

Journeying through Dementia: the story of a 14 year design-led research enquiry

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123. Journeying Through Dementia

The story of a 14 year design-led research enquiry

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ABSTRACT

Journeying through dementia is a design-led research enquiry that interrogates the role of design and creative practice in post-diagnostic dementia support. The broader enquiry spans a period of 14 years, from the utilization of participatory design research methods to co-create the intervention with people living with dementia through to work with policy makers to develop tools for operationalization.

This paper begins by providing an overview of the broader context of the research before focusing on the most recent element of the enquiry that sought to understand the role of design in enabling clinical staff to facilitate the intervention. In this phase of the research, a thinking-through-things methodology named exhibition in a box was employed to understand the requirements of clinicians in delivering Journeying through Dementia. These findings were translated through an iterative co-design process into a series of curated creative tools for clinicians, which were then tested in mainstream health services across two health boards in Scotland.

This is the first design-led research enquiry to interrogate the role of design in clinical post-diagnostic dementia support. Reflections are offered on design as translation in research and the paper shares critical insights in relation to the complexity of co-design in this context.

Keywords: Dementia, design-led research, participatory design, thinking-through-things, co-design

Introduction

Dementia is a term used to describe a group of syndromes including Alzheimer's disease, which are characterized by deterioration in cognitive functioning. Dementia affects memory, mood, comprehension and communication and has been identified by the World Health Organisation (WHO, 2017) as one of the major causes of disability worldwide, impacting on both the person and their caregivers and families

At present it is estimated that 47.5 million people have dementia (Alzheimer's Disease International 2015). In the absence of a cure, emphasis has been placed on the development of approaches and interventions that focus on quality of life. Post-diagnostic support, where individuals are supported to develop strategies to live well with the condition, has formed the basis of global health policy (Department of Health 2016).

Whilst there is a growing interest in the role that design-led interventions can play in promoting quality of life of people with dementia (e.g. Treadaway, 2018), to date little attention has been paid to the role of design in post-diagnostic support in the context of health-care services.

Background

The enquiry described in this paper has its origins in 2006. At that time, the peer led self-care support programme for people with long term conditions named the Expert Patient Programme was garnering support and a plethora of interventions were being designed for people living with chronic health needs. However, in spite of this growing interest, self-management approaches to enable people to live well with dementia were noticeably absent (Mountain 2005).

Our research therefore sought to build understanding of the experiences of people living with dementia and the interventions that they considered to be important and helpful soon after diagnosis. The overarching question our study posed was whether it was possible to support people at an early point of their dementia journey to develop design-thinking skills that could be applied as their dementia progressed. If these skills could be developed and retained whilst people were cognitively able to do this then there was a possibility that they might be enabled to effectively re-design their lifestyle and the broader environments in which they lived to accommodate and respond to the challenges that dementia might bring.

Ethical approval was obtained to undertake the research and over the period of six months people with dementia shared their experiences of living with condition.

An iterative participatory co-design research process with people recently diagnosed with dementia generated a series of topics that individuals identified as being important to support wellbeing. These topics formed the basis of the clinical intervention named by participants as *Journeying through Dementia* (Craig and Mountain, 2012).

The final programme, *Journeying through Dementia* comprised of a 12-week group programme facilitated by a qualified occupational therapist, in which individuals recently diagnosed with dementia would meet for two hours a week and select topics from a range of themes they would like to explore. The intervention sought to enable individuals to develop the necessary design

thinking skills and coping mechanisms required to enable continued engagement in meaningful activities. A menu of themes developed from the research was provided so that each group could effectively design their own programme. Consequently, rather than individuals fitting into a group, the group would meet the individuals' need. Topics were broad and wide-ranging and included: redesigning the environment, building community connectivity, designing communication strategies as well as themes exploring the relationship between creative activities and wellbeing.

Two small empirical research studies to test the efficacy of the intervention were undertaken by the first author (Craig 2014) and by Sprange et al. 2016. The qualitative evidence over these studies indicated that participants experienced a number of benefits. These included increased self-efficacy post diagnosis. Analysis of interviews post-group showed that individuals experienced increased self-confidence:

'What you've done for us has got me to the top... it's put me back where I used to be... what we've been doing in here and saying and thinking has done me so good. if you'd seen me not too far back... off my food... coming here is the thing that got me back to the top.' –
Journeying Through Dementia participant.

Individuals with dementia reported value in sharing of experiences within a group context, vital to wellbeing and valued the opportunity to learn new skills and techniques to mitigate against some of the effects of dementia;

'Clubs help you to meet other old people but they are also nothing like this. Here we meet other people who also have dementia. Rather than just talking, I've been able to learn new things. It's like gold.'

'You know you're telling me things that could alter my life.'

However, it was also recognized that there needed to be greater access to groups of this nature. Sprange et al (2016) concluded that adults with early stage dementia could successfully engage in this person-centred self-management group intervention. The programme met the heterogeneity of needs of people with dementia by being tailored to individual requirements as well as those of the overall group. A successful application was made to the UK National Institute of Health Research to undertake a Randomized controlled trial (RCT) to test the intervention led by Mountain. It also formed part of the Connecting People, Connecting Support dementia strategy document for Allied Health Professionals across Scotland and it is to this latter initiative and research undertaken in relation to its implementation here that this paper now turns.

Reflections on the research

If the design double diamond is seen as the overall research framework it could be argued that through a co-design process, issues had been explored, problems defined, and an intervention had been developed and tested to good effect.

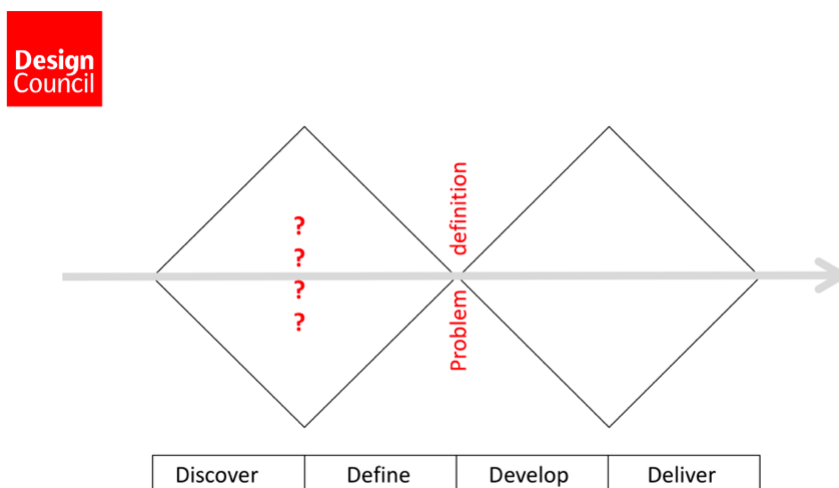


Figure 1: Design Council Double Diamond (Design Council 2015)

However, as the first author began to up-skill researchers and clinicians in the delivery of the intervention for the national RCT, it became apparent that facilitators required more than a manual, setting out weekly intervention plans and paper hand-outs to aid delivery. Facilitators highlighted the challenges of engaging people with dementia in a group setting, questioning how to support differing communication needs of group members and ways to engage with and reach individuals with different levels of cognition. Concerns were also expressed in relation to the amount of time it would take to develop materials to support sessions. The issue was how to turn the themes that had emerged from the research from a 'flat and largely abstract intervention supported by a few hand-outs' into something interactive that had an element and delivered in practice.



Figure 2: Up-skilling Researchers and Clinicians

Current research

Funding was received from National Education Scotland in 2017 and two sites were identified in Scotland by the Allied Health Professions policy lead for dementia. The aim of this element of the enquiry was to build understanding of the requirements of occupational therapists facilitating the Journeying through Dementia intervention in practice. The design-led research sat within a broader improvement science test-and-learn methodology. Twenty occupational therapists from older people's mental health services across Fife and Aberdeenshire participated in four iterative co-design research workshops.

A major breakthrough in the development of this research came when the methodology of *exhibition in a box*, by Chamberlain and Craig (2013) was applied in this study. Inspired by Duchamp's 'Boîte en valise', it is a form of object elicitation and in this research was used to curate a series of creative activities (quotes, images, objects), to scaffold thinking and prompt conversation. *Exhibition in a box* provides a tool and structure for design and health practitioners to creatively engage with older people.



Figure 3: Aberdeen June 2018

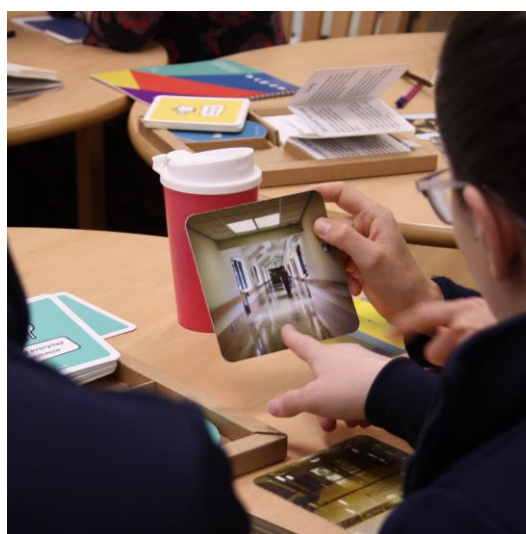


Figure 4: Aberdeen September 2018



Figure 5: Fife November 2018



Figure 6: Wales October 2019

A range of quotes by people with dementia from earlier phases of the research, as illustrated below, acted as powerful provocations about messages the materials needed to reflect.

You need to focus on the ability and the contribution that we can make rather than what we can no longer do.

I felt disempowered because people that spoke to me about dementia always spoke about my loss. Nobody ever said 'there are things you've lost but there are also things you could gain'. They never really took me from the loss of power into action.

Photographs of activities people had found meaningful offered an opportunity to discuss broader needs and perspectives and how the facilitators might support their needs. A range of objects prompted discussion relating to value and values. Consent was given to record conversations and notes were taken throughout the co-design workshops with participants encouraged to include written comments in response to the artefacts that were shared. After each workshop this data was collated and analysed using a simple thematic analysis (Braun and Clarke 2006) and the next iteration of objects and materials were crafted to embody and respond to this feedback.

The final iteration culminated in a research-informed set of materials, which formed the basis of the intervention used by therapists in the delivery of Journeying through Dementia in Scotland across two demonstrator sites. An evaluation of the impact of the intervention was undertaken by the therapists using measures in quality of life (QoL-AD) and the therapists were interviewed by the policy lead in relation to their experiences of facilitating the programme with the materials.



Figure 7: Demonstrator Sit Pilot Kit 2019

Findings

Analysis of the data collected during the co-design workshops identified four main themes, which were then incorporated into the design of the materials:

Communication through research

Participants in the workshops identified the need for materials to act as prompts to promote engagement and scaffold communication. An iterative process culminated in sets of images and word cards to support individuals with dysphasia or anomia. Fact or Fiction paddles were created to enable participants with limited speech to respond to True or False statements shared by the therapists and in doing so to enable group members to untangle and to challenge some of the myths surrounding dementia. These elements were reflective of the range of sensory and learning styles of participants. Feedback by the therapists was positive:

‘The quotes open up a conversation...I feel like that too’ - (Participant, Fife)

‘The photographs help to get conversations started about difficult topics’ - (Fife)

‘The fact and fiction paddles allow you to talk about dementia in non-threatening way’
(Participant Aberdeen)



Figure 8: Demonstrator Site Pilot Kit Elements 2019

Communication about

The materials communicated important messages about how people with dementia attending the groups were valued. Therapists described how challenges in resourcing services meant that information for groups frequently comprised of photocopies of photocopied material. Not only was this a challenge for participants in groups who had sensory impairments such as poor eyesight but staff expressed concern that poor quality materials carried hidden messages about lack of professionalism and potentially undermined participants sense of worth. Early designs, which were based around a simple cardboard packaging structure, were rejected as it was felt that the material was 'too basic' (see Prototype 3 in Figure 9 below). The final selection of materials sought to redress this balance. Responses to the final design were overwhelmingly positive both in the context of participants:

'It's kind of ageless, the design is not stigmatising'; 'The design inspires hope and creates excitement' and also for the therapists; 'I feel that it will add to the quality of life of my patients as well as to my working life'; 'It's an excellent resource for patients and to celebrate the good work that OTs do offer.'

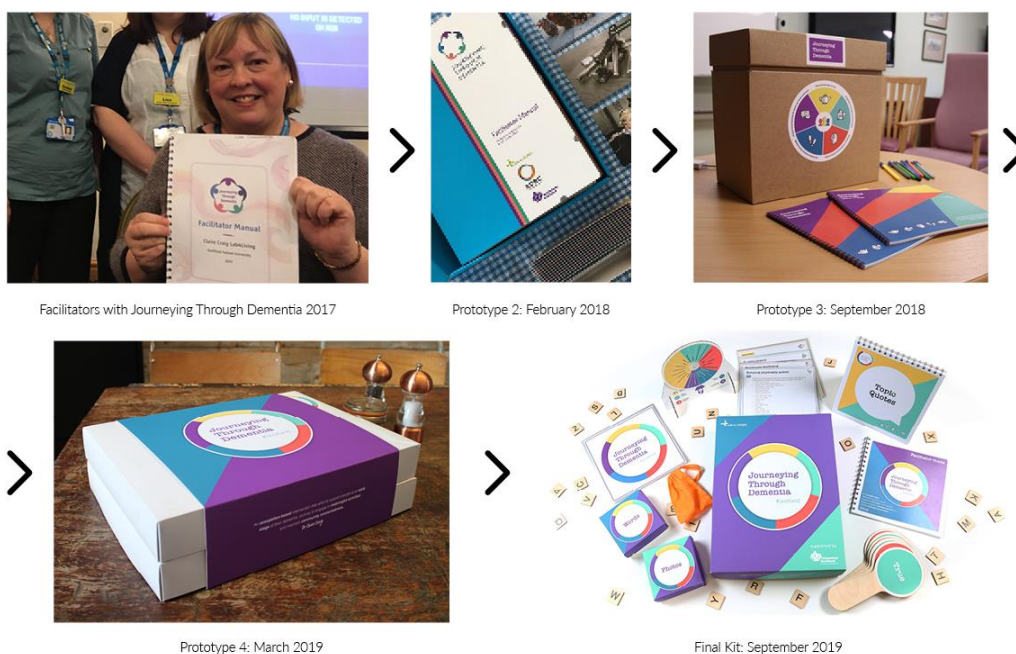


Figure 9: Journeying Through Dementia Kit development 2017-2019

The incorporation of the colours and symbols of the policy document Connecting People, Connecting Support (CPCS) as part of its visual identity was highlighted as a particular strength. Therapists felt that it embodied professionalism and communicated to managers the evidence based nature of the intervention:

'It is so great to have a resource we can use to move towards early intervention and demonstrate we are implementing the CPCS policy.' (Participant, Fife)



Figure 10: CPCS policy themes

The importance of detail

One of the key themes emerging from the research was the overwhelming importance of subtle details. Clinicians shared how the distinctive colour palette that ran throughout the resource (including the invitations) was key for participants especially as invitations to groups were often lost amongst other appointments because they all looked the same. Signage not only directed group members to the toilet/bathroom but also the way back to the room. Lamination of elements of the materials ensured that they met with stringent health and safety requirements in many settings and increased durability. As one therapist highlighted,

'This may sound ridiculous but it is these details that can make the difference between whether something sits on a shelf and remains unopened or whether it is used in practice.' (Participant, Aberdeen)



Laminate signage



Laminate signage in use



Portable kit

Figure 11: Details within the kit

Balance

The final theme emerging from the workshops was the importance of balance. This was achieved through the inclusion of fun elements (spinning wheel and true and false paddles) as well as the more serious components of the intervention addressing the symptoms of dementia. Feedback was positive;

'The resources are so well designed and engaging' (Participant Fife)

'There needs to be some fun. Talking about dementia can be very depressing.'
(Participant Fife)



Topic of Conversation Spinner



True or False Paddles

Figure 12: Interactive elements within the kit

The final theme

Finally, the materials needed to have sufficient structure to support the therapists to deliver the intervention but not so prescriptive and restrictive as to prevent the therapists from exercising their clinical reasoning skills and enabling customisation to the context. Feedback from therapists was that the materials achieved this. The overwhelming strength was the multiple ways that the clinicians felt they could use the materials, achieving a level of personalisation.

'I really like the layers of options' (Participant, Aberdeen)

'It's very adaptable and can be responsive to the situation' (Participant, Aberdeen)

'Person centred and easily adaptable to various settings' (Participant, Fife)

Testing in practice

Five therapists then tested the final iteration of materials across two demonstrator sites in Aberdeen and Fife. Evaluation of the intervention by the Allied Health Professions Lead for Scotland concluded that;

‘Journeying through Dementia has been a key component in the delivery of the dementia strategy for Allied Health Professionals in Scotland. Evaluation of its impact in the first 2 demonstrator sites in Scotland showed that 71% of participants who engaged in the programme reported improved quality of life (QoL-AD)’



Figure 13: Facilitators and contributors in Fife

The evaluation highlighted that Journeying through Dementia was a high-quality resource, which provided a structure to each session but also offered flexibility in being able to adapt that to the needs of the participants and incorporate 1:1 and out of venue sessions to support programme delivery. The topic wheel and booklets proved beneficial to support initial discussions around selecting appropriate sessions but as the facilitators and participants built relationships this process became easier.

Having a ‘menu-led’ approach was incredibly valuable in supporting a person centred approach, the dynamics of the intervention in which the participants were very much supported and encouraged to select sessions most applicable to them and be active participants in the groups further empowered people to take ownership of the group as the weeks progressed. The power of being able to share experiences, proved invaluable and was commented on frequently by the participants (Grey et al 2019).

Discussion and conclusion

This paper has explored the value of design in the development and implementation of a dementia post-diagnostic support interventions. From co-creation of the intervention with people with

dementia through to the development of materials to operationalize the Journeying through Dementia programme, it demonstrates the importance of involving stakeholders throughout the research process and in adopting a truly integrated approach. Involvement of Therapists in this phase of the study identified key requirements the materials needed to fulfil to enable operationalization of the intervention. The significance of this phase of research cannot be underestimated as the subtle design requirements identified highlight. One therapist summed this up when they said;

‘it’s the difference between being only being given a recipe -book and being given the recipe book with the utensils and ingredients required to create something.’

There is a danger that much research fails to be implemented because it ends when an intervention or product has been created without due attention being paid to the final phase, an understanding of the needs of the clinicians and facilitators who will ultimately deliver this. This can result in a lack of adoption as described by Frank et al. (1996). A similar picture can exist in healthcare. One of the challenges of implementation research is that large scale experimental studies often remove variables that make them relevant to the range of contexts to which they might be applied. As a consequence, ‘interventions which fit closely to the content of one setting e.g. are acceptable, operationally feasible, affordable and culturally congruent, may be a poor fit in another setting’ (Goodyear-Smith 2015).

This study has reinforced the value of the involvement of design researchers throughout the enquiry, particularly in the phase prior to implementation. The exhibition in a box methodology offered a mechanism through which key messages could be communicated. Further funding from the Scottish Self-Management Alliance has been awarded for roll out of the intervention across a further nine sites in Scotland and the research is being replicated in Wales. Our journey with Journeying through Dementia continues.

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