FROM PRODUCT TO PROCESS: REFRAMING DESIGN RESEARCH METHODS TO SUPPORT WELL-BEING IN THE DEMENTIA CARE ENVIRONMENT

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Abstract
The paper reports on the findings from a PhD study that investigates how creative activities can support the subjective well-being of individuals living with dementia in the residential care environment. The methodology for the study drew on theories and tools located in the field of design research; developed using data gathered from qualitative interviews and observations of dementia care units and activity sessions. Design research and dementia care both require the practitioner to have an empathic understanding of the lived experience of others. Methods to support an empathic understanding are well documented in the field of design, but are normally used to generate insights that affect change within the designer. This study demonstrates that tailoring these methods to be accessible to dementia care staff can provide opportunities that generate insights not just for the designer but also for participants. Tools were designed and delivered to care staff (n=11) through facilitated workshops in care homes (n=5). Through engagement in creative activities these tools provided opportunities for staff to reflect on the abilities and well-being of residents; and helped them to develop an awareness of their own tacit knowledge. The paper presents the methodological framework on which these tools were based and discusses the potential benefits that such tools hold for the field of dementia care; through innovative practical approaches to support training and delivery of high quality care.

Keywords: Dementia care, Well-being, Creative activity, Mindfulness, Applied research.

Introduction
Dementia is considered “one of the major challenges for development in the twenty-first century” (WHO and Alzheimer’s Disease International, 2012) due to its impact on the economic and social landscape. The global cost of dementia care stands at USD $818 billion, exceeding the market value of companies such as Apple and Google (Prince, et al., 2015). However, in light of recent estimates for diagnosed cases this cost is expected to rise to USD $2 trillion by 2030 (ibid). Figures from the Alzheimer’s Society show that 80% of service users in long term residential or nursing environments are experiencing a form of dementia or Alzheimer’s related disease (Alzheimer’s Society, 2014).

Dementia care provision requires specialized approaches and services, placing greater demand on resources and staff well-being than any other long-term illness in older people (Prince, et al., 2013). Staff well-being is fundamental to that of residents as reduction in the well-being of staff correlates with a decrease in the quality of care provision for residents (Baker, et al., 2015).

Using design research methods this study developed ways to access the tacit knowledge of dementia care staff to inform new strategies that support those caring for individuals living with dementia. The findings suggest that these methods have the capacity to develop innovative approaches that support staff training and the delivery of dementia care.

Background
This paper presents the final stages of a PhD study undertaken within the Centre for Applied Research in Inclusive Arts and Design (CARiAD), an interdisciplinary group whose research contributes to academic knowledge through engagement with participants. Previous project stages collected qualitative data through observations of dementia care units and activity groups, as well as interviews with care practitioners, care managers, activity facilitators, artists and experts to gain an understanding of how creative activities can support the wellbeing of individuals living with dementia (Coleman, et al., 2016). Findings from this data identified that the impact of activities designed for residents living in the care environment relied, to a greater extent, upon the acceptance of these activities by care practitioners. Therefore the aim of the study presented in this paper was to obtain a holistic understanding of the lived experience of care practitioners, and to contextualize this knowledge in specific relation to how the well-being of residents living with dementia is supported within the care environment.

Method
Design research methods include tools that provide designers with insights into the lived experience of participants by revealing the values, preferences, needs, and beliefs of the end users (Wright and McCarthy, 2008). Such methods and tools have been used to provide insights and inspiration for health care strategies (Crabtree, et al., 2003); for understanding the values of individuals with early onset dementia (Wallace, et al., 2013); and as avenues into the lived experience of others (Mattelmäki and Battarbee, 2002).

Using tools that were adapted from design research methods the study delivered workshops in five care homes with eleven front line care practitioners. The workshops were designed to collect data on how participants understand, value, and use activities to support the well-being of residents living with dementia. The tools invited participants to reflect on questions through the act of making, in this case through the creation of collages; the definition of making within this methodology is considered as “not just a performative act of reproduction, but a creative act which involves construction and transformation of meaning” (Sanders and Stappers, 2014). Using creative activity in qualitative research can provide deeper understanding for the researcher by encouraging participants to think “in non-standard ways” (Mason, 2006); to avoid automatic or “readymade” answers that may occur through verbal interviews (ibid); and provide avenues to access and communicate tacit knowledge (Gauntlet, 2007).

The tools used in this study drew upon themes identified in previous stages of the research, and required participants to respond to open ended questions in order to: i) consider the world from the perspective of individuals living with dementia; ii) reflect upon the role and delivery of activity within the context of dementia care provision; and iii) to contextualize the preferences, abilities, experience, and beliefs of residents in relation to activities or strategies that support their well-being.

Participants
The project was partnered with Gwalia Cyf (now part of the Pobl Grwp) a leading social service provider located in South Wales, UK. Access was granted for the study to take place on the organization’s premises and sessions were conducted in common rooms in five separate locations. Eleven participants took part in the study, consisting of four sessions with two participants, and
A presentation was given to the organization’s managerial staff, detailing the project’s aims and objectives, following which all care home managers present requested to take part in the study. Each manager forwarded the names of two front line care practitioners who care for people living with dementia. Introductory meetings were arranged with the care practitioners in each of the five care homes, the introductory meetings lasted approximately one hour and served as an opportunity to present the aims and methods of the project, as well as an opportunity to address any participants’ questions. All participants agreed to take part in the project, with an additional participant being recruited in one home after demonstrating an interest during an introductory meeting.

Workshops
The workshops were conducted at the participants’ place of work and were arranged during their regular working hours. Each involved three separate activities, followed by a discussion that was facilitated by the researcher, and lasted for approximately an hour and a half in total. All participants gave consent for digital video and audio recordings to be taken, and the researcher retained the completed activity sheets.

Ethics
The study received approval from the University’s Ethical Review Board allowing data to be collected from care staff using specific methods and protocols. In addition, the methods were discussed with gatekeepers from Gwalia Cyf, prior to any contact with front line staff, to confirm the appropriateness of the study and identify any potential issues that had been overlooked, of which there were none.

Analysis
Each session was transcribed verbatim and coded using the qualitative software package NVivo for Mac. Data was analysed using Thematic Analysis (Braun and Clarke, 2006) with the names of all staff, residents, organisations and geographical locations omitted from the data.

Findings
The act of making visual artefacts is a process that takes time and, unlike methods that require instant responses, allow participants the opportunity to engage with the question, consider the issues, and change their views before giving a response (Gauntlett, 2007). Images hold multiple meanings at any time that can differ depending on viewer, time, and context in which they are viewed (Sturken and Cartwright, 2001); furthermore images are able to “elicit emotional as well as intellectual responses” (Weber, 2008). Therefore it was anticipated that the methods used in the sessions would facilitate considered responses to open ended questions, and allow participants to make their own inferences on which were the relevant and pertinent points to be addressed in the discussions which followed. However, as well as providing a rich source of data the sessions can be seen as beneficial to the care practitioners themselves by providing an important opportunity for reflection.

Developing awareness of tacit knowledge and skills
Through descriptions of supporting resident’s well-being within the care environment, practitioners stressed the importance of tacit skills and knowledge. These skills involved recognizing the emotional state of residents, being empathic to their psychological needs, knowing or understanding how their needs can be met, and delivering appropriate strategies to meet them.

“A lot of it is getting in their personal space or reading their body language... to know that they’re a bit upset. Perhaps they need a cup of tea, or a little chat, or [you] take them out of the situation that they’re in at the moment... It’s just learning.”

This process did not only occur on a one to one basis, but was a significant factor in maintaining a wider supportive environment, meaning that care practitioners regularly manage the psychosocial dynamics between groups of residents.

“You’ve got to be able to read people and you’ve got to be able to change a sad or an angry moment into something else... You’ve got to be able to control what’s going on really.”

The complexity of skills required to support the well-being of residents appeared to be overlooked or taken for granted by the practitioners. One reason was due to the unpredictable nature of the working environment, requiring practitioners to react to a wide variety of circumstances in meeting the demands of physical and psychological care provision. One participant summarized their daily experience on the unit as “a rollercoaster” and another explained the situation as requiring the need to “split yourself up into fifteen parts.” The sessions provided an opportunity to reflect upon examples of practice, which served to highlight the nuances and skills that are involved; one participant described their role as being both a “detective” to understand the environment, and as a “clown” using humour to brighten situations. The sessions were viewed as enjoyable and even “productive” opportunities in which practitioners became more mindful of their interactions with residents, and the skills they use to support resident’s well-being.

CP 3: “It’s been a good exercise today, I’ve enjoyed it.”
CP 4: “Makes you realise what we actually do.”
CP 3: “Until you stop to think and write it down, and you get help to write it down.”
...
CP 2: “Because you’re just on automatic pilot in there aren’t you?”

Encouraging a change of perspective
Communicating or expressing ideas through images encourages a way of thinking that relies on metaphors and inference, doing so can lead to a shift in perspective that can highlight previously unseen realities (Weber, 2008). The structure of the sessions was designed to invite the participants to reflect on questions pertaining to the wellbeing of residents, by shifting participants’ focus away from their role as carer and to think empathically about the lived experience of residents. Again, reflection on resident’s preferences, psychological needs, and abilities was seen to provide benefits to the relationship between carer and resident as several participants expressed that the sessions enabled them to “think about the individual” and “to understand how [residents’] minds work.”

Reflection upon the lived experience of residents provided insights for participants that led to an awareness of knowledge that can be seen to support the personhood of residents. During one discussion care practitioners came to recognize a resident’s...
ability to sense and respond to the emotional state of others, the value and significance of which had gone unnoticed in the day to day routines of the dementia unit.

CP 2: “She can tell straight away if there’s something wrong. Say if I’ve got something wrong [outside of work]… she’ll say...Are you alright?’ But, she’ll say it in her own way…She knows.”

CP 4: “Yes she does. It’s mad isn’t it?”

CP 2: “Yeah it is, when you stand back and think about it.”

Discussion
The paper connects with the conference theme by presenting a study which supports an argument that methods drawn from design research have the capacity to support a humanistic approach to dementia care and offers a potential framework for developing strategies to support well-being within the care environment.

The findings in this paper suggest that there is a potentially significant link between dementia care and design research, and that link is identified as empathic engagement. Empathy towards the lived experience of individuals with dementia is integral to Person Centred Care (Kitwood, 1997), an approach that is considered the bedrock of high quality dementia care. Kitwood describes empathy as “an attempt to understand what a person may be going through, listening carefully to what they say, noticing what they do, and making sense of it all by drawing on our own experience” (ibid). During the 1980’s Kitwood and the Bradford Dementia Group advocated an empathic approach to understanding the lived experience of dementia by applying qualitative research methods from the social sciences (ibid). At the same time the design industry sought ways to gain an understanding of the needs of the end user and similarly began applying methods of social sciences (Sanders, 2002). Empathy became integral to the design process with Wright and McCarthy (2008) echoing Kitwood’s description by stating that a designer needs to be attuned and attentive to the needs and emotional experience of the end user. The means to achieve an empathic understanding have progressed significantly within the field of design research and include methods to provide opportunities for rich dialogues (Sanders and Stappers, 2014); to promote an understanding of daily experiences (Mattelmäki and Battarbee, 2002); and arguably go beyond Kitwood’s definition by not just seeking to understand what a person is experiencing but to obtain deeper insights into personhood by making their beliefs, hopes, and dreams perceptible (Gaver, et al., 2004).

The main purpose of design research methods is for the end user to communicate aspects of the self, thus providing insights and inspirations that inform the designer. However, rather than informing the relationship between designer and end user this study demonstrates that it is possible to reframe these tools in ways which inform the relationship between end user and a third party (i.e. between care practitioner and resident). Therefore, rather than consider these tools as just part of the design process, this paper proposes that there is significant potential in integrating these tools into the care environment to provide insights that support an empathic approach to care. In essence shifting the focus of the methods from development of products, to facilitation of a process that benefits both care practitioner and residents.

References


