

561. Designed with Dementia: Developing Creative Communities

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ABSTRACT *This paper presents an ongoing research project situated within the investigative context of design and dementia. The work adopts an open approach to working with people living with dementia by recognizing and utilizing the inherent personal creative abilities that every individual possesses no matter their cognitive ability. Through a series of carefully developed co-design workshops, 'Designed with Dementia' supports people living with dementia to express themselves fully. Their input is highly valued and is held in the same esteem as any other collaborator. In this project, participants become collaborative designers helping to propose possibilities, evaluate and select solutions, give their knowledge and skills freely, and generally 'make things happen'. In particular, co-design is used here to engender sociable interactions and collaborations, change existing patterns of behaviour amongst all the participants, and look to change assumptions and pre-conceived ideas.*

Keywords: Co-design, Dementia, Collaboration, Creative Communities



Introduction

In the UK, dementia and how we respond to it has reached a crisis point. It is a problem that improved public awareness or a better diagnosis alone will not solve. The UK Government believes we need to see profound changes to the way we view the person living with dementia (All Party Parliamentary Group on Dementia 2016). With this in mind, the 'Designed with Dementia' co-design project presented in this paper helps to show that people living with dementia can continue to make a significant contribution to society after diagnosis. The approach taken here actively involves a range of stakeholders in the co-design process such as care workers, people living with dementia, and their family and friends to help ensure the collaborative project is valuable and useful. The co-design work presented in this paper has been carefully developed to be appropriate to people living with dementia serving emotional and practical needs by responding to their shared cultural interests. Moreover, the co-design work aims to help people recently diagnosed with dementia to build their self-esteem, identity and dignity and to keep them connected to their community. The project discussed in this paper is one of a number of ongoing projects that target these aims.

The Nature of Dementia

Dementia is a broad umbrella term used to describe a range of progressive neurological disorders. Common symptoms of dementia can include problems with short term memory where new information is difficult to retain. Everyday experiences, people and places can become unfamiliar, confusing and personally challenging. Language can become troublesome and methods of communication restricted as words and intentions become confused. People with dementia may lose interest in engaging with others socially, they may become quieter and more introverted impacting self-confidence. Amongst older people, dementia makes the largest contribution to the need for care (Prince et al. 2013). The demand for dementia related health and social care services continues to increase as a result of demographic changes. Responding to this challenge will require innovative ways of supporting people with dementia to live well from the early stages of the illness. People need support from the point of diagnosis to come to terms with this life altering illness, to remain connected to their community and enable them to live well.

Design and Dementia

This ongoing research aims to develop a number of disruptive design interventions that break the cycle of well-formed opinions, mindsets, and ways-of-doing. The idea that nothing can be done to help people with dementia often leads to feelings of hopelessness and frustration (Batsch and Mittelman 2012), perpetuating a sense of stigma, isolation, and generally negative reaction. Many people living with dementia have a sense of inadequacy and low self-esteem, with personal perceptions of their status within society reduced as a result of diagnosis (Katsuno 2005). Generally speaking, people living with dementia are not considered as contributing to UK society. Rather, they are seen as a social and economic burden. Rarely are people living with dementia deemed capable

of contributing to the UK's GDP by designing and developing new products and services. This ongoing work, however, sets out to directly challenge this assumption. A 'designing with' perspective has been applied where the person living with dementia is not viewed as a 'subject' but rather as an 'active participant' in the project (Sanders and Stappers 2014). Emphasizing fun, our approach encourages the development of richer, more varied solutions to everyday issues (Bisson and Luckner 1996). The co-design work presented here adopts a largely interventionist approach, which is based on a number of recent theories emanating from research in economics, business and design (Christensen and Overdorf 2000; Scharmer 2011; Rodgers and Tennant 2014) that celebrate jumping straight in, doing things in order to learn new things, and valuing failure.

Designed with Dementia is a design proposition that utilizes the latent creative abilities of an individual's personal knowledge and skills (Kelley and Kelley 2015). Here, people living with dementia are highly valued and their inputs and collaborations are held in the same esteem as any other party. In the process, all the participants become co-designers helping to propose possibilities, choose solutions, provide services and 'make things happen'. Co-design is predominately about 'change' (Brown 2009; Heath and Heath 2011), which relates to making a difference in the world around us. In this scenario, the actions of the designer and the people that they work with are inter-linked by collective responsibility and the desire to make a difference. In this work, the incentive for change and opportunities for co-design do not revolve around resolving the condition of dementia. Rather, this work is interested in the power of the individual, the value of their lived experience, and their continuing inclusion in society. Ultimately the purpose of this project is to do stuff with people, to try things out, and to accept occasional failings as long as action has been undertaken and the results evaluated and used to improve the next approach.

Designed with Dementia

The 'Designed with Dementia' intervention, 75BC, is an ongoing collaborative project that celebrates the life and work of the Glaswegian comedian Billy Connolly. The co-design project between the authors and a dementia support group based in Bridgeton in the East End of Glasgow involved a series of recent visits to the 75BC murals in Glasgow and to the American artist Tschabalala Self's exhibition at the Tramway Gallery, Glasgow. During this project, five people living with dementia produced a range of visual representations of Connolly using collage to create a series of textile designs in the style of Tschabalala Self (Figure 1). The artworks make use of fabric patterns originally produced in the Bridgeton area of Glasgow alongside patterns from Glasgow's wider creative community. Two forms of Billy Connolly have been used here; Big Banana Boots from early in his career and a more recent picture at Dressed to Kilt in 2011. All of the group members composed their designs and colour schemes in accordance with these two original images. Some followed a clear plan whereas others adopted a much more freeform expression in their representations. The intention of the 75BC co-design project is to use the images created by the five people living with dementia to highlight their inherent creativity and to support the 75BC celebrations.



Figure 1: Tschabalala Self artworks (top) Billy Connolly at the People’s Palace (bottom) all of which were photographed by the co-design collaborators (people living with dementia)

Stage 1 introduced the group to undertaking primary research; during a visit to Tschabalala Self’s exhibition at the Tramway Gallery, Glasgow the participants were given a digital camera and asked to photograph the artworks, focusing on their composition and their structure. Each participant was asked to photograph what appealed to them. The photographic investigation was rooted in a conversation the authors had with one of the participants in a previous meeting. The participant talked of his pride in his niece being a photographer and how he never had the chance to take photographs. Armed with a digital camera each, the participants set about eagerly photographing the exhibition from different perspectives, selecting what to photograph and how. One participant was particularly adamant that only two of the artworks appealed to her and those were photographed because of the vibrant background colours. Having previously visited one of the three Billy Connolly 75BC murals in Glasgow, discussions between the authors and the participants had already taken place regarding the three murals and what the group felt about them; they were not convinced the murals represented Billy Connolly as they thought of him. This discussion led to a follow-up visit to the Peoples’ Palace in Glasgow in order to see the original Billy Connolly artworks and to see others that were not chosen (Figure 1).

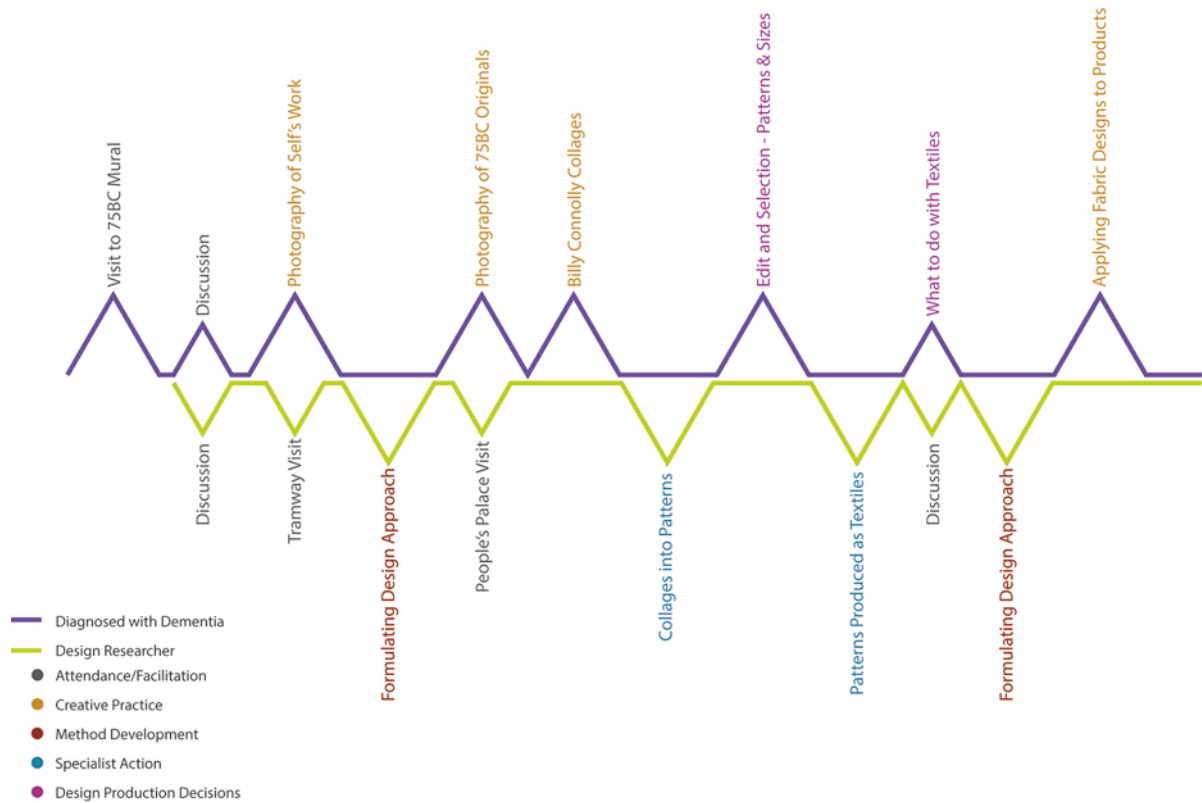


Figure 2: Diagram of the 75BC textile co-design journey

Stage 2 incorporated discussions, reviews of visits and photographs taken which informed the authors in the development of a kit for the next workshop. The process of Tschabalala Self became the inspiration for creating new visual representations of Billy Connolly. Self's layered scraps of materials stuck and stitched onto canvas create highly expressive figurative artworks. The participant photography of which, document the elements of layering, pattern and colour the group deemed important. To borrow from this approach a range of highly decorative textile patterns were selected to form the basis of a kit for making the new Billy Connolly artworks. More iconic Billy Connolly poses were then used to create collage kits where heads, legs, bodies, hands, feet and clothing were cut into small portions of pattern. Sixteen pattern variations for each part were offered to the group from which they selected the elements they wanted to use. These parts were then stuck down to make a collage of Billy Connolly. The process was open to individual participant interpretation. During the making of the individual collages, it was observed that each participant's image selection and decision making was particularly important to them. For example, one participant stressed that he wanted the right hand and right boot to match but that *'the hands and the feet shouldn't match'*. This was a clear personal choice of the participant and an articulately expressed creative decision relating to the organization and arrangement of the constituent parts. Another participant was adamant that she was not interested in making the image in the form of a human figure. Instead, she stated *'I'm waiting until everybody has got their parts and then I'm going to*

use the parts I want'. After this, she then proceeded to select multiples of figure parts to create her more abstract patterns.

The outcomes from the Stage 3 consisted of multiple sheets displaying human figures collaged into patterned silhouettes along with two highly abstracted forms. Throughout the process unexpected arrangements occurred driven by individual decision making.

In this project, the co-design decisions and actions displayed the often-leading roles played by the people living with dementia illustrated in Figure 3. Here, decisions, discussions and actions have informed the direction of project. Adapting regularly to these choices, behaviours and actions the authors regularly re-evaluated the potentials of the outcomes. The applications of the visual outcomes as designs, were driven by the design conversations that occurred. On viewing the 'Big Banana Boots' images alongside the abstracted arrangements (one of many unexpected outcomes) it became apparent that the new images had the potential to become patterns in their own right. Given that textiles initially informed the project, it was by happenstance that the idea of creating a repeat textile pattern for a new local fabric was developed (Figure 3).



Figure 3: Designing the Billy Connolly figures (top) New Bridgeton textile fabric design proposals and selection (bottom)

Thus far, in this collaborative project the process of co-designing developed through the actions and reactions of the workshop participants. That is, every participant’s creative input has been valued and taken into consideration throughout and achieved through mixed methods including, discussion, creation of new visuals, photography and collaboration. In the next stage, the authors responded to the designed outputs that the group had created. New arrangements were made through repeating their original Billy Connolly designs. Here, spacing between original elements

and the figures was maintained in their original state. The only aspects reconfigured were the surrounding blank space and the alignment or rotation utilised to make repeating patterns.

In stage 4 the group of participants reviewed the eight patterns that had been created with a view to choosing three patterns to get produced as a printed textile. The group selected four. Here they also agreed on the production scales for each pattern (Figure 4). These were then produced as prototypes in heavyweight cotton using a digital textile printer. In the following workshop, the group were shown the prototypes and given templates of ubiquitous household furnishings (derived from previous discussions) through which they could explore the idea of making their own home furnishing collection imbued with their fabrics.

Within the creation of the Bridgeton 75BC textile designs, individual and collective working, design facilitation and experimental practices have resulted in a series of textiles and products that are the result of a highly collaborative process. At times, it may appear that certain elements of the project directed and perhaps restricted the participants in a particular direction. However, it is fairly common in professional design practice that restrictions can help inform a designer's output. Even the designer-maker, producing items for their own collections will necessarily restrict their creative practice. In this co-design project, experimentation, conversation and serendipity played out and the ebb and flow of ideas and creativity has resulted in a truly collaborative collection of new textile designs.

This ongoing work is intended to explore how far these designed outcomes can go in the sense of production and potential sales. Ultimately, it is viewed that through exhibition and commercialization the impact of the group's work will challenge societal assumptions and preconceptions about the capabilities of people living with dementia. This project looks to take their designs into phases of wide broadcast and personal consumption in the same ways that any designer would intend to do. Though an ongoing project, the work has already formed the focus of a participatory exhibition where more than 200 participants from a cross-section of society experimented with the tools and techniques that have been utilized by the Bridgeton group.



Figure 4: The four textile fabrics (top) and the textile designs being applied to products (bottom)

Conclusions

Reflecting on this co-design work, it is abundantly clear that people living with dementia can offer much to society after diagnosis. Working closely with stakeholders including carers, family members, and collaborating organizations such as Alzheimer Scotland, the authors have received very positive feedback on this co-design work. Participants have stated that the co-design experiences had been very positive; they have been interested, engaged, and enjoyed the co-design project; there had been concentration, focus and discussion during the co-designing activities. Impact has also been seen in a number of 'spin-off' projects, discussions, themed activities and outings. The project presented here shows how co-design methods and tools can enable people living with dementia to make a significant contribution to society after diagnosis. Specifically, this work has shown how design thought and action can contribute to changing the perception of dementia and shown that whilst the mood and behaviour of the person may be profoundly affected, their personhood is not. Moreover, this co-design project has helped reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and keep the person with dementia connected to and thinking about their local community. The widespread assumption that people living with dementia cannot take part in mainstream activities, and that they have no quality of life or capacity for pleasure and positive involvement has been dismantled by this project. While the symptoms associated with dementia affect the way a person living with dementia interacts with others, and some activities may be inappropriate as a result, there are still many activities such as designing in which they can participate. Moreover, people living with dementia should be encouraged to make decisions or partake in decisions that affect them for as long as possible to maintain their dignity and self-esteem. This has been at the heart of this project.



By the year 2030, over 80% more people aged 65 and over will have some form of dementia (a moderate or severe cognitive impairment) compared to 2010. Design, in general, and design research, in particular, needs to embrace these challenges head on.

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