Introduction
Individuals living with dementia can face challenges in supporting their subjective wellbeing as the means to do so can be reduced through cognitive decline. For those in the care environment these issues can be exacerbated as access to the physical or social avenues, previously relied upon, are limited or removed entirely (Kitwood, 1997). For older individuals participation in creative activity has been shown to support wellbeing in ways that are in accord with human flourishing (Desmet & Pohlmeyer, 2013); such as health improvements, reduced medication use, increased levels of interest and engagement, as well as broadening social interactions (Cohen et al., 2006; Cutler, 2009). Brod et al. (1999) suggest that the domains that support wellbeing are the same in those living with dementia as those who are not. However, they conclude that the unique characteristics of the disease dramatically shape these domains, and that in order to support wellbeing in this context one needs to adopt a disease specific conceptualisation of the term in areas that “directly [relate] to cognitive, behavioural, and social changes accompanying disease progression” (ibid).

This paper describes research undertaken during the preliminary stages of an ongoing PhD project looking at ways in which creative activities can support the subjective wellbeing of older individuals with dementia living in the care environment. An ethnographic approach was used to identify how the context of dementia shapes creative activity within this environment with the aim of applying this knowledge to new strategies. The context, approach, and methods of the project are presented and followed by a brief summary of selected findings. The subsequent discussion poses the question as to whether Experience Design (Hassenzahl et al., 2013) offers a framework for new creative strategies to support wellbeing in the dementia care environment, and a brief outline for future research is presented.

Context
Dementia is a syndrome used to describe a set of progressively degenerative symptoms associated with neurological diseases affecting the functioning of the brain, for which there is currently no cure (WHO, 2012). This year a person will be diagnosed with dementia every 3.2 seconds, equating to 9.9 million new cases (Prince et al., 2015). A recent review of statistics estimates that there are currently 46 million people living with the disease. This figure is expected to nearly double every twenty years (ibid). The prevalence of dementia increases significantly with age and...
improvements in health care and quality of life have enabled a rapid growth of those aged 60 and over. Therefore, an ageing population combined with projected cases of dementia presents considerable challenges for the social, economic, and service sectors. A situation that the World Health Organization describes as “one of the major challenges for development in the twenty-first century” (WHO & Alzheimer’s Disease International, 2012).

Amongst this major challenge is a call to find ways to mitigate the pressure facing dementia care services. Current estimates indicate that global dementia care costs stand at USD $818 billion, which is calculated to rise to USD $2 trillion in 2030 (Prince et al., 2015). Care needs to support an elderly person with dementia are significantly more demanding than many other chronic long term illnesses (Prince et al., 2013). As symptoms progress these increasing needs mean that many of those living with the disease require professional support, often becoming residents of long term care (Train et al., 2005).

In the UK one third of individuals diagnosed with dementia are living in long term care environments. This figure means that 80% of service users in residential and nursing care are living with a form of dementia or cognitive impairment (Alzheimer's Society, 2014). A predicted increase of service users combined with a challenging economic context means that strategies to support quality of life and wellbeing for residents will need to be efficient, resourceful, and focused.

**Activities and wellbeing**

Participating in activities is fundamental to the pursuit of wellbeing (Lyubomirsky, 2007), and can be regarded as intrinsic to human nature (Csikszentmihalyi, 1993). For those living with dementia activities remain fundamental avenues to supporting psychological needs (Kitwood, 1997), and can be regarded as more important to an individual’s wellbeing than their physical and social environment (Perrin, 1997). Whilst creative activities have been shown to benefit the wellbeing of residents living with dementia (Palmiero et al., 2012), studies show that activities in the care environment are only successful in supporting wellbeing if delivered in the correct context (Cohen-Mansfield et al., 2012). However, within the residential care environment time constraints, targets, and limited resources often mean that attaining to physical care needs take precedent over the psychological needs (Green & Cooper, 2000). Activities are delivered by untrained staff (College of Occupational Therapists, 1996), often in large groups to as many residents as possible. In this context activities risk becoming a ‘box ticking’ exercise, or perceived as passive entertainment rather than meaningful engagement, which can leave residents sidelined or disengaged. Activity done purely for the sake of ‘doing something’ holds little value and will fail to contribute to a sense of wellbeing (Harmer & Orrell, 2008), the essential and defining factor is that the activity should be considered meaningful by the participant. Meaningful and therefore pleasurable activity can be defined as that which successfully allows an individual to meet and fulfill their psychological needs (Hassenzahl et al., 2013).

Therefore the research seeks to build an understanding of how creative activities can provide avenues to fulfill the psychological needs for residents, and to ask whether we can use this understanding to develop sustainable activities that are inline with the requirements of the care environment.

**The project**

The research presented in this study formed the preliminary stages of an ongoing PhD study aiming to identify how ludic (non goal orientated) creative activities can be used to support the subjective wellbeing of older individuals living with dementia in residential care.

The PhD project is located within the Centre for Applied Research in Inclusive Arts and Design (CARIAD), a multidisciplinary research group that uses participatory design methods to address social challenges. Amongst the group’s research portfolio are: LAUGH (Ludic Artefacts Using Gesture and Haptics), an AHRC funded international collaboration to develop innovative playful devices for people living with late stage dementia; and HANDS (Helping Assist with New Devices for Seniors), a portfolio of inclusive and participatory design research projects investigating innovative ways to increase the subjective wellbeing of people with dementia.

This project’s partner and main stakeholder are Gwalia Cyf, a leading social care provider who has granted access to a number of specialist dementia units in residential and nursing environments located in South Wales, UK.

**Methodology**

Designing for wellbeing undoubtedly involves understanding the subjective experience of the user (Kaufmann & Engel, 2014). However, residents in long term care are often living with mid to advanced stages of dementia, and can be experiencing severely diminished reasoning, comprehension, and even limited access to the subjective domain (Ott et al. 1996). Limiting the inclusion of those who are being designed for, based on the same limitations that one is trying to support, presents a paradox which contrasts Kitwood’s (1997) key principle to view the person and not the symptoms. Bond & Conner (2001) presents a sound argument for inclusion by suggesting that “there are no unique methodological challenges in researching dementia. Rather, the complex nature of dementia and dementia care highlight the methodological challenges of investigating complex social phenomena.” And indeed studies such as Kaufmann & Engel (2014) demonstrate the value of such inclusion by applying qualitative methods to obtain first hand data on the subjective experience of those living with late stage dementia. However, it is clear that such an approach would require considerable knowledge and experience of both the ‘complex nature of dementia,’ and of applying research tools and methods within challenging social phenomena. As both this knowledge and experience
were beyond the current range of the PhD researcher, an approach that designed for people with dementia rather than with people with dementia was chosen. Inline with the literature (Brooker, 1995; Lindsay, 2012) the preliminary stages focused on gaining an understanding of the field, thus an ethnographic approach (Atkinson, 2001) using observations and interviews was applied in order to do so.

**Procedures**

Involvement with the CARIAD research team allowed the author to shadow qualitative interviews, observations, and pilot studies all of which were undertaken within the dementia care environment. This experience provided valuable grounding for the protocols, methods, and personal approach that is required in conducting research in sensitive and complex areas.

Initial meetings were conducted with key managerial staff members from the stakeholder, Gwalia Cyf, in order to explain the aims of the project, and as an opportunity to discuss the proposed ethnographic methods of conducting observations and interviews. The stakeholder granted the researcher an honorary working contract, which provided the same level of insurance and access as care staff whilst on site.

Following this, approval was successfully obtained from the University’s Research Ethics Committee to conduct observations of dementia care units and activity groups, as well as to collect data through formal and informal interviews with care staff and activity service providers. Literature suggesting that differences in managerial approaches can influence the structure of the care units, and the variety of activities provided to residents, (Harmer & Orrell, 2008) raised the question as to whether focusing on a single care provider may impact on the generalisation of findings at later stages. Therefore the ethical approval allowed for research to be undertaken with care providers other than the project’s main stakeholder.

Initial aims focused on familiarization using traditional ethnographic methods of observing and talking to those who worked in the field. Focus at this stage was on obtaining insights into the variety of creative activities that are available to residents, to explore how these were delivered, to identify the resources being used and how they were applied, and to identify activities that were deemed to be successful in supporting wellbeing and to ask why.

The goal being to use this data to find patterns (Hassenzahl et al., 2013) in activities that support wellbeing, and to use these patterns as a framework for developing new strategies or activities in later stages.

**Methods**

**Interviews**

Case study interviews (Yin, 2014) were conducted with a range of individuals involved with delivering creative activities for dementia care services. The intention was to understand the term ‘activities’ from as many viewpoints as possible such as front line staff, project managers, and activity providers and facilitators. Following informal agreement to take part in the study all participants were sent a project information form and consent form, both having previously been approved by the University Research Ethics Committee.

Wherever possible the interviews were conducted in person at the participant’s place of work and were audibly recorded. In two instances a personal meeting was not possible and the interviews were conducted using Skype, in these cases screen-capturing software was used to make both audio and visual recordings. As the aim of this stage was to explore the field, semi-structured interviews were used in order to allow flexibility in questioning, and to peruse key points which may emerge (Silverman, 2013). The interview questions were tailored slightly to fit the participant’s job and focus on their area of expertise, but the core questions remained the same throughout. These core questions focused on eliciting practical knowledge as well as opinions and experiences on the style of activity provided to residents, how activities were delivered/facilitated, how activities were tailored to specific needs/environment, how activities provide pleasure, and how activities are evaluated. Each interview lasted between 45 minutes to an hour.

**Participants**

Participant selection was made from a snowball approach through the course of the research stage. Interviewees included a member of Gwalia Cyf’s care team, recommended by managerial staff on account of their ability to support residents using playful and meaningful activity. An activities coordinator who managed a service delivering a horticulture activity, to a broad range of dementia units, for one of South Wales’ leading mental health and wellbeing charities. Also, three creative arts facilitators specializing in print making, clay sculpting, and drama therapy/clowning who had been involved in a two year project delivering creative activities within the care environment to the project’s stakeholder. An expert interview was conducted with John Killick, a poet, creative practitioner/facilitator, and well cited author on dementia who’s work supports the promotion of personhood for those living with the disease through methods that celebrate and advocate the creative and playful possibilities within dementia care (Killick, 2012).

**Observations**

In parallel to collecting interview data observations of facilitated activity sessions were conducted in a variety of residential care environments. In total five activity groups delivered by trained practitioners were observed; these included a horticulture activity, a music and movement group, two ‘quiz and reminiscence’ activity sessions, and an intergenerational clay-sculpting event involving local school children. Each activity session lasted between 1 and 2 hours.

In order to contextualize the data it was felt that an understanding of the daily routine within the care
environment was necessary. As such observations of four different dementia care units were undertaken on days when there was no organised activity session run by a trained practitioner. Six separate observations took place in care units, each observation session lasting for approximately four hours. The sessions took place between the hours of 8.00 am to 6.00 pm in order to view as many different aspects of the working day as possible, including medication rounds, in-house activity sessions, quite periods, and meal times. Only the common areas of the care environment were observed such as lounges, activity rooms, and dining areas. It was the author’s decision not to conduct observations through the evening or early morning as it was felt that this would be too obtrusive for both carers and residents, furthermore informal conversations had suggested that most activity takes place during the day.

For both the organised activity sessions and the daily routine observations, jot notes (Walford, 2009) were taken in situ using a discrete notepad and pencil. These notes were then reflected upon and written up in long hand once off site, either the same evening or as soon as was possible. Observational data collection focused on both the physical and social environment. Notes were taken regarding the number of residents in the room, number of staff in the room, layout of the room, types of activities that were engaged in, objects and materials used in activities, levels of engagement of staff and residents, interactions between staff and residents, accessibility and availability of activities to residents.

Analysis
Audio and visual recordings of the interviews were anonymised and transcribed verbatim. The software package NVivo 10 for Mac was used for data management. Thematic analysis (Braun & Clarke, 2006) was chosen for its flexibility and accessibility to early stage researchers. As this stage was concerned with forming an understanding, rather than confirming or developing theories, an inductive approach was used to analyze the data. Patterns and themes that appeared across all interviews were valued as significant, as well as those that gave rich descriptions and specific examples.

Although only quotes taken from the qualitative interviews are cited as examples in this paper, it was the knowledge obtained from the observational studies that contributed to the active analysis of this data set and in identifying the patterns and themes that were of interest.

Findings
The findings presented are a summary of a selection of key points that address the question of how creative activities can be used to support subjective wellbeing for residents living with dementia in the care environment. This is followed by a bullet point summary, and a short discussion in which a direction for future research is presented.

Creative outcomes
In-house arts sessions appear to be a common staple on the activity timetable within the care environment. These are often described as ‘arts & craft’ activities, and are run by members of care staff. The methods used are generally based on simple techniques and resources. Using themes such as seasonal events or holidays they tend to focus on producing outcomes, such as seasonal decorations, which can then be used to turn available windows, shelves, or walls into temporary exhibitions within the building. The artefacts can however appear quite crude or overtly simplistic in nature, which may lead staff to be conscious of the outcomes. When talking about a window display depicting paper cut outs of seasonal fauna a staff member involved explained,

“I didn’t want to do more in case it looked like a nursery.”

Kitwood stresses that the provision of meaningful activity ‘requires a great deal of skill and imagination to meet the need for occupation, in a way that does not impose false solutions, crude and ready-made’ (Kitwood, 1997). A deficit of activities designed specifically for this demographic (Treadaway et al., 2014) results in activities being chosen for residents that are based on the physical and mental ease with which they can be completed, leading to products that have been designed for a much younger age group being considered suitable.

Creative process
Funding requirements often stipulate that tangible outcomes, or products, are an essential goal of professionally delivered arts projects. However, for the creative practitioner, an emphasis on producing these outcomes can impact on the sessions by taking the focus away from the creative process.

“If you have to make a product you have to start… timetabling, you have to start nudging people in certain directions because you need them to do certain things.”

Rather than sessions center around completing an outcome or achieving a goal the creative practitioners expressed a clear value in the positive experiences that arose through the process. In these instances it was the case that laughter, positive atmosphere, as well as ‘engagement and satisfaction’ were, to them, important indicators of success.

“A lot of it is just how it feels [on] every visit, if people are having a good time and... the staff are happy, and the residents are happy then you know that’s successful.”

“And that [residents] got into it, they had this lovely feeling of getting drawn into the material and that focusing thing, ...what do the psychologists call it? Flow.”

This point is demonstrated in an account of a resident living with advanced stages of dementia and experiencing very limited communication, mobility, and hand use. Over a number of weeks the resident found meaning in the process of drawing.

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This point is demonstrated in an account of a resident living with advanced stages of dementia and experiencing very limited communication, mobility, and hand use. Over a number of weeks the resident found meaning in the process of drawing.
“[He] liked to draw, he liked to have a pencil or a pen in his hand, and you could see him start to sort of make marks. And it was, somehow, he was guiding, you know, it was giving him something to actually focus on.”

Within the context of dementia the smallest action can take on profound meaning (Snyder, 2001), here engagement in the act of mark making for a sustained period indicates a significant level of meaning. Crucially, it seems to suggest that engagement and pleasure in the process appears to be accessible to residents despite diminished cognitive functioning (Murphy et al., 2010) means an activity that may be fluctuating physical abilities associated with dementia (Sullivan et al., 2002), including opportunities to contribute to self identity, facilitate a sense of agency, provide meaningful purpose, and to feel valued by others.

**Avenues towards personhood**

A shift in focus from product to process opens further opportunities in which creative activities can support personhood. Dementia can lead to the loss of an individual’s ability to engage in previously valued skills through cognitive and physical decline. This loss of skill not only reduces the opportunity, or avenues, to fulfill psychological needs, but it can lead an individual to withdrawal from activities in order to avoid embarrassment or shame (Snyder, 2001).

“She loved art because she’d done it, [but] she’d also lost that, because she’d got more impaired over the years. So sometimes she’d be really depressed about how little she could do now. Staff were always like, “Oh I don’t know if she’ll come today.” And we’d always say, “Oh invite her to come.” Because she loved being in a group, she always had interesting things to say or she’d be our critic; she’d go “Oh yes that’s very good.” And she loved giving us advice... And we really valued that in her.”

Considering the session as only a linear activity, or a set of practical steps to make an artefact or outcome, risks missing the range of opportunities that are available to support wellbeing. The data showed facilitated activities were able to provide opportunities for experiences that can lead to significant benefits for an individual with dementia (Sullivan et al., 2002), including opportunities to socialize, contribute to self identity, facilitate a sense of agency, provide meaningful purpose, and to feel valued by others.

**Flexibility**

The importance of flexibility was evident in the props and materials used as well as the preparation of activity. Often when entering the care environment the activity facilitator faced a range of unknown variables. Only on arrival would they know who they would be working with, how many people would be in the group, the mood of the group, whether any individuals may be experiencing distress or require additional attention. The same is true for daily care provision, fluctuating physical abilities associated with dementia (Murphy et al., 2010) means an activity that may be accessible to a resident one day may be unsuitable the next.

A flexible approach also played an important part in allowing the activity to take unexpected turns.

Moments in which residents defined the direction of the activity resulted in successful, meaningful, and surprising interactions.

“In one session I had a ball with the world printed onto it. And some people could see it was the world, the globe, and they would talk about where they’ve been. And for other people it was just something to squeeze like one of those stress balls. And [in] one session we just ended up blowing the ball across the table. It was great because suddenly everybody had to fill up their lungs, so that was very life affirming... And that didn’t come from me, I didn’t even think of that, what a brilliant idea!”

Recounting an intergenerational project run with a local school, a creative practitioner provides an account of a resident with dementia who had been very disengaged with previous activities. Choosing not to participate in the same way as the rest of the group, who were all creating clay models, two members of the group used the materials to develop their own activity.

“The one that caught my attention the most was [name excluded], the guy that could be quite, you know, he spoke quite poetically about the war. He teamed up with this very shy girl and they started playing tic-tac-toe on the clay, drawing on it and then wiping it off, taking advantage of the fact that it was such a changeable material. And they started playing this game, and they played it for ages. And they were both totally into it, just very amused you know, laughing away to each other and if anyone talked to them they’d be like, you know, ‘Don’t interrupt!’ And get back to playing their game of tic-tac-toe on this sheet of clay. So that surprised me, I never would have thought about suggesting doing that.”

The ability to make connections and come up with new possibilities is indicative of creativity. Here the term creativity should be not be restricted to outcomes or activities but instead can be considered in a broader sense. A creative mindset within this environment allows for unexpected moments to emerge, and to be turned into memorable events.

**Engagement**

Asking participants to engage in any creative activity will always have limitations, many of which can be attributed with associations with the word ‘creative’ itself (Weisberg, 1986), causing those who do not consider themselves ‘creative’ to take flight. However, a recurring theme within the data was the willingness of residents to take part in new creative activities.

“The average person who is functioning well will have that thing, ‘Oh no!’ Or maybe if they can draw they’ll be, “Oh yeah I can draw.” But there’s an ego involved which isn’t there with people with dementia, they don’t, I don’t think they’re that self conscious.”

Data showed that residents were willing to try new activities and experiences (Snyder, 2001), and that activities could become opportunities to celebrate life, to have fun, and to feel connections to others and to the self (Dupuis, et al., 2010). However, to access the
opportunities in these areas requires a sensitive ear and for the creative process to be valued.

**Perception of creative activities in the care environment**

The value attributed to creative activity within the care environment can be low. It is unclear whether this is because simplistic methods set the standard, whether time constraints, appropriate resources, or personal preferences of care staff play a factor. The impression that one creative practitioner had was that some staff were skeptical as to the validity or effectiveness of the sessions.

“It was like; ‘These people turning up with paper and pencils and trying to get these people to draw was just ridiculous.’ You could see it, them thinking that”

At times some care staff viewed the creative activity sessions in terms of passive entertainment rather than as opportunities for considered engagement, with residents being 'wheeled in’ part way through an organised and carefully facilitated session and expecting them to ‘pick it up.’ A similar impression from another creative practitioner offers potential insight into why this opinion might be held.

“I think when we first went in, the carers were a bit like ‘Oh here we go, you’re just going to wind everybody up and then leave us with chaos.’ Circus comes to town, you know, and there’ll be residents who’ll be stressed and anxious and uptight after we’d gone.”

Positive wellbeing in residents leads to improvements in mood, reducing agitation and behaviours described as disruptive and negative. Once the effect of the activity sessions had resulted in benefits to the mood of the residents then the potential value of the activity was made manifest.

“The residents were in fact calmer, more likely to chat, more likely to laugh, eating better. [They] seemed much more positive in themselves and so the carers seemed to warm up quite a bit.”

Interview data shows that support from care staff was crucial in facilitating an atmosphere that was conducive to creativity and freedom of expression, the care staff who ‘understood’ the purpose and potential benefits for residents were described as ‘the glue that kept it together,’ and as valuable links between facilitator and residents.

**Summary of findings**

— Creative activity can support wellbeing for residents living with dementia in ways that adhere to Kitwood’s model of psychological needs.
— Avenues to wellbeing can be increased by focusing on the creative process, and not the end product.
— Experiences that provide pleasure are valuable resources in this environment for both residents and care staff.
— Contextualizing activity through the lens of dementia is required to recognize meaning in the smallest detail.

— Creative activities may face barriers in terms of value within the care environment.
— The values associated with strategies will determine staff acceptance and therefore influence the likelihood of long-term application of these strategies.
— Visible benefits to the wellbeing of residents can lead to an activity being valued.

**Discussion**

In researching ways that creative activities can support the wellbeing of people with dementia the data shows that avenues to support wellbeing can be identified in the outcomes, the process, and the facilitation of activity. Empathy with the process of creativity appears to contribute to an approach that recognizes, understands and values the opportunities for pleasure in the processes of engaging in arts based activities.

If diagnosis figures are correct then the demands on the dementia care sector will require solutions that maximize every available resource. Creative activities can support the subjective wellbeing of residents, and happy residents ease the pressure on care staff. Therefore a significant design challenge will be to provide ways in which creativity can be recognised as a valuable resource.

Financial constraints often mean that external activities are amongst the first expenses to be cut. For strategies to achieve an impact they need to be adopted by care staff in order to sustain long term application. Therefore a successful approach to designing strategies for wellbeing within this environment would need to understand the values that are felt to be significant to care staff.

Creativity exists within the daily care environment. It may not always adhere to an artistic definition of the term, but it is evident in the adaptive ways care staff use their social skills to support residents, in the methods they develop to understand individuals who have lost the capacity of verbal communication, and in the ways they can create an atmosphere of fun and humour amid challenges. The avenues to support personhood that creative activities provide are important and valued, but accessing these avenues through traditional arts based approach may not always be recognised.

If the term ‘creative’ comes with connotations and expectations, then designing for experiences (Hassenzahl et al., 2013) could offer ways of harnessing these avenues in ways that are more conducive and acceptable, by removing the focus on the act of creating and instead reframing beneficial patterns as opportunities for positive experiences.

**Future direction**

Future stages of the project will seek to identify a framework for creative strategies that support the opportunities for wellbeing as outlined in this study. It is intended that the future methodology will be informed and supported by the data gathered during this preliminary stage and will focus on identifying...
strategies that are in line with the needs, resources, and values of the care environment.

In line with Visser et al. (2005) data collected from interviews with care staff revealed only a certain level of depth, particularly when approaching potentially sensitive subject areas. Therefore an approach using generative methods (Sanders & Stappers, 2014) will be applied in order to obtain a deeper and richer data set.

Areas of specific focus will include the following:
— Defining what the term ‘activity’ means to care staff: preliminary findings suggest that the definition of ‘activity’ can be used by staff to refer to a broad scope of interactions with residents, ranging from one-to-one conversation to organised group events.
— The values that care staff feel are important in supporting the wellbeing of residents; the values that staff attach to activities/strategies appear to determine the success of implementation of the strategies, therefore identifying and promoting these values may support successful frameworks.
— How the daily reality of the care environment may influence opinions and feelings towards activities; it is also clear that activities/strategies must be tailored to the working routines and pressures of the environment in order to be considered accessible, practical, and meaningful.
— Identifying current strategies to support wellbeing; focusing on patterns that can reveal how activities/strategies are best delivered, when they can be appropriately delivered, and why they work.
— Identifying potential barriers to creative activity; in order to reframe patterns and develop experiences that are accessible to all.
— Identifying the physical and psychosocial resources available within the environment; as stated the challenges facing this environment mean that all available resources should be fully utilized.

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