strategy” (Clarke and Keady, 2002, p. 29). However, while academics such as Clarke, Keady and Wilkinson, whose research focuses on people
with dementia, argue that much has been gained in giving voice to older people within public policy, and have themselves contributed to the growing body of literature on how to do participatory research within healthcare settings, they also argue that the power relations within research must continue to be addressed:

The relative positions of marginalised people in society (such as older people and the ageism they experience) can be reflected in the researcher/researched dynamic. Whilst it is essential to include the views of people with dementia it is also important to recognise and take account of these inherent power inequalities and allow care and time to enable people to participate fully (or not as they choose). Wilkinson, 2002, p. 17

While my own research does not focus specifically on people with dementia, it does include people who may nonetheless be viewed as marginalised. Thus, it is paramount that the voices of older people, rather than those of their relatives or carers, are given center stage through their participation in the research. By extension it is also important that ethical considerations around power and questions of risk remain central to the research.

3. Risk for People Living in Care Homes

In order to think about ethical forms of research with participants – in this case older people living in care homes - it is important to consider the status of those people and their particular experience of marginalisation. In connection with this I would argue that positivist notions of risk are central to the marginalisation of older people as adverse outcomes and hazards to health and wellbeing are seen to be a natural and objective result of ageing (for a discussion of positivist theories of risk see Denny, 2005, p. 10, 1). This view within popular discourse of older age as something that is inherently risky is powerfully articulated by a Mass Observation respondent in 2009:

As a pensioner I am certainly sick of the portrayal of my age group by government reports and news... My vision is too poor for me to follow drama, but I watch news and documentaries. I am sick of the habitual representation of my group – passive, dependent, vulnerable, scroungers, a financial burden, ill, demented, a drain on the public purse, isolated, vulnerable, an escalating problem etc. (quoted in Bazalgette et al. 2011, p. 66).

While academic discourse recognises the multiple factors that shape older age, normative representations and understandings still tend to assume a medical model of ageing that is based on the deterioration of physical and mental wellbeing (Konton, 1998, p. 169). Indeed, despite the advances made in recognising the voices of older people in social care and health policy, recent public discourse has again (re)positioned older age as a ‘problem’ to be solved (Bazalgette et al. 2011). Indeed, the Demos research conducted by Bazalgette and her colleagues goes on to suggest that so habitual are these ageist attitudes that “people who might themselves be on the receiving end of discriminatory attitudes towards older people have themselves internalised these attitudes [which] demonstrates the pervasiveness of ageist stereotypes” (Bazalgette et al. 2011: 61). Julia Twigg, author of Fashion and Age (2013) likewise, discusses the self-discriminatory effects of ageism (Twigg, 2013, pp. 33-34). This disconnect between the way in which older age is framed in public discourse and the experiences of ageing by people in the later stages of their life may explain why there is a resistance to view oneself as older: “Many of our volunteers showed a powerful resistance towards the idea of considering themselves as ‘older’ or ‘ageing’. A woman in her 70s from the
Highgate 1 group confirmed that ‘it is others who are old not ourselves.’” (Bazalgette et al. 2011, pp. 55-56).

Developing this notion of internalised ageist attitudes, it is interesting that all but one of the participants in my study discuss their decisions or acquiescence to other people’s decisions about moving into a care home and the process of transition in terms of not wanting to be “a burden”. This is expressed time and again both through their gratitude to their families for the work done on their behalf and in their own decision-making process about their things, which was driven by a sense of wanting to limit any inconvenience to their relatives. This sense of one’s relationship to others as being framed by need and by extension by a sense of burden also characterises a number of the participants’ attitudes to the care home. This is specifically evidenced by their reluctance to ask for things to be changed or to challenge how things are done, if there is no functional reason, because they do not wish to make too many demands or “cause trouble”. Two of the participants for example, expressed dislike of the curtains in their rooms which could easily be replaced, but have refrained from asking for them to be changed. Their reasons for this revolve around a feeling that they don’t want to make or cause a fuss and that any requests for work to be done on their behalf must have good reason. When it comes to the curtains, which they observe are well-made and of good quality, personal taste does not constitute a sufficiently good reason to create extra work for loved ones or care staff. This subtle weighing up of legitimate and illegitimate requests alongside a desire to put the convenience of family members above personal preferences suggests the readiness with which residents conceive themselves in relation to ‘burden’ and might suggest that concerns about the internalisation of ageist attitudes are well founded.

The centrality of risk to normative concepts of older age outlined above are further compounded when considering older people in residential care. This is in part because care homes themselves have for some time suffered from a public image problem. Well-founded concerns about the quality of care alongside a policy shift to encourage ageing in place; that is at home, have served to cast the care home as the place of last resort. Indeed, if the assumption that ageing in place means aging at home then ageing in a care home would seem to imply ageing in a non-place (for an exploration of this see Chadhury 2003; and for an examination of the idea of the uncanny in relation to care homes see Schillmeier and Heinlein, 2009). Added to this is notion that care homes are, in the words of several of the participants in my study, a “place to die”. The research findings by Bazalgette et al also echo these sentiments:

Almost universally, great fear was expressed at the idea of needing to move into residential care. [...] A man in his 80s from the South East London reading group expressed similarly strong feelings about residential care, saying: “Now that, I find, is a grim prospect. A waiting room before catching the boat across the Styx... grim” (Bazalgette et al, 2011, p. 83).

One of the volunteers overseeing a discussion group in London likewise noted: “One of the ways of not being a burden is to choose to go to a residential hotel or care home. People going into sheltered accommodation often do so before they really need to go so that their family do not need to worry” (Bazalgette et al, 2011, p. 84). Again, these views – and experiences - of care homes could be seen to be underpinned by what Help the Aged identify as “evidence of ageism in policy development over the years” in which long term care has been conceived in terms of ‘managed decline’ rather than “one requiring a dynamic, positive approach to ensure that older people lead a fulfilling life” (Meyer,
2007, p. 11). It is perhaps understandable why within this framework of ‘managed decline’ prospective residents would view care homes negatively or as a ‘waiting room’.

Residence in a care home is thus conceived in terms of multiple layers of risk. On the one hand the decision to move into a care home is often taken because it represents a solution to the perceived risks of remaining at home whether related to physical hazards or problems around care provision. On the other hand, moving into a care home can be seen to pose a new set of risks in terms of loss of independence, social ties and community, home and home possessions and ultimately a loss of sense of self. Added to this, the continued stigma associated with care homes may also be seen to pose a risk to a sense of self and status. This perhaps gives rise to the question as to whether the negative associations that care homes have come to hold within popular discourse may contribute to a heightened perception of risk which itself can be self-fulfilling? While an answer to this question may be beyond the scope of the paper, what is important to highlight is that not only is older age framed as risky within popular discourse but that perceptions of risk are inextricably interwoven into the act of moving into a care home as an older adult. Moreover, it must be acknowledged that older people living in care homes are caught in a complex process of negotiation in which they are both aware of the stigma attached to care homes and may indeed hold some of the views that underpin this stigma but are working at the same time to balance this against their need to make a life for themselves in a care setting through, I would suggest, a process of self-developed risk management strategies. This is a finely balanced, even precarious, act that the researcher must be sensitive to as they develop a research relationship with their participants but one which is rarely discussed in design literature.

4. Risk and research in care homes

Before going any further, it is perhaps worth taking a moment to consider what is meant by risk within a research context. The definition used by the Research Council UK Ethics Guidebook, which the AHRC employs, is notably vague: ‘Risk is a vague word which covers harm, as well as practical matters such as incurred costs and practical inconvenience’ (http://www.ethicsguidebook.ac.uk/How-is-risk-defined-66 ). As noted in the previous section risk is often conceived in scientific or positivist terms in which risk refers to the probability that a particular course of action will result in an identifiable harm and which posits risk as an ‘objective hazard’ with clear causal connections between the action and outcome (Denny, 2005, p. 10, 12). However, risk has also been theorised within sociocultural theory to encompasses a view of risk as something that is mediated and/ or constructed through social and cultural processes (see for example Lupton and Tulloch, 2003). While the research councils do not provide an explicit definition, the presumption that the job of risk assessment should be carried out by researchers and their research institutions implicitly places the concept of risk at the positivist end of the spectrum, with its emphasis on the role of experts in defining risk and the ability to determine objective hazards and causal relationships.

As a PhD researcher I have to admit that I have unconsciously adopted this position in my desire to obtain ethical approval for my research. However, in part, in light of the issues discussed in the previous section in which it becomes clear that normative perceptions around risk and older age and those held by older people themselves are often quite different, I would propose a social and cultural understanding of risk is most useful. This more fluid and responsive understanding of risk is adopted and advocated by academics in the field of dementia studies who argue that “perception and management of risk are not necessarily the sole prerogative of health and social care practitioners” and point to the differing perspectives on risk among practitioners, people with dementia, and their
family carers (Clarke, 2000, p. 84). This position, I would argue, has implications both for my own research and perhaps for ethics procedures more generally, in that the views of participants on the potential risks of research should be sought as part of the review process.

However, I have to admit that the recruitment process raised issues around risk, in particular to mental wellbeing, which caught me by surprise. Secondary research had flagged that the transition into a care home can be a traumatic or at least unsettling experience for some people and that this would require sensitivity in my inquiry (see for example Brownie, Horstmanshof and Garbutt, 2014). However, from my reading of other (design) research projects looking at objects and place making in care homes (see for example Groger, 1995; Nord, 2013; Bennett, 2015; Milte et al., 2016; van Hoof et al., 2016) it seemed that the invitation to talk about one’s things was regarded as a positive and self-reinforcing experience. Moreover, since both secondary research and my own initial discussions with care home staff confirmed that the transition process was often managed on behalf of older people, including the selection of their things, rather than by the older people themselves I also conceived the research as potentially empowering.

What I found though was that people were acutely aware of their own mental wellbeing and the potential precarity of this and were therefore cautious about embarking on any activity that might cause reflection and by extension, disturbance to their carefully constructed equilibrium. For example, in one care home I first introduced the study topic to a group of residents at their morning activity class. This gave rise to a lively discussion and remarks about the importance of the subject, although some skepticism too about whether any general conclusions could be drawn. Following from this I then met individually with a number of people from the group over the course of a few weeks, most of whom were enthusiastic and expressed interested in being involved and almost invariably proceeded unprompted to tell me stories about their things.

However, when I returned a few days later a number of these residents informed me that on reflection, or after having “slept on it” they did not want to proceed. Reasons included, being too busy, and not having anything interesting to say. One resident for example told me that she couldn’t reach any of her things so didn’t think she would be much use. While I explained that her experiences were important I also recognised that there were perhaps other reasons for her reticence, which was confirmed by the care home staff when I talked with them. One other resident was much more explicit, stating that she worked hard to keep up appearances and that a discussion about her belongings would risk upsetting this. “I’m not really a person anymore” she told me. Such sentiments were of course very distressing, as was the expression by residents that they had nothing interesting or important to say. However, it was also apparent that they had developed acutely sensitive risk assessments for their own wellbeing and that it was important that my recruitment process should do nothing to unsettle this. Again, the care home staff also gently agreed.

Nonetheless, this has left me with the uncomfortable sense that my research – and other research like it – perhaps attracts particular personality types or people with good mental health which leaves the voices of others silent. This dilemma is still being considered within the ongoing research.

Another ethical dilemma relating to mental wellbeing that has arisen through the research, was the response to some of the questions that revolved around what could have been done better. For example, one participant became suddenly upset when discussing some of the things she hadn’t brought with her while other participants were reluctant to suggest that their families could have done things differently. In other interviews the participants’ position in relation power, or lack of it, also became evident through their reluctance to say anything that could be interpreted as a criticism of their family or the care home for fear of seeming ungrateful or making an unnecessary fuss. It
should be stated that at the point of writing this paper these issues are current and live, however, bearing the power dynamic of the researcher/participant relationship in mind I do not want to press the participants. I am also aware that the benefits of their insights may felt more by future residents than by themselves and while this is something that has given them a sense of altruistic purpose in the research it may make them less inclined to open themselves up to more risky engagements. Nonetheless, in the face of this reluctance I have begun to explore the potential for design or cultural probes to open up a more supple space for imaginative thinking that might release the participants from their sense of gratitude and allow them to think unhindered about ideal or preferred scenarios. However, this was not part of the original research plan agreed with the participants and so will necessitate a discussion with them as to whether they would be happy to take part in these probes.

My hope that participation in these probes will offer a freedom of expression that side steps what might be interpreted as a form of self-discipline in interview responses is supported by Wallace, Wright and McCarthy’s research into personhood in dementia which employed a design probe approach (Wallace et al. 2013). Writing about the benefits of probes they state: “Firstly they enable the inquiry to take multiple perspectives at the same time and furnish participants with the space to think in unobvious ways. Secondly they allow participants to gravitate towards the questions and modes of response that feel comfortable to them” (Wallace et al. 2013). They go on to list other advantages but these seem most pertinent here. While design/cultural probes have been described as producing often ambiguous and fragmentary data (Gaver et al., 2004) and have attracted some criticism regarding the reliability of the data they produce I would argue that this is to misunderstand their intentionally speculative approach. It might also be noted that the speculative nature of cultural probes and the value placed on uncertainty does not preclude the design of probes that are informed by an in-depth and situated understanding of the context in which they are to be used. Moreover, designers, and increasingly also academics from other disciplines, point to their co-productive nature, especially if they are used as a spring board for further conversation once the probe has been completed (see for example Cristoforetti et al., 2011; Halse and Boffi, 2016; Lindley and Wallace, 2015; Wallace et al., 2013). However, it perhaps their potential to create more liberating spaces for expression that leads me on the final and concluding part of the paper about ethics.

5. Insights and conclusions about risk and ethics

As the discussion in the preceding sections illustrates, questions of risk weave right through the subject of the research as well as the way in which is it conducted which gives rise to complex ethical issues around power and participation. The conference strand of which this paper is part asks: “How can the exploration and improvisation inherent in design research be related to healthcare ethical protocols, whilst also broadening notions of ethical research to include co-ownership and co-direction with participants?” My answer to this is that there is a growing recognition within health and social care research – particularly that which involves marginalised groups - that research must involve some element of co-ownership or co-direction if it is to be considered ethical. This moves ethics beyond the mechanics of institutional ethical approval procedures to a much more fundamental critique of whose voices should be heard within research, how they should be heard and who should be orchestrating this. Of course, this is something that participatory designers such as Pelle Ehn, Gro Bjerknes and Tone Bratteteig (the latter also more recently with Ina Wagner) have been championing for some decades. However, while the aspiration may be there the ethical procedures in both disciplines still lack the flexibility to fully support participatory (design) research which by its nature is responsive and therefore does not fit easily within a presumption that all risks
can be identified and mitigating action mapped out in advance (Birch and Miller, 2014; Manzo and Brightbill, 2007).

Indeed, the socially and culturally constructed nature of risk means that participants’ perceptions of risks may be different to those of the researcher or ethical review board members. For example, as discussed above, one aspect of the research which I anticipated would be potentially empowering was in practice the riskiest aspect from the participants’ perspectives. However, as Clarke et al. point out, while ethics procedures conceive risk almost entirely in negative terms “positive risk taking is often admired and is recognised as being essential to a rewarding engagement with life” (2009, p. 92). It was with this in mind that I conceived the cultural probes as a means to reframe risky questions. Another approach that may be seen to address these points is the feminist position of ‘an ethic of care’ which proposes that “empathy and relationships rather than objective decisions” should direct the research process (Manzo and Brightbill, 2007, p. 36). In this framework “ethical decision making and behaviour is rooted in commitment to others” and in action that enables “effective engagement” (Manzo and Brightbill, 2007, p. 36). It is these qualities, I would finally conclude, that design methods such as cultural probes as well as co-design techniques, give creative space to. They offer participants the opportunity to take risks within an ‘ethic of care’ that may provide scope to participants and researchers think beyond the way things are usually done and even the power structures they may normally be confined by. To do this requires a situated understanding of the fluid and sometimes contested nature of risk and its relationship to ethics.

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