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Dialogical Props and Individuals with Dementia

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Abstract
This paper will report on the use of dialogical (Wright and McCarthy, 2008) artefacts in a design-centred research engagement with persons who have dementia. These dialogical tools facilitate discourse through the presentation of concepts relevant to the participant's life. For example, the 'Age Traveller' prop could prompt discussion around what his/her life might be like in the future. It is a compass made to point to decades of life such as 40s, 50s and so on.

The paper will push forward the notion of what dialogical objects, that is, artefacts that prompt dialogue, can be and the roles they can perform. The paper will discuss how they may facilitate getting to know someone and help gain insights around perceptions of dementia, thereby capturing complex dynamics from lived experience. They draw on design probes (Gaver et al, 1999), theatricality (Gerber, 2007), fiction (Blythe, 2014), dialogue and my design practice (Coombes, 2013).

I will discuss how we can use objects to form empathic dialogical links when conversation is difficult. What constitutes reality for persons with dementia can at times be at odds with how others experience life. To be mindful of this, I attempt to enter, through small, gentle acts of theatricality and fiction, into their world rather than expecting them to conform to ours. Each prop is instilled with a sense of theatricality that allows the participant and researcher to share a real or fictional experience, such as travelling through time with the 'Age Traveller'.

Within this paper I am opening up, not only what these artefacts are and how they serve, but also the realities of the engagements, both when they went smoothly and when they were very difficult experiences. I will discuss the relevance of humanist sensitivities to research involving people with dementia that develop through the work with dialogical props.

Keywords: dementia, dialogicality, props, design research approaches, empathy, personhood, perceptions

Introduction

This paper will report on and discuss the use of designed artefacts as dialogical pivots, anchors, doors and catalysts for a design-centred dialogical approach to researching alongside people who have dementia. I have designed and made what I call 'dialogical props' to facilitate dialogue that goes beyond the verbal to non-verbal ways of communicating and relating between individuals, artefacts and the researcher that acknowledge felt life. I will be referring to the participants by the names that they have chosen and myself in the first person to further the point of seeing each agent as individuals who bring their own agency and experience with them rather than being portrayed as generic symbols such as participant and researcher.

Perceptions of people with dementia have ranged from zombies (Behuniak, 2011) to disappearing people (Health, 2012). The language that is used such as 'demented' and the idea that they wander without meaning or purpose implies that people who have dementia are lesser. Traditional notions of self as cognitively based are now challenged by the concept of personhood (Kitwood, 1997), going from an intellectualised vision of people to one that takes into account the whole person, their experiences, emotions, skills, thoughts and relationships. If these negative perceptions change then there is potential for relating with others, seeing the human of value despite perceived differences.

This study involved an extended period of time with two persons with dementia (separately), Aiden and Dawn. Aiden has dementia with Lewy Bodies and lives with his partner/carer while Dawn has Vascular dementia and lives alone. Dawn is a very lively chatty woman though Aiden is very quiet in comparison, by all accounts very different people. I have also been befriending Aiden throughout this time, getting to know him better than Dawn.

Like a lot of research situations involving people, there can be things to adapt to and obstacles to overcome. However, what comes up while working with those who have dementia can be distinct. This paper will discuss how during this research I had to be able to adapt and respond to these circumstances.

Dialogicality

The underlying concept of Dialogicality, expressed by the literary philosopher Mikhail Bakhtin (Bakhtin and Emerson, 1993) is that there is always more than one consciousness involved in human action. While reading a book the reader, writer and characters have dialogues with each other (Wright *et al*, 2005).

Here Wright *et al* argue for dialogical knowledge and knowledge of self as coming from the relational circumstances people have with others or other things (Wright *et al*, 2005). What

dialogism means for this paper is that when one portrays an experience it is interlaced with the multiple voices, perspectives and experiential discourses of others.

Wright and McCarthy (Wright and McCarthy, 2005) argue for an emphasis on felt life and sense making while placing creative imagination and ways of seeing at the centre of a dialogical approach. They draw from Bakhtin's view of character driven novels and the multiple expressions of human experience that can be perceived through their characters, as centres of value, as a way of gaining understanding of the moment based cognitive and affective experience of the characters as well as real people (Wright and McCarthy, 2005). This alludes to the importance of moments (Allan, 2010, Brackey, 2007, Killick, 2013) and transitional or liminal spaces (Thomassen, 2009, Turner, 1987, Turner, 1979) the props can inhabit and contribute to the dialogic.

There is a dialogue (Wright and McCarthy, 2008) that needs to take place between oneself and another in one's own mind in order to perceive another's inner world while maintaining an awareness of oneself. Bakhtin's aesthetic seeing (Wright and McCarthy, 2008) includes the idea of both people in dialogue being able to actively listen (Bakhtin and Emerson, 1993). This dialogic approach is entangled with empathy.

Empathy

Part of what I have tried to create beyond a safe empathic environment is a dialogue that connects multiple parts of selves within a research meeting involving dialogical props.

Empathy can be described in many ways such as regaining a naivety of childhood, open to other ways of seeing, or the suspension and amalgamation of identities. The act of empathy can draw from personal experience but also from the imagination such as when a poet inhabits an other (Margulies, 1989).

If time is taken to create a safe space (Gerber, 2007, Johnstone, 1981), to really connect (Young, 2015), to get to know, perceive similarities and accept differences (Young, 2015) inspiration can come that is intertwined with more genuine and deep insight (Coombes, 2013). Both Young and I promote the idea that when you really listen to someone they perceive it and are more likely to feel safe. This, however, is not a constant state. There are ebbs and flows within interactions that temporally affect the depth and focus.

In my experience, empathy starts in the situation with a participant but the connections, relationships, interpretations and reflections that continue after the initial circumstance allow more to enrich potential insights. Relationships are developed and there is a concern for their wellbeing (personal communications with Jayne Wallace, 2014 and Claire Craig, 2013). The researcher can have an affect on the participants but it can work both ways (Wallace *et al*, 2013). Empathic research contains vulnerability, commitment and the "willingness to be confronted about those mistakes" ((Brown, 2007), p.38) made. This illustrates the complexity and messiness

involved in deep human-to-human interactions, especially involving dementia. Emotions and thoughts arise in the moment and can linger beyond.

Dialogical Props

Six props were designed and made, duplicated then shared with Dawn and Aiden one at a time. The props included Your Dice, Magic Tags, Yolks of Life, Assistive Marvels, Age Traveller, and Secret Life of a Wishbone. Secret Life of a Wishbone was created but not given to Aiden and Dawn due to time restraints. Each prop focuses on different questions around the lives of people with dementia such as past, present, future, and relationships. Each dialogical prop has at least one theatrical, fictional, metaphoric and surreal element to them and allow for various ways of interacting. These props relate directly to aspects of Critical, Fictional and Speculative design, including encouraging discourse and using imaginative narratives. They are imperfect, non-prescriptive objects as scaffolds for dialogue. Like reading a book they require imagination (Bleecker, 2009).

Props have the broadness of background relating to the theatre and fictional or potential realities. Design fiction objects (Bleecker, 2009), Dunne and Raby's vision of Speculative Design (Dunne and Raby, 2013), as well as a lack of value or different aesthetic.

While there were six dialogical props developed and made this paper will focus on two (Figure 1) to illustrate various aspects of the props and how they were employed. Though shallowly mentioned in the abstract the Age Traveller shows a different aesthetic and physical way of interacting with a dialogical prop. Magic Tags consists of three tags. The fabric one has *Something you wear.* written on it. The brass one is inscribed with *Something precious to you*. Whenever possible I have hand written instructions to help with the impression of the props being from a person to a person rather than being a generic production. The card one has *Something not precious to you.* written in pencil on it. Additionally, there is a large card tag with preliminary instructions.

> Please explore your home to discover:
> - Something you wear
> - Something precious to you
> - Something not precious to you
>
> Please bring your findings and their tags to the next meeting.
> The next step will then be revealed.
> Thank you.
> Matt

At the next meeting Aiden and Dawn were asked to imagine that he or she has the ability to enhance the things that were chosen, using the magic tags, to make them better for them. Neither Dawn nor Aiden had made their choices for the next meeting despite Aiden's partner and carer

being encouraged by me to ensure it happening. Loved ones both further complicate and add value to a research situation with dementia.

Dawn and Aiden did not seem to have any trouble making the choices on the spot. While Aiden chose a wastepaper bin as not precious, Dawn decided that death was not precious to her. In both cases the thing that was chosen to be precious to them was a person they loved. Aiden immediately chose his usual coat, which was in sight, while Dawn deliberated because she could think of so many things (she used to work with in the clothing industry) before choosing a 'chunky' winter coat. This already erects bridges to their realities. How they perceive certain relationships, an awareness of change and an acceptance of death.

Figure 1: Three dialogical props, Magic Tags, Yolks of Life and Age Traveller

Figure 2: Yolks of life in situ 1 & 2

Yolks of Life are three wooden eggs, halved, with a brass hinge and coloured rubber bands. Each one represents a relationship, private (inside) and public (exterior). Dawn and Aiden were asked to look through a collection of magazines to find images that represent things they have learnt from three different people. I found that the experience of looking through the magazines with Dawn (she asked me to help) and discussing the images to be used facilitated interesting conversation and interaction. Although Dawn had strong opinions about the images she encouraged me to stick the images on the eggs (Figure 2) myself. With Aiden, however, we did not get past the

choosing of people. This is absolutely fine. Aiden got transfixed on a particular relationship and the ethics of applying this person to an egg.

Though I have only touched the surface of what has gone into the dialogical props, the importance of imagination and materiality there is a glimpse of what potential creating objects have.

Researcher as Person

Emotional dissonance

As stated above, when spending long amounts of time with someone in an empathic way it takes energy, emotional labour. As people who are researchers we do not always feel in the best place to be empathic and truly listen to others and so have to act. This emotional dissonance (King, 2012), awareness and intelligence all contribute to the complexity of working with individuals who have dementia. Support is needed to ensure some of the subjects, thoughts and emotions that come up do not have a detrimental effect on the researcher. During this research I had the support of a supervisor who has much experience with design research involving people with dementia as well as my volunteer manager from the Alzheimer's Society. Despite this, it is not always easy to know when you need to talk to someone, how much you are holding the things that come up for you as an individual and even the positive effects these interactions are having. I started volunteering as a befriender as part of my research. This has informed my research greatly, including my befriendee becoming one of the participants in my study.

Sundowning

During one of the research sessions Aiden's mood changed. I backed off and stopped recording. He did not recognise his home as his home or his partner as his partner. He decide that he wanted to leave in his car but his partner did not want him to for fear of his safety. I had been a passenger with Aiden every week for months so, after standing back to allow Aiden's partner to try to rectify the situation, I made a judgement call and suggested that I could go with him. He still recognised me. This type of mood swing is referred to as Sundowning (Khachiyants *et al*, 2011) because it usually corresponds with dusk though there is little concrete explanation why this happens. The situation I described was unusual because it happened with full daylight. I trusted my knowledge, skills and instincts to quell an escalating circumstance though until one experiences this type of situation it is difficult to predict one's reaction. In my opinion, having spent so much time with Aiden through befriending while not knowing him prior to diagnosis enabled a genuine human response.

Researcher Appropriateness

While I've been stating what I believe is necessary during engagement with those who have dementia a question remains, can anybody learn to be effective in this area of research? People are drawn to working with dementia for various reasons, such as a colleague that is already in the area or having sensibilities that lend themselves to caring about the wellbeing of others. I have been told through personal communications that there are creative people who work in the field of dementia that are there for selfish reasons or it was a direction that became available when they did not succeed at being solely a practitioner. While it is difficult to know the numbers of these people it does imply that, even with training, may not be appropriate for deep empathic work. With the reflection that comes from working closely with individuals having dementia insights into and questions about oneself also arise. It takes an emotional toll but can be incredibly rewarding. Why am I doing this work and how can it be best for participants and myself? I would argue that a dialogical approach employing potentially open physical mediums is a step in the right direction, though needing more investigation.

Conclusion

In this paper I have purposely not stated what a good design is when working with people who have dementia but rather given tastes of a range of principles, sensibilities and ways of approaching the complexity of doing design research that engages people with dementia. There is a continual balancing of multiple perspectives, thoughts and emotions for each individual researcher who attempts to delve deeply into the physical and felt lives of those with dementia. Gaining empathy is not simple. Engaging people with dementia on a profound level, allowing yourself to be in their realities, and acknowledging your place as a person and a researcher in these interactions takes an openness and bravery that should be transparent for all researchers wanting to work in this way. Combining the dialogical, the empathic, notions of theatricality and fiction forms a methodology which hopefully takes in account some of the nuances and subtleties that are interwoven throughout potentially enjoyable and empowering liminal spaces. I am not stating that this is the only approach but maybe you can find things here to help you enhance your own.

References

ALLAN, K. 2010. In a moment, for a moment, in the moment. *In:* GILLIARD, J. & MARSHALL, M. (eds.) *Time for Dementia: A collection of writings on the meanings.* London: Hawker Publications.

BAKHTIN, M. M. M. & EMERSON, C. 1993. *Problems of Dostoevsky's poetics*, U of Minnesota Press.

BEHUNIAK, S. M. 2011. The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society,* 31**,** 70-92.

BLEECKER, J. 2009. Design Fiction: A short essay on design, science, fact and fiction. *Near Future Laboratory,* 29.

BLYTHE, M. 2014. Research Through Design Fiction: Narrative in Real and Imaginary Abstracts. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems.* Toronto, Canada: ACM.

BRACKEY, J. 2007. *Creating Moments of Joy for the Person with Alzheimer's Or Dementia*, Purdue University Press.

BROWN, B. 2007. *I Thought it was Just Me (but it Isn't): Making the Journey from" what Will People Think?" to" I Am Enough"*, Penguin.

COOMBES, M. 2013. Empathy and the Individual. *Research Through Design 2013.* Newcastle Upon Tyne.

DUNNE, A. & RABY, F. 2013. *Speculative Everything: Design, Fiction, and Social Dreaming*, MIT Press.

GAVER, B., DUNNE, T. & PACENTI, E. 1999. Design: Cultural probes. *interactions,* 6**,** 21-29.

GERBER, E. Improvisation principles and techniques for design. Proceedings of the SIGCHI conference on Human factors in computing systems, 2007. ACM, 1069-1072.

HEALTH, D. O. 2012. Dementia TV Ad 2012. YouTube: Department of Health.

JOHNSTONE, K. 1981. *Impro: Improvisation and the theatre*, Routledge.

KHACHIYANTS, N., TRINKLE, D., SON, S. & KIM, K. 2011. Sundown syndrome in persons with dementia: an update. *Psychiatry Investig.,* 8(4)**,** 275-87.

KILLICK, J. 2013. Living in the moment. *Australian Journal of Dementia Care,* 2**,** 8.

KING, D. 2012. It's frustrating! Managing emotional dissonance in aged care work. *Australian Journal of Social Issues, The,* 47**,** 51.

KITWOOD, T. 1997. *Dementia reconsidered: The person comes first*, Philadelphia.

MARGULIES, A. 1989. *The empathic imagination*, WW Norton New York.

THOMASSEN, B. 2009. The uses and meanings of liminality. *International Political Anthropology,* 2**,** 5-27.

TURNER, V. 1979. Frame, flow and reflection: Ritual and drama as public liminality. *Japanese Journal of Religious Studies***,** 465-499.

TURNER, V. 1987. Betwixt and between: The liminal period in rites of passage. *Betwixt and between: Patterns of masculine and feminine initiation***,** 3-19.

WALLACE, J., WRIGHT, P. C., MCCARTHY, J., GREEN, D. P., THOMAS, J. & OLIVIER, P. A design-led inquiry into personhood in dementia. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, 2013. ACM, 2617-2626.

WRIGHT, P. & MCCARTHY, J. 2005. The value of the novel in designing for experience. *Future interaction design.* Springer.

WRIGHT, P. & MCCARTHY, J. 2008. Empathy and experience in HCI. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems.* ACM.

WRIGHT, P., MCCARTHY, J. & MEEKISON, L. 2005. Making sense of experience. *Funology.* Springer.

YOUNG, I. 2015. *Practical Empathy: For Collaboration and Creativity in Your Work,* USA, Louis Rosenfeld.