

Towards Design and Making Hubs for People Living with Dementia

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Abstract: This paper reports on the authors' Arts and Humanities Research Council (AHRC) funded work that is developing and implementing innovative design interventions that encourage people living with dementia to remain creatively active, promote dignity, and encourage independence. This work examines how the integrative, inclusive, and collaborative actions of co-design and design disruption as theoretical approaches, involves people living with dementia in rethinking and reshaping or circumventing existing forms of dementia care. Moreover, this work seeks to change mind-sets and extant prejudiced ideas about what people living with dementia might be capable of undertaking. The inclusive activity of collaboratively designing with people who are not designers themselves, seeks to challenge and alter preconceived ideas about the capabilities of people living with dementia. The paper highlights a number of innovative interventions showing how people living with dementia can be empowered by design and how they can be supported in informing conditions where their personal identity, values, knowledge, skills, experiences, perspectives and thoughts are integral to the production of new ideas and ways of thinking and doing co-design.

1 Introduction

The UK has an ageing population where there are now more people aged over 65 than those under the age of 16. The impact of this creates increased pressures on the National Health Service (NHS), and on local and regional health and social care services. Key concerns in regards to this aging population include the prevalence of the five most common chronic conditions among the over 65s – arthritis, heart disease, stroke, diabetes and dementia – with the latter expected to increase 25% by 2020 and more than 50% by 2050. In order to counteract the increasing pressures of aging health and mental healthcare issues current

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government policy aims to encourage people to remain active, engage in regular exercise and refrain from behaviours that could have a detrimental effect on their health. This research focuses on developing and implementing innovative design interventions, that seek to encourage people to remain active, promote dignity, and encourage independence particularly for people living with dementia.

2 The Wicked Problem of Dementia

Supporting people as they age, in particular people living with dementia, involves the design and production of various tools, devices, systems and services that are multifaceted, holistic and interdisciplinary in nature. These activities comprise diverse parties and stakeholders, overlapping disciplines and specialists. The degenerative nature of dementia requires that these solutions and interventions must be adaptable to progressive changes. In regards to dementia what makes the situation all the more difficult is that no two individual's journeys are the same and therefore there can be no singular prescribed approach. Instead, the nature of support requires insights where parties from various backgrounds converse and, most importantly, act to help to alleviate tensions, strains or blocks and create a valued quality of life (Phillips, 2006). Family members, clinicians, support workers, and the person living with dementia need to work together to develop tailored responses to each person's situation that can ensure personhood (Kitwood, 1997). As Cross (2011) articulates, design is a human activity derived to respond to human behaviours and requirements and for making novel and informed solutions. As such, designers are well placed for working in challenging areas such as supporting people living with dementia. It is here that the designer's ingenuity for making things such as service, product and spatial designs, and intervening to improve the status quo is increasingly being incorporated into health and social care contexts (Muratovski, 2016).

The work in this paper looks at how the inclusive and collaborative approaches of co-design (Scrivener, 2005) and design disruption (Rodgers and Tennant, 2014) involve and empower people living with dementia to rethink and reshape or circumvent conventional approaches to their personal dementia care. Moreover, this work seeks to change mind-sets and existing prejudiced ideas about what people living with dementia might be capable of doing. The activity of collaboratively designing with people who are not designers themselves seeks to challenge and alter preconceived ideas about the capabilities of people living with dementia. In this work, co-design is used as a facilitating proposition that supports people to act and respond independently and collectively. Here, people living with dementia inform activities of designing through personal engagement, knowledge, insight and emotional sensibilities that may have been disregarded as a result of their diagnosis. They are then invited to act upon these insights and responses through further design actions. This work shows how people are empowered by design, how they find ways to inform a situation or be supported in informing conditions where their personal identity, values, knowledge, skills, experiences, perspectives and thoughts are integral to the production of new designed ways of

thinking and doing. The thinking being particularly important in forming propositions, responding to opportunities and decision making that leads to new realities through self-efficacy (Cervone, 2000).

3 Towards Design and Making Hubs for People Living with Dementia

Designed with Dementia encompasses a suite of design projects that have been undertaken with people who are living with dementia in collaboration with Alzheimer Scotland. The projects cover a number of inclusive creative processes and explorations into how we can use design thinking and making to unlock and reveal personal and collective capabilities, utilising and stimulating interests and arranging new ways of doing things. Essential to this approach is the idea that design is a social activity and as such forms a space for shared enjoyment and fun in safe experimental conditions (Rodgers and Tennant, 2014). Here, each person's input is valued and any failure is not seen as problematic or undermining but as a positive part of the process or something to be learned from and responded to. The authors have undertaken a variety of projects to develop, reveal and present designed solutions with and by people living with dementia. These projects have helped "shake things up" through their actions that highlight their capabilities, individually and collectively and that direct projects with people who do not have a diagnosis of dementia. The resultant thought-provoking outcomes challenge assumptions, which have also developed people living with dementia's self-esteem and confidence through personal experiences.

Throughout these projects, design kits, tools and devices have been developed to further ongoing conversations and to build the importance of those individuals taking part. Within this work the most important actions have come from open and fun conversations that lead to creative and productive actions. The importance of this work lies in how people living with dementia have been able to form ideas, develop solutions and propose new designs for public appreciation, consumption or use. The Designed with Dementia projects highlighted in this chapter include 75BC and a Glasgow Stained-Glass Window. Both of which have used collaborative design processes to create new artefacts, where individual and collective actions have demonstrated participants' self-efficacy. The projects range from intimate small group-focussed practices through to larger projects that have engaged in excess of 200 people who are living with dementia across the UK. The public impact of these designs has resulted in excess of 1000 people visiting and buying the designed artefacts in new pop up Designed with Dementia shops.

4 Designed with Dementia: 75BC

The Designed with Dementia intervention, 75BC, is a collaborative design project that explores representations of the Glaswegian comedian Billy Connolly (Winton and Rodgers, 2019). Inspired by visits to the 75BC Exhibition at the People's Palace, Glasgow and to the American artist Tschabalala Self's exhibition at the Tramway Gallery, Glasgow the group developed an idea of what Connolly meant to them and how those thoughts might be represented, which resulted in the design of new fabrics and products. What occurred in delivery of their ideas was a co-design approach that became recognisable as a typical design process. At the core of this process were discussions, decisions and creative actions undertaken with all of the participants in an open forum that included a series of stages:

- **Stage 1** Primary research where the participants used digital cameras to photograph artworks focussing on composition, structure and other attributes.
- **Stage 2** Use of a kit that repurposed Tschabalala Self's processes, participants created new representations of Connolly based on their data collection and views.
- **Stage 3** Create new pattern representations of Billy Connolly from the unexpected arrangements in Stage 2.
- **Stage 4** New 75BC patterns were printed in various scales on paper where four were selected and produced as prototypes in heavyweight cotton.
- **Stage 5** The group chose to create a range of interior products (*e.g.*, lights, cushions, rug, bed linen, a sofa and lounge chair in the new textiles (Figure 1).



Fig. 1 The processes and results of designing and applying the 75BC fabrics

The 75BC designs, along with other participatory resources the group had co-designed featured in a public engagement event in Lancaster in March 2018. Here, over 200 people explored the group's designs and engaged in creative textile design activities. The impact included changing perspectives of those who visited, generating new understanding of the capabilities of people living with dementia.

5 Designed with Dementia: Glasgow Stained-Glass Window

This Designed with Dementia project included excursions to the Scotland Street Museum, Glasgow designed by Charles Rennie Mackintosh and to St Mungo's Museum of Religious Life and Art, Glasgow. During both visits, the importance to Glasgow of Mackintosh and his influence on contemporary stained-glass design formed a significant part of the group's discussions. This encouraged them to explore further the design of stained-glass artefacts through a collaborative workshops that included:

- **Stage 1** Photographs were taken of Mackintosh's designs and the group took part in a stained-glass workshop using different techniques such as using pre-cut tiles of colour and stained-glass colouring pens.
- **Stage 2** Production of a prototype Mackintosh-style pendant light using lighting gels and stained-glass panels, and pens to explore pattern designs.
- **Stage 3** The theme of this session was the Glasgow coat of arms. The participants collaged elements of transparent line drawings and texts in order to generate their own layouts.
- **Stage 4** Development of the ideas that emerged in earlier workshops using black printed transparencies that the group could arrange to form a collective image, which became the basis of their new stained-glass design.
- **Stage 5** The final image was scanned and produced as a transparent design for the participants to colour using acrylic paint (Figure 2).
- **Stage 6** Reflection has led the group to define new possibilities for their stained-glass design, which has resulted in preliminary designs for a new light.



Fig. 2 Prototyping the stained glass window for Glasgow

Framed within a backlit panel the work is now presented as existing somewhere between an artwork of the city and a prototype design of a stained glass window. Using similar design processes, people living with dementia have designed and generated ceramic products including a set of hand decorated plates based on Sophie Cave's 'Floating Heads' at the Kelvingrove Museum, Glasgow and a set of travel postcards based upon the Riverside Museum, Glasgow.

6 Designed with Dementia: Pop Up Shops

As this work moves towards the creation of inclusive design and making hubs for people living with dementia, the authors have pilot-tested the idea in a number of Designed with Dementia pop up shops in Glasgow, Lancaster and Edinburgh. Each pop up shop is unique showcasing an array of designs created by people living with dementia. Each Designed with Dementia pop-up shop runs for several days, located in an existing (unused) retail space in the city centre, showcasing and selling a wide variety of uniquely designed items created through workshops such as those described in the previous sections of this paper. The Designed with Dementia pop up shops clearly illustrate how design plays a key role in empowering people living with dementia by helping to improve their decision making, greater social interaction, and personal achievements whilst supporting those individuals to work as part of a larger creative collective.



Fig. 3 Designed with Dementia pop up shops

The pop up shops have showcased and sold products such as table-ware, tote bags, mugs, coasters, aprons, ties and pencil cases (Figure 3). All of these designed products have been designed by people living with dementia. This has involved creating artwork, making design decisions on scale, repeat patterns, material choices, and creative direction. These activities involve knowledge and skills that professional graphic and textile designers draw on in their day-to-day work. The Designed with Dementia pop up shops provide an inclusive and innovative platform to witness first-hand what people living with dementia are capable of through the design work created, manufactured, exhibited, and disseminated. We show how people living with dementia can offer much to society and we hope to change public thinking about what is possible after a diagnosis of dementia. In some of the pop up shops, it has been possible for the public to make artefacts using toolkits that have been developed by people living with dementia.

7 Analysis

A range of positive comments have been made by the co-designers (people living with dementia), their carers, and their family members throughout every stage of the design projects described in this paper. These comments have driven key

activities in the projects that have been undertaken. A selection of some of the co-designers' comments made during these projects is shown in Figure 4.



Fig. 4 A selection of co-designers' comments made during the projects

These comments clearly articulate positive feelings on the design activities conducted and they suggest value in the design exploration work. Equally important here is the voice that each participant (co-designer) has had in making decisions that have informed the design outcomes and key influences within each project. The suite of Designed with Dementia projects described here were conceived to support and nurture the opinions and decision making of the co-designers (people living with dementia). A significant consideration within all of the projects has been that the design sessions must be enjoyable and must offer a safe space for diverse ideas to formulate where differing opinions can occur. The responses and feedback collected from the co-designers during the series of co-design projects described in this paper are rich and informative. In a reflection session after the pop up shop in Glasgow, one group stated: *"I thought that was absolutely brilliant"* (Participant 1) *"It was, it really was... I thoroughly enjoyed making whatever, but I still didn't think it was good enough to sell kinda thing."* (Participant 2) *"And it was"* (Participant 1) *"It definitely was"* (Participant 3) *"It certainly made you feel quite good."* (Participant 2) *"It's good for your morale and good for your confidence."* (Participant 3) *"Thats the thing about it, is what you value you canna buy."* (Participant 1). During the co-design sessions, the co-designers were happy and felt confident to assert their opinions openly: *"Nah it's no' for me..."*, *"It gave me the creeps..."*, *"No. I know how it's been done, and it's been done well, but I don't like it"*, *"but that's the one I want"* were just some of the phrases collected as the co-designers (people living with dementia) discussed various project tasks and actions. The rich discussion of what the shop meant to

those involved along with the clear decision making and creative understanding collected in the workshops shows value in nurturing personal assertion of people living with dementia through design activities. In the co-design process and review of a wide variety of outcomes verbal, written and artefact feedback has been collected that talks of empowerment and challenges recognised aspersions which are best described by one group in the statement *“A lot of people come in think we just sit here we don’t do anything. People with dementia can do great things.”*

Furthermore, during the workshops, pop-up shops, public engagement events, and exhibitions of the co-designed work the value of what has been designed and exhibited has been ascertained through a number of means including feedback commentary cards and “share your thoughts” prompts. This has allowed the authors to collect diverse sets of opinions, perceptions, and comments from the general public about what might be important in terms of how we view people living with dementia and their place in wider society (Figure 5).

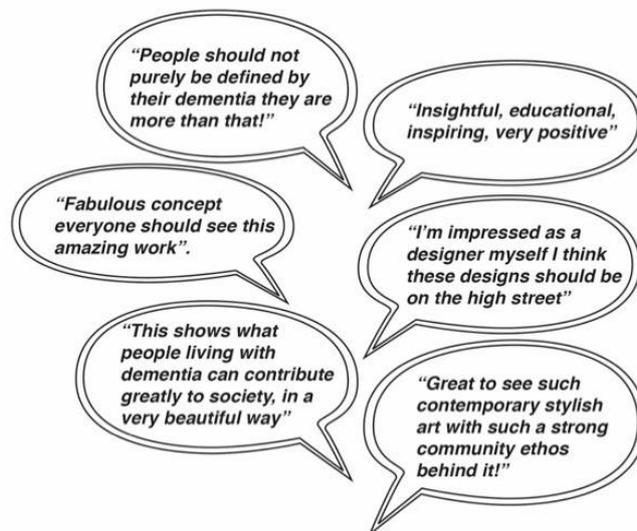


Fig. 5 Comments made by members of the public during the design projects

A large number of the feedback commentaries talked of personal experiences of dementia and the unexpected nature of what had been seen, interacted with and even bought within the pop ups. Included in these views was the recognition that at the centre of the activity was individual and collective capabilities: *“A very inspiring project, It puts the person first rather than their dementia”*. The feedback, in the main, focusses upon what is seen as uplifting responses to the stories and products: *“It’s really great that this is the outcome and that it is all really different”*.

The impact of what these interventions have done is difficult to measure and comprehend but significantly the fact that the public have bought products,

embedded with stories, that will exist within their homes and will form points of discussion. Where the income generated by these products will further support the designers who created them in future care and activities. During this work it is evident that our “open-doors” policy in these design and making hubs for people living with dementia reduce the closed off experience of normal dementia support centres. The welcoming environments aim to engage all aspects of society but happen to put people living with dementia at the forefront of the environment through presence or imbedded practices and objects. In doing so the approach of creating discussion, sales and action spaces might support the high street to fill voids with community focussed charitable offerings. By filling empty spaces within shopping centres – the centres benefit from rates alleviation and the centres can create more community focussed and dementia aware environments.

8 Why are these Interventions Important?

All of the co-design projects presented in this paper have afforded a large number of people living with dementia opportunities to use design as a social activity. Their involvement in the co-designing processes described here have delivered new ways of looking at what is possible, new creative interactions, the creation of innovative tools and products for many people (not just people living with dementia) to enjoy. To evaluate the impact of these co-design projects much consideration has been given to the conversations, comments and feedback that have accompanied each co-design session. Equally important has been the observed responses by the people living with dementia to what has been going on in the co-design activities. More often than not these observations have revealed a clear willingness on the part of the people living with dementia to be involved, to take control of their own design output, and to lay claim to authorship/ ownership of the creative outcomes produced. Through their demonstration of creating their designs, the people living with dementia regularly displayed independence in thinking and acting, and the importance of personal preferences. The actions, comments and feedback received in the co-design projects presented here show a strong desire of people living with dementia to be involved as well as engaging with and driving the design decisions that are needed to be taken. In all of these co-design projects, the people living with dementia have shown a strong sense of eagerness and enjoyment but also pride and esteem in their co-design work.

9 Conclusions

In the co-design projects presented in this paper, the iterative and inclusive nature of the design work leads to extended and interlinking thought processes, which in turn, results in design solutions that display the power of people living with dementia and the meaningful ways in which they can interact with and inform the world. This view presents a situation where design acts as an instigator and mediator in small and large social transactions. But more than that, the work

presented in this paper has allowed the authors to access the insights, ideas and comments of people living with dementia that has resulted in designed outcomes that are directed by the people living with dementia and made accessible for the enjoyment and appreciation of other people. We believe that many of the artefacts designed in these co-design sessions have the capacity to generate financial income for their designers and as such provide alternative ways in which people living with dementia might support themselves and their families. Moreover, we believe the co-designed work presented here has the potential to change the opinions and perceptions of many in society who believe that a diagnosis of dementia represents the end of a person's creative and other abilities.

Furthermore, the personalised yet collective participation in these co-design activities supports the person living with dementia to have a better quality of life. Where the activities and contributions they make and undertake reinforces the right to active participation and citizenship, the inclusive nature of the co-design activities and resultant designed outcomes provide meaningful and relevant engagement for each individual. The co-design sessions aim to maintain the fabric of their life for as long as possible. Giving additional time to a person with dementia saves time and other valuable resources in the long run. Supporting a person to do things for themselves, rather than carrying out the task for them, maintains function and skills in their other activities of daily living. Throughout the co-design sessions described in this paper, every individual was involved in decision making, offering advice and feedback, and tasks that stimulated their motor skills. The co-design sessions have helped support the UK Government's agenda of keeping people both mentally and physically active. This approach to support continues to empower the person living with dementia to retain personal agendas within their lived experiences reaffirming capabilities and stopping people from being deemed incapable before their time. What design affords people living with dementia, in this context, is group-led and collaborative social interaction, and ultimately the production of designed outcomes that can be purchased and used by audiences beyond the natural reach of the participants. This paper clearly shows that the co-design sessions described here build self-esteem and empower people living with dementia whilst changing preconceived ideas surrounding dementia care and creating a wide range of designed outcomes that are desirable for many.

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