



THE MAP OF ME: CARING THROUGH CLOTHING

An empathic co-design, art-based intervention that explores personhood through garments of significance for people living with dementia

A thesis submitted in partial fulfilment of the requirements of the University of Wolverhampton for the degree of Doctor of Philosophy

**TARA BAOTH
MOONEY, BA,
MA**

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Abstract

This thesis demonstrates the research process of an ecopsychosocial intervention called the 'Map of Me: Caring Through Clothing' (MoM), which uses garments of significance as a trigger to excavate the lived experience of people living with dementia.

The global prevalence of dementia is over 50 million and is set to rise to 152 million by 2050 (Alzheimer's Disease International, 2021). People who live with dementia often live at home and are cared for by primary carers, or they live in specialised care facilities with trained staff. There is currently no cure available for most types of dementia (Alzheimer's Disease International, 2020).

The research sits within the qualitative and art-based research methodology traditions, using inductive reasoning and mixed methods for data collection, which includes observation, case study, narrative, workshops and drawing. The work is informed by practice, specifically three iterations of the MoM process, to co-create forward interventions to be considered for the future care of the person living with dementia (PLWD) and their primary carer. It is a novel empathic co-design framework that weaves best practice nursing and dementia care, using items of significant clothing to excavate lived experience. This thesis illustrates how lived experience drawn from narratives instigated by significant garments contributes to an exploration of self, personhood and the interrelationship between a PLWD and their primary carer. Further, it uses art-based research methods of drawing, reflective writing and object excavation to

uncover intangible and tangible understandings of everyday human interactions with garments. It positions the person at the heart of their own 'ecosystem', surrounded by meaningful interrelationships and objects within their environment.

The Map of Me: Caring Through Clothing framework has been co-designed and tested over time with the participants. A set of procedures, resources and recommendations has been formulated as a result of the research.

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Acronyms and glossary of key terms

Affordance: The use or purpose that something can have, that is part of the way it is seen or experienced. Within the MoM ensemble of elements, the perceived affordance is important, as is the implicit understanding of how to interact with an object, person, set of fabrics, environment.

Caring Through Clothing: This term refers to the emphasis that is placed on the role of garments in actively contributing to the participant's forward intervention/care plan on their journey through dementia.

Co-presence: This refers to the act of bearing witness to another in the co-presence of narrator and listener. It is a mutual exchange of witnessing another's 'tellership' or story in an act of co-tellership (Ochs and Capps, 2001).

Co-tellership: Derived from the anthropological approaches by Ochs and Capps (2001) and Georgakopoulou (2007) where shared stories are co-constructed by multiple narrators, in a response to our need to comprehend and acknowledge the enigmatic aspects of lived experience.

Ecopsychosocial intervention: A counter term for non-pharmacological intervention that describes what the intervention is, instead of what it is not (Zeisel, 2016). It is a term that describes a holistic amalgamation of ecology, psychology and social community, particularly useful for describing alternative interventions for people living with dementia. It places personhood and sense of self within the context of the person.

Ensemble of elements: This term describes the collection of elements developed to support the MoM intervention. The 'ensemble of elements' comprises all of the components that make up the intervention. This includes the researcher, who fulfils the roles of researcher, facilitator and designer, the 'suitcase of stuff', the 'garments of significance' (identified from the lived experience of the participants). In other words, it describes the community of elements and conditions that were necessary to enable potency and adaptability for the MoM.

Forward intervention: A forward intervention is similar to a forward care plan, which is co-created by the participant living with dementia, their primary carer and their health care team. Forward intervention is one of the key principles of the research presented. Like a care plan, it enables the participants to co-craft their own future sense of self and personhood. It is an act of personal empowerment.

Garments of significance: The term 'garments of significance' has evolved within the MoM process over the course of the research. The term emanated from the idea of 'cherished garments' as presented by Fletcher (2014, 2016) and Chapman (2006), and developed in tandem with participants' lived experience through their garments.

Linear and non-linear narrative: In the context of this thesis, these terms relate to the idea of self. Narrative as logical sequence versus narrative expressed in degrees of importance and/or emotional significance. As the MoM

depicts the life timeline of the individual, there is the potentiality to move outside the linear and into a less spatially restricted idea of time and space.

Lived experience: This is the study of the lifeworld as we immediately experience it, pre-reflectively, rather than as we conceptualise, theorise, categorise or reflect on it (Ricoeur, 1992).

Living in memory: Over the course of this research, the idea of living in the presence of memory became evident as a practice that occurred solely with the person living with dementia. It was directly related to the phenomenological experience of holding, touching and feeling a garment of significance and entering the presence of memory.

Map of Me (MoM): This is the umbrella term for the intervention containing all elements that were developed over the course of this thesis. It is a methodological ensemble of elements that make up the lived experience of the person living with dementia and their primary carer. It is a collection of important objects, people and habitual remnants of lived experience.

Narrative and storytelling: The stories contained within this research were presented during the research process as an 'ecology of interactions' comprised of co-presence and co-tellership in both linear and non-linear exchange, contributing to the overall context of the narrative while also feeding into the context within which the narrative took place (Ochs and Capps, 2001; Georgakopoulou, 2007).

Person/people living with dementia (PLWD): This term identifies the participants of this study as living with some form of mid-stage dementia.

Personal ecosystems: An ecosystem is a system formed by an ecological community, an assemblage of things and an environment that all function as a unit. In the context of this research, a personal ecosystem is an ensemble of related objects, relationships and elements specific to an individual within the context of their environment (Kitwood, 2012: 3).

Personhood and sense of self: A phenomenological experience of the self as a unique consciousness. Personhood and sense of self are discussed at length over the course of this thesis. They are related to how one becomes in the world.

Person-centred: The person living with dementia is at the heart of the process.

Primary carer: This is an umbrella term for the main person(s) caring for a PLWD. It can be a carer, a partner, a friend or a family member. In the context of this thesis, it identifies the participants of this study who are accompanying the PLWD on their journey.

Researcher (facilitator/designer): This is how I refer to the roles undertaken within the project. The awareness of overlapping roles was important to enable myself, as researcher, facilitator and designer, to understand the necessary boundaries and objective/subjective shifts throughout the process. Over the course of the thesis, I will use the term researcher to denote all three of these

roles unless I am referring to one or other of the roles specifically.

Suitable space: This term is used throughout the study to describe a secure physical space where the participants felt at ease and away from distracting external influences such as loud noise or other people entering the room. This was a space where exploration of self could be supported during the workshop sessions. The attributes for such a space in the context of this thesis are discussed in Chapter 6.

'Suitcase of stuff': This is a term for the assemblage of objects and materials gathered and presented in a vintage suitcase for use in the co-design process. The word 'stuff' in the OED is used to describe matter, material, articles or activities of a specified or indeterminate kind that are being referred to, indicated or implied. This was a suitable term for the scope of the contents of the suitcase.

Tangible and intangible elements: These terms represent elements in the personal ecosystem and within the lived experience of the individual. Tangible elements are physically represented items of significance and meaning. Intangible elements are elements that live within the memory of the lived experience but are not physically represented as such.

Time frame of intimacy: This phrase emerged from participants' engagement with the MoM and describes them bearing witness to one another's stories and presence, usually emanating from interactions with the garments of significance.

Statement of original authorship

I hereby certify that the submitted work is my own and was completed while registered as a candidate for the degree stated on the title page. I also certify that I have not obtained a degree elsewhere on the basis of the research presented in this submitted work.

Signed: Tara Baoth Mooney

Date: 31/03/2021

Dedication

This thesis is dedicated to my parents Brian and Nóirín, who nurtured in me curiosity and a sense of justice.

To my siblings, Kathy, Coirle, Turloch and Breacan with whom I shared wonder, and to my nephews, Barra, Euan and Aidan.

It is also dedicated to the remarkable men and women who came on this research journey with me; it has been a privilege and an honour.

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Preface: Mapping the personal journey of the map of me

Ar scáth a chéile a mhaireann na daoine – People live in each other's shadows. (Irish proverb)

I am an artist and designer with a deep commitment to using empathic approaches to care that spans the breadth of people, their environs and context within the broader ecosystem of the world. I work with cloth, specifically garments, to explore their potential as a conduit for conveying human lived experience.

I arrived at this PhD circuitously, having lived and worked in China from 2005–2007 as the design director of an outerwear company. It was here that I saw first-hand the devastation that the clothing industry was having on the land, air and water. It prompted a deep response, which shifted my focus from designing new garments to reassessing existing garments' worth.

I have always had a strong affiliation with textiles, particularly clothing that was handed down within my own family over many years, where garments of significance were shapeshifted and reimagined to greet a new generation/wearer. The family home was a perfumery, and this added another sensorial layer within which to experience the world. The attachment to clothing in my own lived experience piqued my curiosity and has led me to this body of work where I have been compelled to examine the hidden presence of human

lived experience held within clothing and textiles. Through clothing we forge personal systems of identity constructed with deliberation and care. I return often to the idea of garments as cladding, sitting between shelter and the situated self. I see this external cladding as integral to one's own ecosystem, the habitat within which clothing can instigate emotional durability, prompt communication and act as a 'holding' shelter for personhood and sense of self.

Figure 1 is a visual representation of a 'live enquiry of lived experience' through garments of significance. This was a developmental drawing of self-curated garments of significance from my past and present lived experience created at the same time as the visual diary of 'the Travelling Wardrobe'.



Figure 1: Live enquiry of lived experience through garments of significance

The research is brought into an area of ever-increasing importance with the onset of Covid-19 and the ensuing devastation of the elders in nursing homes. It highlights the need for older people living with dementia to have resources and elements from their lives with them to accompany them on their ongoing journey. My own experience of breast cancer opened up questions for me around vulnerability, personhood and sense of self. This has informed the inquiry but not the research per se.

The MoM project has evolved from research as part of my Master's dissertation called *Diary of Our Daily Threads* (2011). This research explored the relationship that people can have with cherished garments associated with a loved one who has passed away. Using an empathic design methodology, in *Diary of Our Daily Threads*, I, as the researcher, explored textiles as vessels in which memory and lived experience could be collected, treasured and honoured as part of the grieving process. The research revealed that cherished garments held potential to instigate valid and profound levels of emotional connection between the person safeguarding the garment and the loved one who had passed away.

It is about putting life back in where only a vague memory or a bare trace was visible to those who bothered to look. It is sometimes about writing ghost stories but also striving to understand the conditions under which a memory was produced in the first place toward a counter memory for the future. (Gordon, 1997)

The sudden death of my brother Breacan brought a renewed poignancy and relevance to the work around memory and garments when I discovered a sweater of his in my house a couple of months after he had passed away. The garment itself was a light navy cotton sweater, which I had chosen with him the summer before, when he visited me in London. The circumstances around the sweater reappearing imbued it with a particular significance that was previously absent. The idea of certain clothing unfolding from cherished garments to become 'garments of significance' (Mooney, 2011) through the lived experience of the person who owned them caught my attention. For just as the garments' actual significance was shifted into focus so too was the connection with my brother reinforced by the effect of the presence of the garment. This was my own lived phenomenology and it is this idea that began to seed and evolve into this body of work. Sarah Ahmed touches on this phenomenon in the introduction to her brilliant book on the politics of emotion. Drawing from the writing of Descartes, she speaks about feeling arising not from the essence of the object itself but from how the object affects one by taking the shape of the contact we have with the object (Ahmed, 2004).

In her textbook on sustainable fashion, Alison Gwilt used the example of 'The Purse' from this author's *Diary of Our Daily Threads* project to illustrate that textile artefacts that have been gifted to individuals by a friend, relative or other, since deceased, have the capacity to evoke responses, provoke emotion and create a space for narrative and communication (Mooney, 2011; Gwilt, 2014). Many of the participants from this study identified links between time, memory,

narrative, form, ancestry, social activity and place while handling what to them was a textile artefact of significance (Mooney, 2011).

The ideas presented around garments as receptacles for lived experience can be applied to forge connections, or to reap and share narrative. Hence, the instigation for this research, which moves to a deeper level and examines the capacity for aspects of self and personhood to be unlocked, accessed and explored by interacting with particular textile artefacts and/or garments of significance. For the individual, textile artefacts and clothing can act as a vessel to hold personal and emotive experiences. However, on a social level, this type of interaction with a garment of significance can act as a conduit, forging links between a person living with dementia (PLWD) and their family/carers. This reinforces the idea that garments of significance can act as instigators of collaborative and reciprocal experiences; they can trigger storytelling, which roots them in co-tellership and co-presence, and through the research process presented in this thesis, garments of significance can contribute to an empathic, co-design approach to some of the issues related to the progression of cognitive decline.

The process set forth can also be seen as a forward intervention in the form of an advance care plan, grounded in lived experience, which pre-empts cognitive decline and sets in place a process of experiences around personhood that can be accessed as cognitive decline progresses.

A significant prequel to the research was my 'Travelling Wardrobe'. This was an initiation into working with textiles and memory as active elements within my own ecosystem, developed when I recorded, through drawing, my own travelling wardrobe over a period of three months while I was commuting fortnightly between the UK and Ireland.



Figure 2: Excerpt from the visual diary of 'The Travelling Wardrobe'

Figure 2 is an excerpt from the visual diary of 'The Travelling Wardrobe' in which I visually recorded garments in drawings over time, while travelling, as they moved in rotation between the wardrobe, suitcase, washing machine and clothes drying horse. The selection of recorded garments rarely changed,

determined primarily by need and purpose. The visual record through drawing, highlighted the importance of my garments as essential elements of my own habitat. It also illustrated which garments were more present than others at different times while I was on the road. The use of drawing, as a tool to highlight everyday habit and use practices, was the instigation for the drawing method that was developed and used during the research to record and reflect on tangible and intangible objects. I discuss this further in Chapter 4.

Textiles by their nature are present as immersive objects. We habitually interact with them, by wearing them, wrapping ourselves in them or immersing in their sensory and aesthetic value. The amalgamation in a textile of touch, scent, sound and sight (among other sensory responses) gives them a multisensory capability that exceeds many other materials used on a daily basis. Also, clothing in particular has the capacity to act as a physical and psychological interface between the body and the environment it inhabits (Twigg, 2010: 16), absorbing and swelling with the interaction of lived experience like the skin on a drum. It is an extended layer of visibility, it is situated shelter and protection, and it plays a part in rendering, representing and making our identity – both to others and to ourselves.

Chapter 1: The Map of Me: Introduction to the Thesis

1.1 Introduction: The Map of Me: Caring Through Clothing

This practice-led thesis sets out to provide an intervention-based study of the complex world of the individual living with dementia and seeks to make a real-world contribution by offering an intervention called the Map of Me: Caring Through Clothing (MoM) to explore personhood and sense of self. The MoM process is rooted in an empathic co-design, art-based approach that places the PLWD and their carer/family at the core of their own 'ecosystem'. The MoM uses garments of significance to enable the actuation of lived experience by excavating and co-mapping the participants' sense of self and personhood. This can then act as a forward intervention for the PLWD as well as their community of carers, family and friends.

This research contributes to a deeper understanding of everyday human interaction with garments, positioning the person at the centre of their own ecosystem, surrounded by meaningful relationships and objects within their environment. It demonstrates that an empathic approach coupled with a process of co-design can be considered to draw attention to garments of significance as a vehicle to explore personhood and sense of self. For the purpose of this research, the MoM has been developed with three PLWD and their primary

carers. The focus is on the PLWD situated within the environs of their community. This shifts the current paradigm from an individual and isolated culture of care to a community and co-present culture of 'ecosystems of care' (Kitwood, 1997), which can be further understood as composites of many personal ecosystems – each a complete entity within itself and each contributing to the larger set of component entities.

The MoM is many things. It is a complex ensemble of elements, encompassing a set of processes around lived experience, held with participants and embedded in a series of empathic co-design workshops. It is also a collection of important objects and people. It is here that 'garments of significance', photographs and drawing are used as a lens through which personhood and sense of self are explored. As the participants were re-introduced to objects from their personal family archives, their creative and imaginative responses to their past and present lives enabled co-construction of lived experience through story in the form of co-presence and co-tellership. This empowered the participants to co-create a forward intervention for their ongoing journey into the future.

Figure 3 shows the PLWD at the centre of their own ecosystem surrounded by the people, objects, clothing, habits and other elements that make up their habitat.

At the heart of my own ecosystem

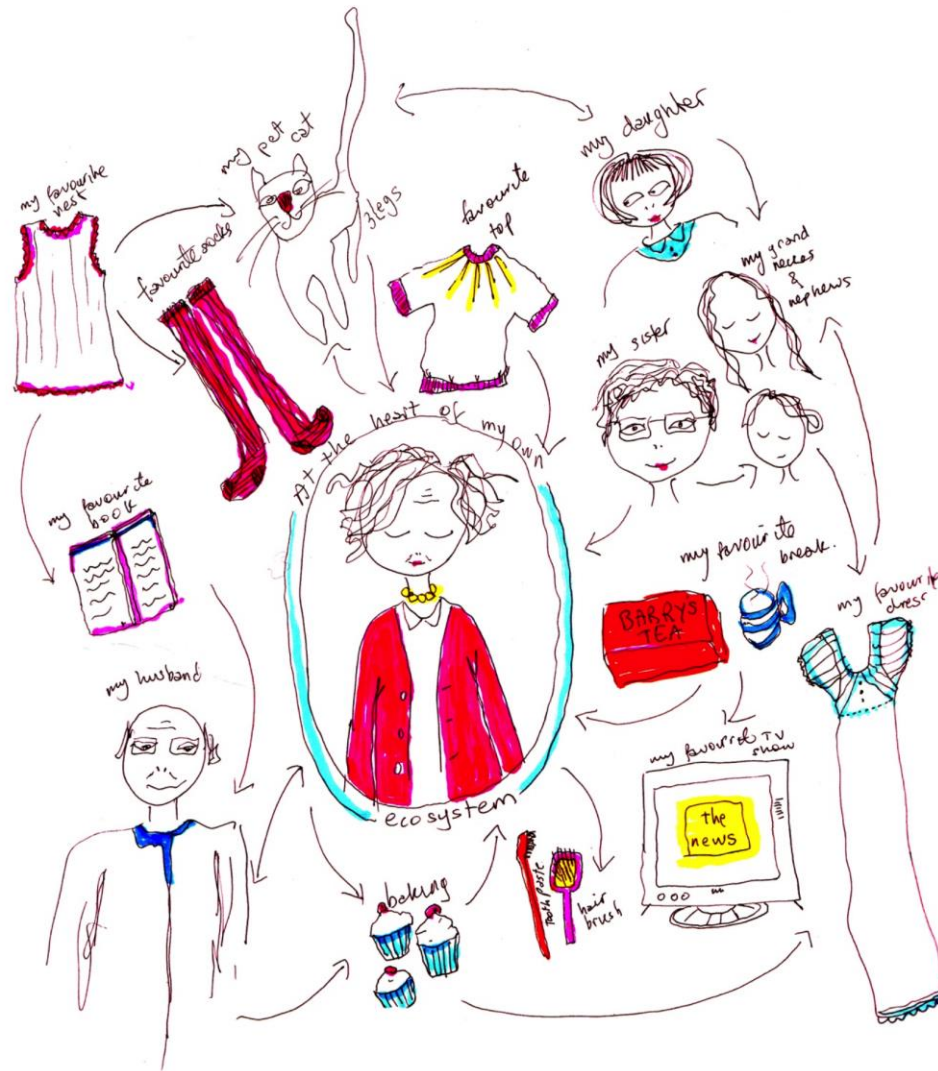


Figure 3: At the heart of my own ecosystem

With the strains and profound changes experienced by the PLWD and their primary carer, often their sense of self and their interrelationship with the carer suffers. This study is an exploration into the effectiveness of a forward intervention such as the MoM on each of these interrelationships.

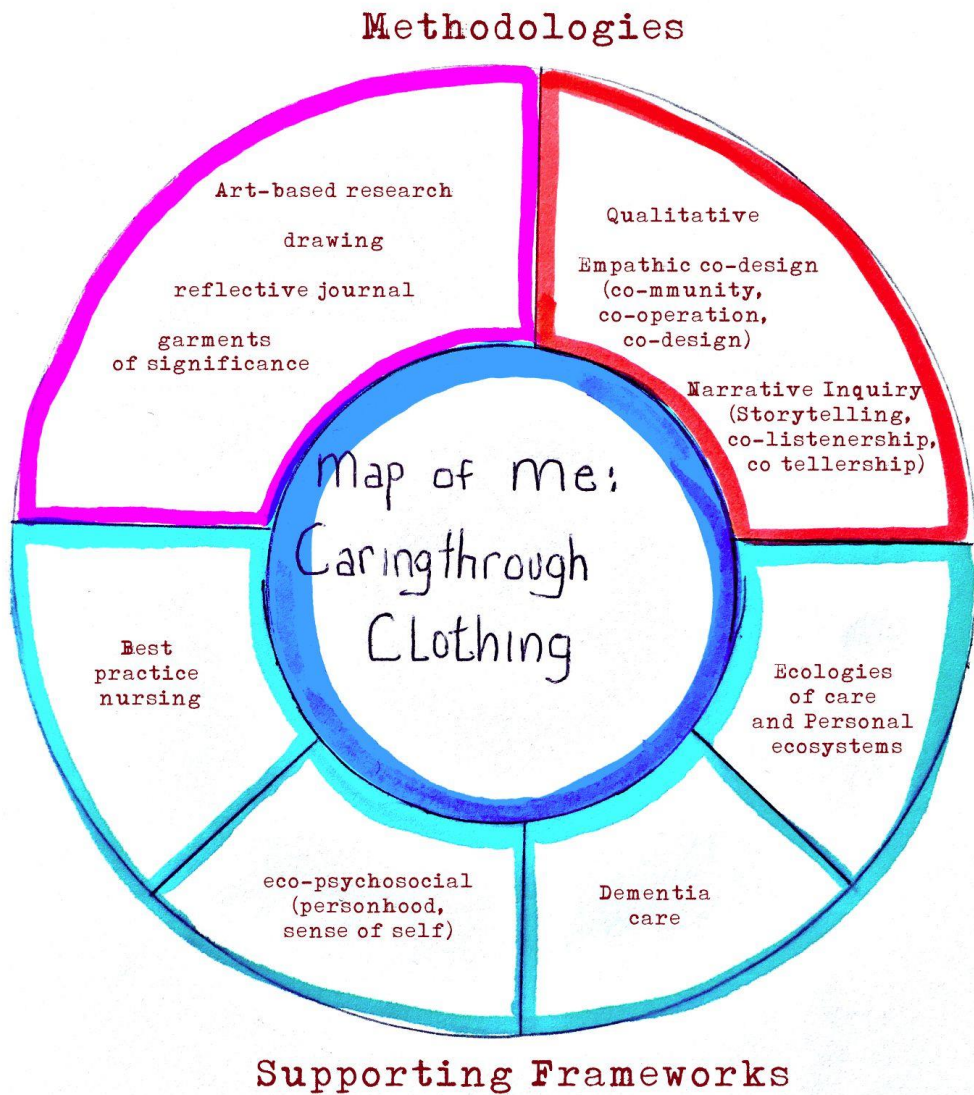
The individual MoM that represented the present, past and future lives of each participant within their own ecosystem were co-created during that empathic co-design process and were supported by garments in the 'wardrobe' and the extended realms of photographs along with drawings of the participants' garments and objects of significance – some of which were not physically present. The map portrayed information emanating from a running sense of the participants' selves through time, while also exploring where their personhood was situated along the journey/timeline.

It is well documented by Zeisel (2020) and Zeisel et al. (2017, 2018a, 2018b,) that the progression of dementia and its subsequent unfolding for every person is considerably diverse but the manner in which care and treatment is delivered does not account for this difference (Treadaway et al., 2018; Zeisel, 2020). The MoM process addresses this with a person-centred design process that involves and responds to the individual needs of all participants.

This thesis proposes that the MoM process can be viewed as a forward intervention for the PLWD and their primary carer. It is not a closed or fixed process as it holds the potential to continue its evolution with the participant and their carer/family members through the progression of the dementia journey.

The MoM process was conducted while the PLWD had capacity to recall and engage with the cohort. Co-designing with people living with mid-stage dementia in this study has meant that moments of personhood were often consciously captured through garments of significance and at a later stage were recalled and

shared, thus reinforcing the sense of self through co-presence, co-listenership and co-tellership (Ochs and Capps, 2001; Georgakopoulou, 2007). The MoM was developed alongside the participants during the time frame of the research. This intervention is a series of positive actions within a living system; that is, an interconnected system of people and relationships, constantly in flux, which houses a bounty of people's lived experience. It is important to note that although this practice-led research resulted in a recommendation for the MoM framework for future research and application, it did not set out to develop a 'toolkit' per se. A toolkit is often fixed and contains a set of tools. That was not the intention. Rather, the MoM intervention is an 'ensemble of elements' that make up the lived experience of the PLWD and their primary carer. The MoM process houses an ensemble of elements that have importance because they are centred around the lived experience of the PLWD and their carer. It is framed as a collaboration with the individuals who actively took part in the case studies. Because the MoM is a co-designed, forward intervention that adapts to a variety of the lived experiences it needs to address, it also holds the potential to enable many PLWD and their primary carers to access their own sense of self and co-tell their own stories within a suitable environment. Most significantly, the MoM is an iterative, exploratory and co-designed art-based process that began after a prior period of co-presence and observation, and a determined and fully agreed process of the researcher 'holding the space' for self-discovery with collaborators.



- Art-based research
- Qualitative
- Support Frameworks
- Map of Me

Figure 4: The MoM in relation to relevant fields of knowledge

Figure 4 shows an illustration of the mixed methods research design that brought approaches from diverse disciplines together in this model. The following areas of study were employed with theoretical underpinnings drawn primarily from the fields of qualitative and art-based methodologies: empathic co-design (Fals-Borda and Rahman, 1991; Koskinen, 2013); narrative inquiry (Ochs and Capps, 2001), which was used to draw out the small stories of everyday interaction, with co-presence and co-tellership bearing witness to these stories (Ochs and Capps, 2001; Georgakopoulou, 2007); and an art-based research methodology (McNiff, 1998; Prior, 2018), which used garments of significance, and drawing as reflective practice – to physically map moments of personhood on to the MoM as part of the co-design process and to represent missing excavated elements from the lived experience of the participants (Petherbridge, 1991; Lyons, 2012).

The following supporting frameworks underpin and inform the approach to this work: dementia care, ecopsychosocial supports for personhood and the ‘senses of self’ framework (Neisser, 1993), where five interpersonal aspects of self were adopted as an initial structure upon which personhood and sense of self could be mapped. This was merged with best practice nursing research methods from the field of experiential nursing (Dewar et al., 2013) and ecologies of care with personal ecosystems (Kitwood, 1995; Neisser, 1998; Nolan et al., 2006; Dewar, 2011).

By absorbing and integrating the latest developments, theories and ideas in these diverse yet overlapping fields, this thesis brings new knowledge and new

practical approaches to support the community of PLWD and their carers. As individual ecosystems that exist within a larger ecosystem of care, the thesis illustrates how this cohort, over time, was enabled through co-presence and co-tellership to co-create their own forward interventions and future engagement within their personal environs. The extensive database of findings including excerpts from the workshop transcripts has been summarised in the Appendices.

The final draft of this thesis was written within the context of the 2020/21 Covid-19 global pandemic, which saw the health of the world's ageing population devastated not only by the virus itself, but also by a critical lack of forward planning to protect society's vulnerable elder citizens. While the pandemic broke out after the case studies for the PhD had been completed, the framing of the pandemic and the attitude towards social and governmental valuing of the world's elder population is a highly relevant context in which to consider this forward intervention-based study and its implications for the future of interrelationship and care.

In 2020, an estimated 50 million people were living with dementia worldwide. This number will almost double every 20 years, likely reaching 152 million by 2050 (Alzheimer's Disease International, 2020). Dementia is a collective name for over 100 progressive brain syndromes that affect memory, thinking, behaviour and emotion. Alzheimer's disease is the most common cause of dementia. Other causes include vascular disease, dementia with Lewy bodies, and frontotemporal lobe dementia (Alzheimer's Disease International, 2021).

Dementia is experienced differently by each individual, making treatment and care particularly challenging (Alzheimer's Disease International, 2021). Many people with dementia live at home and are cared for by professional carers and/or partners or friends. Although various organisations are active in supporting them, carers often work alone with the PLWD until specialised care is required. Alzheimer's Disease International (2021) has stated that over 50% of carers, caring for a PLWD, globally have suffered with some form of ill health as a result of their caring responsibilities, even while expressing positive sentiments about their role.

The use of ecopsychosocial treatments for dementia is rising, as it becomes more apparent that medical interventions are often not effective (Zeisel, 2016). To date, there is no cure as such. Therefore, interventions that use a multisensory approach – such as combining physical and cognitive stimuli along with reminiscence therapy, multisensory therapy, music therapy, life story work and art therapy – have been seen to be beneficial (Heyn, 2003; Ellis et al., 2007; Cheryl and Riley-Doucet, 2009). The arts have been shown to be effective for supporting the health, well-being and cognition of people living with dementia (Camic et al., 2018). There is a continued need to further develop meaningful interventions that will improve the quality of the lived experience of both the people with dementia and their family and carers (Young et al., 2016). Interventions are needed that enable communication between the PLWD and their interrelationships of care and interaction (Gjengedal et al., 2018) .

Also needed are interventions that stimulate the creativity of PLWD (Camic et al., 2018).

Approaches to creating suitable care for PLWD to date have been largely developed through interior design and structural interventions, along with therapeutic interventions. These are often applied to care-housing situations, to elevate mood and to improve the general environment of the PLWD. An example of this is the sensory garden, in the New Cross dementia care unit in Wolverhampton or the sensory room at the Hamilton DOMUS room, University of Western Scotland (see Appendix 2). However, these interventions do not always address the ongoing lived experience of the PLWD and their carers. This is the lacuna that this research is tackling.

The research has necessitated the collation of some of these existing interventions (Appendix 1) and has analysed their initial intent as well as identifying particular areas that are not being addressed. Although some of these interventions do target sensory elements such as touch, sound, smell and sight, many are limited in their capacity to encourage meaningful interaction between the PLWD and their partners/carers; they are finished products, without the capacity to be modified or customised, as might be required for the ongoing journey that the 'user' is experiencing. The use of the participant's own individual lived experience is only one of the essential elements identified over the course of this research that is often missing from many of the aforementioned interventions. In short, many of these existing interventions do not present as adaptable to the individual needs of their user group. The MoM as a forward

intervention process addresses this deficit by using garments of significance to facilitate storytelling and narrative around moments of lived experience, engagement and human interaction, which support and reaffirm sense of self and personhood during the ongoing journey that is living with dementia.

1.3 Research questions

This thesis addresses two central questions:

- To what extent, and how, might the inherent sensory and other qualities of garments be used to co-create an ecopsychosocial intervention to excavate the lived experience of people living with dementia?
- How can the aforementioned intervention then be used to co-design an empathic framework to trigger memory through shared storytelling with the overall aim of exploring sense of self and personhood?

The MoM: Caring Through Clothing process evolved as an ecopsychosocial response to these questions. Prior research has shown that garments can potentially hold within their fibres the sensory triggers that evoke memory (Mooney, 2011; Fletcher, 2012, 2014, 2016). The first question looked at whether garments could enable a deeper excavation of lived experience through the phenomenological process of interacting with said garments. Working with people at the mid-stage of dementia rather than a more advanced stage of the disease meant that the participants were able to engage fully with the process as well as giving consent. There was a deep understanding of consciousness

around sense of self and personhood, which could be harvested for the PLWD and their primary carers to then revisit later on.

The second question addressed that same interaction with garments as a unique way of triggering responses and translated it into a methodology that could be used by others with mid-stage dementia and potentially other groups of vulnerable people in need of interaction and collaboration.

There is no assumption in any part of this research that any one person's life, identity, agency or dementia is the same as another's. However, the constituent elements surrounding us as humans within our individual situated context are similar. Components, ways of being, habits around garments and how we wear them, objects and what they instigate and mean, food and the sharing of food, relationships with others and communicating lived experience. The research questions have arisen from a consideration of the lived experience of PLWD and their primary carers, through the lens of 'garments of significance'. The garments acted as ways in, entry points to exploration of self, personhood and the interrelationship between a PLWD and their primary carer/partner/family member through shared storytelling, co-presence and excavated lived experience.

1.4 Personhood, people and clothing

Personhood is a nascent modular process of lived experience that dynamically shifts through sensory perception, reflection, memory, imagination, agency,

emotion and desire, to social engagement, bodily awareness, embodied action, relation to place and evolution of the self. According to Ricoeur (1992), the self is ever-evolving and unfolding over time. The 'site of the self' is the body (Entwistle, 2000) and emergent paradigms in fashion and textiles identify dress or the wearing of garments as a 'situated body practice' that is part of the lived experience of people's lives (Twigg and Buse, 2013). Hence, for the purpose of this research, textiles and clothing can be interpreted as part of that ever-evolving and unfolding of self as it relates to the world in which we live.

This study examines the potential for textiles and garments to act as a stimulus for the PLWD and their partner/carers to affirm some of their life-experience and to enable them to relate to others in their world. As body and spirit exist in tandem as both sentient individual and social entities, dress is an outcome of both social factors and individual actions (Entwistle, 2000); in other words, social otherness is part of who we are (Stanghellini and Rosfort, 2013).

The French philosopher Paul Ricoeur (1992) maintains the idea of 'personhood' by distinguishing between 'idem identity' (that which is always the same) and 'ipse identity' (the identity of a character that remains identifiable as it unfolds over time). The 'synchronic self' relates to personhood as it is, concerning the stable and permanent self, similar to Ricoeur's 'idem identity'. The 'diachronic self' relates to one's sense of self as it unfolds over time, similar to Ricoeur's 'ipse identity', and concerns the evolving, shifting and dynamic aspects of the self (Ricoeur. 1992; Northoff and Wagner, 2014). 'Becoming' a person is the realisation of one's potential through unity of self, social interaction and lived

experiential meaning (Cohen and Marsh, 2002). Theories of personhood focus on the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being (Kitwood, 1997). Neisser (1988) gathers the self into five distinct entities that rely on each other and are intertwined but can be identified as separate. The environmental, interpersonal, private, memorial and conceptual selves deal with varying means for us to understand what self and being truly is. We are situated in our environment, we relate interpersonally with others, we experience certain things such as pain singularly, yet we share our experiences with others (Neisser 1988; Kitwood, 1997; Hughes, 2014). So too our environment often determines the clothing we wear, and clothing can shape how we are perceived by another; our experience of a particular colour, texture, smell related to clothing and textiles is particular to the person experiencing it and no-one else. The overall conceptual context of how clothing features in the lives of people is dependent on lifestyle, work, occasion and life per se as it is lived (Twigg and Buse, 2013).

The MoM is a forward intervention that is informed by the inherently sensual nature of garments to explore memory captured and released, along with sense of self, as presented by Neisser (1993). It was developed in line with best practice care and nursing, on the recommendations of Kitwood, with subsequent research that is being continued by Dewar and Nolan. By focusing on garments of significance, the essential elements required for positive interactions between a PLWD and their primary carer(s) were present.

1.5 Methodological approach

This is an art-based, qualitative research study that utilises mixed methods to accommodate the interdisciplinary nature of the research. It is designed in this way to be accessible across disciplines. Within the art-based and qualitative methodologies are working practices and methods from empathic co-design for dementia (co-design workshops), art-based research (drawing and garments of significance for knowledge retrieval) and narrative inquiry (semi-structured interviews, feedback sessions). The following four areas support the research and comprise dementia studies, ecology (personal ecosystems and ecosystems of care), best practice nursing studies, ecopsychosocial supports and personhood.

The methodology has been designed to generate the emergent practice and knowledge retrieval while also demonstrating the iterative nature of the process. It has been tailored to respond to the research questions, which ask whether people's own garments of significance can be the starting point of an ecopsychosocial intervention to explore lived experience for PLWD. A further question asks if this then can be the basis for an empathic co-design framework that enables PLWD to explore their sense of self and personhood through a process of active interaction with the participants and their garments.

Drawing from ideas around empowerment through quiet activism, Kye Askins' paper 'Transactions' describes it as everyday acts of subversion and community. He writes about one project that brought together many different social groups, including asylum seekers, refugees and settled residents, to

address issues and social change together in community in Newcastle, England (Askins, 2016).

This study taps into empathic co-design (Koskinen, 2003; Kouprie and Visser, 2009; Manzini and Rizzo, 2011) as well as co-construction of life stories and lived experience while gradually identifying the needs of the participants and, to a lesser extent, the needs of the immediate community surrounding the PLWD. This is similar to community activism in that it involves people at different levels of community. The importance of the 'co' section of these phrases – co-presence, co-design, co-tellership, co-mmunity, etc. – cannot be underestimated. The work of Hackney (2013, 2018) and Shercliff and Holroyd (2018, 2019) could also be described as quiet activism within community. It is in the space between relationship and communication, through working co-operatively and co-llaboratively that humans can identify real issues and needs and areas of improvement for their lives as individuals and within their respective communities (Hackney, 2013; Hackney et al., 2018).

This methodology was developed with the understanding that co-design and activism, engaged participatory making, and collaborative crafting have proven in recent years to be effective ways of bringing people together to work with cloth-based objects. The *Journal of Community Research* published two special issues in 2018 that explored the ongoing quiet activism of change and empowerment being manifested through stitching together in community (Shercliff and Holroyd, 2018). The aim of these powerful initiatives is multifaceted, covering a broad gamut of elements from the reviving and

harvesting of the skills of making and co-production, with the actual relationship between materials and co-making together, to the often subtle but significant effect of collaborative practice within a small group or community of people (Hackney et al., 2018). Within this study, the human element of lived experience straddles connection, sharing, co- design, co-production and imagination, where the effect of interacting with garments can alter their state of existence from being perceived as inanimate closed objects, to open, potent holding areas where they are animated by relational activity and interaction.

Coupled with this renewed focus on the importance of collaboration within a co-design context is the 'design' work that has been developed in progressive care settings. The work of Tom Kitwood through the 'Dementia Care Mapping' process is a key foundation underpinning the ongoing work of Belinda Dewar and Mike Nolan through best practice nursing in dementia care (Kitwood, 1997; Nolan et al., 2006; Dewar, 2011). The evolution of these frameworks has taken place over the past 19 years in care settings with care practitioners, patients and family members. They have been empathically developed and are focused on and informed by PLWD and their primary care givers. This has led to an evolution of care giving and design for PLWD that recognises the need to include and work through co-design together on the complex problems presented by living with dementia (Kitwood, 1997; Zeisel, 2006; Hendrik, 2020).

This study has taken those best practice care frameworks and from them has developed a working practice model that was the starting point for the MoM project. This model has been blended with the empathic co-design approach.

This includes a long period of observation, 'semi-structured' interviews based around questionnaires relating to clothing, textiles and the sense of self and personhood. These are discussed in more detail in the literature review (Kitwood, 1997; Nolan et al., 2006; Dewar, 2011). Participants were encouraged to visit their own clothing with significant meaning such as capes, family heirlooms, quilts, dresses, christening gowns and an apron – to act as a starting point to stimulate interaction and discussion around what it means to have a sense of personhood.

The co-design, collaborative, co-present paradigm can empower people by facilitating the creation of a democratic creative collective. This can further pave the way for reflection and can be a useful means to address issues that matter to the people involved. It regards people as the experts of their own life experience and enables them to identify areas of need, while also exposing the tacit knowledge required to change their lives in ways that are meaningful to them (Spaniol and Bluebird, 2001; Hackney 2013; Hackney et al., 2018). Thus, all participants seek to empathically understand what is needed, engage in active co-creation to reach agreement on possible outcomes and share in the responsibility of implementing change, assessing process and achieving outcomes (Wagner, 1998). This is discussed in more depth in Chapter 3. This approach looks to current practice in care settings as a starting point for the research. There has been a shift in care practice for over the last two decades initiated by Kitwood's (1997) work on personhood and dementia care mapping.

However, across the spectrum of care for this vulnerable group, more participatory progress needs to be made. If we consider that co-design can and should be an act of progression to improve the current situation and lives of the people involved, then design for older people must include older people in its conception, gestation and manifestation:

If one agrees that a person with dementia must be recognised as a person with thoughts, emotions and wishes then this person should – like anyone else – be included as a person who can and should actively be included in research and design. (Hendriks and Wilkinson, 2020: 127)

Niels Hendriks develops this discussion further when he makes the argument that designing with users is a political choice to make as ‘every design choice one makes holds a consequence for (groups within) society’ (Hendriks, 2020: 126). Therefore, those design choices and decisions will be more effective when they are co-imagined with the group within society for whom they are intended (Hendriks, 2020).

The study looks at whether these ideas around co-creation could pre-empt the importance of garments of significance when used as triggers to enhance personhood by unlocking autobiographical memory as dementia progresses. It also explores whether this intervention could potentially support and enhance existing relationships between the carer and patient. It also examines whether

participants, through interaction with multisensory items could be enabled to co-create their own resources for their future care.

Over the course of this project, the researcher worked in collaboration with the participants under their continued informed consent. Reflection, analysis and action were a continuous and inductive joint activity between participants and the researcher. One of the benefits of this approach was that it dealt with the complexity of personhood for each individual. This was subsequently taken into consideration for each participant using first-hand empathic interaction and observation as a starting point for the co-design approach.

While many of the interviews were deeply personal recounting of events, they were rarely told in only one voice. An element that emerged through the workshop sessions was that the work was less focused on individual input than the broader collective. For example, Iris and her two daughters repeatedly co-constructed the making of the garments they held and discussed together. Their ownership was distributed as a celebration of the collective act. Their co-tellership enabled respectful listening and animated responses. Therefore, the focus tended not to be placed on any individual for too long. Thus, the idea of ownership of the different elements held within the storytelling and co-design sessions was difficult to assign. In her book *The Primacy of Drawing*, Deanna Petherbridge (2010) looks to the Surrealists to support her discussion on collaborative drawing. Through drawing collaboratively, the Surrealists challenged existing rules around ownership and outcome.

'Surrealist freedoms allowed the exploration of collaborative drawings that challenged narratives of autograph and ownership' (Petherbridge, 2010: 414).

A technique developed by André Breton (1948) that encourages a deeper subconscious engagement without expectation is the drawing game 'exquisite corpse' where the drawing is made collaboratively but without any knowledge of what anyone else has drawn. Isolating the drawing process from its subsequent outcome positions the process in a context of play, with the drawing becoming less about individual expectation and more about the collective shared process. In the research presented here, many of the photographs, garments, narratives and drawings were co-constructed by multiple participants. They were also signifiers of lived experience and comprised both tangible and intangible elements that seemed to be more attached to imagination than reality. The drawings and photographs functioned separately but were also interchangeable. By cutting into and releasing a photo from its square or rectangular frame it often evolved into a different kind of element – not exactly artefact, not mark-making and not representing reality but existing somewhere between these spaces. Rather than placing their narratives along a linear format, the participants creatively engaged with space and time in a series of intersecting loops. By playing with linear representations of themselves in a non-linear way through juxtaposition of drawings of themselves and missing objects, photographs that had been altered and garments of significance, they were enabled to construct a re-envisioned and dynamic family narrative that was not confined to a particular time or space. A photograph is confined by its two-dimensional borders until it

becomes a less defined element within a more dynamic space. Similarly, garments were often released from the narrative surrounding them. Drawing was also co-created, existing without borders, so when combined with other elements it enabled a non-linear placement of time and space. Drawing as a method situated within an art-based research methodology proved, over the course of the study presented, to be an evocative and open means of exploring personhood and sense of self.

1.5.1 Lived experience and Phenomenology.

Lived experience is the study of the lifeworld as we immediately experience it, pre-reflectively, rather than as we conceptualise, theorise, categorise or reflect on it (Ricoeur, 1992). Merleau Ponty (1962) presents the idea that every lived experience is a phenomenon. Phenomenological research, therefore, is the study of lived or experiential meaning. It attempts to describe and interpret experiential meaning as it emerges within consciousness, its relationship to language and both cognitive and non-cognitive experience, and its pre-understanding and pre-supposition (Adams and van Manen, 2008). Max van Manen likens it to a poet directing ‘the gaze toward the regions where meaning originates, wells up, percolates through the porous membranes of past sedimentations—and then infuses us.... exercises a formative affect’ (van Manen 2014:12).

In a practical application, a phenomenological way of being keeps people attentive to the way that human beings live through experience, in the

immediacy of the present, and recoverable only as an elusive past in the mode of 'in-being' (Heidegger, 1962). Phenomenology recovers the living moment of the now, even before we describe it through language with words. When interpreting a phenomenological experience, language can be limiting but it can also reveal elements that might potentially deepen our understanding of everyday life experience. explain that there is a need for both tangible and intangible elements that speak to our 'cognitive and non-cognitive sensibilities' (Adams and van Manen, 2008).

Thus, phenomenological understanding is distinctly existential, emotive, enactive, embodied, situational and non-theoretic. A powerful phenomenological text thrives on a certain irrevocable tension between what is unique and what is shared, between particular and transcendent meaning, between what can be thought and what remains un-thought, and between the reflective and the pre-reflective spheres of the lifeworld.

(Adams and van Manen, 2008: 618)

Both reflective and empirical phenomenology are used in this study for phenomenological inquiry. Reflective phenomenology attempts to unpack the everyday meanings of human experience. Empirical phenomenology attempts to describe events through the lived experience of the person (Adams and van Manen, 2008). The MOM research veers into lived experience captured on a sensorial level that was found to trigger co-tellership, and narrative storytelling.

During the workshops, the person with dementia in collaboration with their primary carer began to co-create their own set of stories and resources emanating from the articles of clothing from their own wardrobe. If, as Merleau Ponty presents, every lived experience is a phenomenon, the prelexical act of holding and interacting physically with the garments was a phenomenon in itself and led to a deeper moment of lived experience when the excavated material was then used as a starting point for discussion and interaction, starting with a description of the item(s) in the participant's own words.

More often than not, the item acted as a transportive portal into lived experience, and the description or story emanating from the participant was rarely related to the garment itself (van Manen, 1997). The garments worked differently as trigger types, often instigating an intimacy between the participants that was not always bound to reality or the actual memory of the event. The garment itself, while usually linked to a particular time and memory in the lived experience of the person, was often a fluid connection – not always strictly adhering to its place in the perceived memory of the person.

The garment potentially also acted as a catalyst for change in the type of relationship between the family members. In Hackney and Rana's (2018) chapter in *Using Art as Research in Learning and Teaching*, Rana discovered that it was only when she was sewing with her mother that the roles they held in the relationship were reversed. Her mother had taught Rana how to sew and with the onset of dementia, Rana became the carer in the relationship; however,

while they were sewing, her mother became the sewing teacher again (Prior, 2018).

The MOM study draws from a number of other research approaches, which include co-creation, compassionate design, co-design, craft and art, activism and reminiscence therapy (also known as 'life story work'). This grouping of research elements when applied with consistency of content and delivery has been shown to increase well-being (Hackney et al., 2018), enhance personhood (Ervin et al., 2013) and actively focus on compassionate and person-centred care for people with dementia (Treadaway et al., 2019b). Similarly, an informal conversation with the director of the DOMUS sensory room in Stirling University, at the Alzheimer Europe Conference in 2015, revealed that using life story tools, such as a reminiscence book or familiar music, as well as sharing the experience of focusing on one's life story could lead to a strengthened sense of personhood. Because garments and clothing often have stories attached to their materiality and history, life story work can be applied to the life story of the garment through the owner and vice versa (Andrews, 2015).

1.6 Key terms used and developed in the research project

The following section explains the source and evolution of a number of key terms and phrases that have been used in this thesis. Many have already been outlined in the glossary at the beginning of the thesis. Some of these terms are

already in existence and some are new terms that have been developed over the course of the research.

As this work is looking at clothing, particularly **garments of significance**, to act as an intervention or trigger, I will give an overview of how this has materialised over the course of the research. The term has evolved from the idea of 'cherished garments', which was developed by Kate Fletcher in her book *The Craft of Use* (Fletcher, 2016). The difference between these phrases is slight. A 'cherished garment' has an obvious emotional effect on the owner/wearer. The garment is obvious, tangible and still in the owner's presence as an item of clothing. The cherished garment is loved and usually guarded. In the context of this research, a 'garment of significance', like the cherished garment, also carries emotional weight, but has the added status within the lived experience of the PLWD and their family of being a significant trigger for sense of self and personhood and can also be an intangible item recalled from memory. Even while it may be missing from the wardrobe of the owner/participant it can still hold a certain amount of power in absentia. The tangible garments of significance within the lived system can act as a portal to lived experience; so too can the intangible garments become garments of significance even after they have ceased to exist in the lived system of the owner.

The use of 'garments of significance' as triggers to initiate a response would have been called a non-pharmacological intervention before John Zeisel (2016) coined the phrase **ecopsychosocial intervention**. 'Ecopsychosocial' as a counter term for 'non-pharmacological' describes what the intervention is instead

of what it is not. Because 'non-pharmacological' refers to what these interventions are not, rather than what they are, non-pharmacological treatments face a special set of challenges to be recognised, accepted, funded and implemented. 'Ecopsychosocial' encompasses the mental, social and relational quality of interventions such as improvisation instead of just saying that no drugs are involved.

The **Map of Me (MoM)** is the ecopsychosocial intervention that was developed over the course of this research project. It is the umbrella term for the forward intervention that contains all of the elements that were developed over the course of this thesis. The MoM uses garments of significance to enable the actuation of lived experience by excavating and co-mapping the participants' sense of self and personhood. This can then act as a forward intervention for the person living with dementia as well as their community of carers, family and friends. **Lived experience** is the study of the lifeworld as we immediately experience it, pre-reflectively, rather than as we conceptualise, theorise, categorise or reflect on it (Ricoeur, 1992).

The term **forward intervention** evolved from banking and relates to the Central bank intervening in forward currency markets (OED, 2021) Applied here it refers to the idea of creating a 'care plan'- a plan that outlines the immediate and future needs of the PLWD. It also provides information on future needs for social care, etc. The care plan is usually co-created by the PLWD and their primary carer and relevant medical and care staff. The MoM is not a care plan per se but acts as an ecopsychosocial 'forward intervention' where the participants interact with

garments of significance and are enabled to explore their sense of self and personhood as well as craft their own future engagement with their primary carer, through empathic co-design workshops. The concept of a forward intervention in the context of dementia care can be seen as an act of personal empowerment for the PLWD and their primary carer.

Sense of self and personhood are phenomenological experiences of the self as unique consciousness. They are discussed at length over the course of this thesis and are related to how one becomes in the world. As discussed earlier, 'sense of self and personhood' hold the duality of 'idem identity' (what is always the same) and 'ipse identity' (the identity of selfhood that remains identifiable as it unfolds over time) (Ricoeur, 1992). Theories of personhood also focus on 'the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (Kitwood, 1997). This is relevant particularly in the context of the idea purported by Kitwood when he described care as happening in 'ecologies' in his approach to person-centred care in the late 1980s at the University of Bradford. This idea of 'ecologies of care' struck me as being important in the consideration of items of clothing relationships and other important circulating elements that inhabit people's lives. As the MoM depicts the life timeline of the individual, there is the potential to move outside the linear and into a less spatially restricted idea of time and space, into a non-linear journey. As far as possible, the co-design sessions did not follow timelines of lived experience in a chronological order, but rather focused on the moments of personhood and sense of self – held within the timeline but not directed by its

boundaries.

So, too, **tangible and intangible elements** represent elements held within the lived experience and broader ecosystem of the individual. Tangible elements refer to objects of significance and meaning that are either physically represented or represented in an image. Intangible elements are elements that live within the memory of the lived experience but are not physically represented in either the wardrobe or a photograph or other representation as such. These intangible elements have been mislaid, lost or discarded over time. However, they are given an experiential shape through co-tellership and subsequently through drawing. Related to this is one of the outcomes from the research. Over the course of this research, the idea of living in the presence of memory became evident as a practice that occurred solely with the PLWD.

Narrative and storytelling: The stories contained within this research were relayed within a context of co-presence and were presented during the research process as part of a whole 'ecology of interactions' contributing to the overall context of the narrative. This is discussed in more detail in Chapter 6.

Co-presence refers to the act of bearing witness to another in the co-presence of narrator and listener. It is a mutual exchange of bearing witness to another's 'tellership' or story in an act of co-tellership (Ochs and Capps, 2001).

Co-tellership is derived from the anthropological approaches by Ochs and Capps (2001) and Georgakopoulou (2007) where shared stories are co-constructed by multiple narrators, in a response to our need to comprehend and

acknowledge the enigmatic aspects of lived experience.

Drawing was an important element of this part of the co-tellership and co-creation of story process. Focusing on garments of significance within the context of their use and drawing those moments of lived experience relayed through co-presence and co-tellership encouraged a different kind of exchange, where the PLWD and the primary carer acknowledged the garments' importance within the lived experience of co-existence, indirectly enabling exploration of sense of self and personhood (Georgakopoulou, 2007: 235).

Further to this, drawing facilitated the manifestation of **linear and non-linear narrative**, particularly in relation to sense of self and personhood. Narrative as logical sequence is not the same as narrative expressed in degrees of importance and/or emotional significance for PLWD. There are a set of recommendations for further research and diverse applications of such.

Directly related to such narratives is **living in memory**, which is the phenomenological experience of holding, touching and feeling a garment of significance usually while in the act of storytelling with another and/or others, and entering the presence of memory.

1.7 Overview of thesis

This thesis describes the research over the course of seven chapters.

Chapter 1 is an overview of the concept. Chapter 2 presents a contextual review that situates the research within the related fields, particularly co-design for

dementia. The chapter looks at some of the existing interventions for people living with dementia and is informed by visits to best-practice Alzheimer units in nursing homes. The chapter includes a critical review of published literature in the relevant domains. It touches upon related research in the domains of dress, personhood and co-design, providing a theoretical framework for the investigation. Chapter 3 presents the construction of the research methodology and the methods that have been used to gather and analyse data from the case studies presented. Chapter 4 presents the MoM and is concerned with empathic co-design of the study. The case studies are described in Chapter 5. Presented here are detailed observations, interactions and presentation of initial outcomes of the investigations. Chapter 6 presents the discussion of the **findings**, including a detailed discussion of the findings related to the theoretical framework described in Chapters 2 and 3. Chapter 7 presents the outcomes and their implications for future research; it also makes recommendations for further research in this area.

1.8 Summary

This chapter introduced the main ideas that led to the research presented, the motivation behind the research and the current context within which the research sits were discussed. The MoM (MoM) has been presented as an empathic co-created forward intervention for PLWD and their primary carers. Also discussed were personhood and how one's sense of self can be reinforced through interaction with a garment of significance. The research questions have

been discussed and the idea of lived experience as a phenomenological happening that can exist outside of a particular time or place was introduced. Listed also were short descriptions of the key terms. Finally, the 'suitcase of stuff' was presented as an open-ended resource for the MoM project.

Chapter 2: Literature Review

2.1 Introduction

This chapter surveys some of the key research in the area of interventions for PLWD, much of which has focused on the relevance of clothing for reinforcing sense of self and personhood.

Both the practical and scholarly contexts in which the research sits are considered. There is a discussion of existing interventions for PLWD and consideration of areas where there is room for further exploration. The research questions and design of the MoM project were formed as a response to address gaps identified by the literature review, specifically around personhood, agency and dress.

Creating a taxonomy of existing interventions revealed that although many of these interventions do tackle certain sensory elements, very few of them have both qualities of being customisable as well as immersive. For example, while a reminiscence app such as the RemPad, which plays photographs and music, is addressing certain issues, it is not emanating from the actual lived experience of the individual person. Similarly, the screen-based interventions were not immersive and promoted a sedentary, non-engaged approach. On the other hand, interventions such as Rebecca Fleetwood Smith's (2020, 2021) work around the significance of garments for PLWD in care homes address a similar issue to this research through art-based and design led practices. The

ethnographic work of Dr Jane Mullins is also a more holistic and rounded approach to working with PLWD.

While there were a lot of objects and interventions that did, in many ways, address deficits in dementia care, few were fully encompassing the lived experience of the individual, the carer, the multisensory factor of interaction with an object and the community factor of interaction with others.

The wardrobe and contents are considered an important site of the self and can act as a point of intervention where co-design for dementia can be considered (Woodward, 2007). The chapter also considers relevant literature around the concept of memory and its relationship to the senses, particularly within dementia care. Finally, it considers the potential for clothing and textiles as creative triggers for exploration of personhood through the use of an empathic co-design method, with a contextualisation of this study in relation to key published texts.

2.2 Designing for dementia

2.2.1 Horizon scan of design for dementia: a selection of existing interventions

The following section looks at some of the interventions that have been in use and were specifically designed for PLWD. The cognitive deficits associated with dementia often preclude patients from being able to communicate their needs and relate to others; they can also affect one's sense of personhood (Clifford et

al., 2013). Design and social interventions for PLWD have been developed to address some of the problems associated with maintaining sense of self and personhood. Research carried out by Christina Buse and Julia Twigg (2015) looks at how one's sense of self can be maintained through the clothing we wear at a material and embodied level, even while living with dementia. Maintaining a sense of self and one's personhood can be a challenge not only for the person with dementia, but also for their partner/carer and for the many multifaceted relationships that orbit them.

Alongside the interventions presented, there are a number of design interventions that tackle different problems associated with cognitive degradation, for example, triggering a memory of practical tasks such as taking medication or eating at a prescribed time and stimulating sensory interaction. Some of these examples are briefly discussed below (see Appendix 5).

Some frequently employed methods of sustaining a sense of continued identity can be, and have been, explored through therapies such as the audio-visual Six Views in a Box (2011). Developed by the Danish Alzheimer's Association and the multinational pharmaceutical company Johnson & Johnson, Six Views in a Box is a dialogue box, co-designed with people who have Alzheimer's, their families and professionals in the care sector. The box contains visual games, books and a documentary video. Together, these provide an effective toolkit for exploration, yet the various elements are not sufficient in themselves and do not give the user a complete tactile sensorial experience. Similarly, RemPad (Reminiscence Enhanced Material Profiling) developed by Prof. Alan Smeaton

and Julia O'Rourke in conjunction with Dublin City University and the Adelaide and Meath Hospital, Dublin (2013) is a research tool in the form of an archive, which allows one to input a profile of the person, with geographical and historical details. The RemPad then generates more historical and cultural details from the timeline around the PLWD's life. However, the RemPad is two-dimensional and although it does have some features that allow for personalisation, it does not provide the user with any other tactile engagement apart from handling the technology. Some of the other interventions are more practical and have been designed to remind patients of daily needs such as the time to eat or to take medication, particularly when the person with dementia is living alone. The Ode (2014) from the Design Council is a fragrance-release system designed to stimulate appetite among people with dementia.

Eindhoven University of Technology has originated a number of sensory interventions such as the 'experience pillow' (Brankaert, 2016). Also worth mentioning is the 'Touch-Tactile Dialogues' pillow, (ten Brohmer, 2016), which is a vibrating e-textile pillow constructed with touch sensors and vibrating motors (Martijn ten Bhömer, De Wever Borre Akkersdijk, Optima Textiles BV and Metatronics) . This pillow was developed as a soothing mechanism to relax individuals living with later-stage dementia; however, the interaction with other people is minimal and there is little space for customisation. In a similar vein, the mood cushion by Rompa provides sensory stimulation but its design features have been pre-assigned. In other words, it is unable to evolve with the progression of the disease as an artefact in any capacity.

The use of technology has the capacity to create worlds within which the person with dementia can enter. It is, however, not the most progressive approach for a generation whose technological ability is limited and often ends up causing more stress than the design intervention warrants. Pallasmaa (2007) talks of the computer as creating a distance between the maker and the object being made. Indeed, many of the interventions around Alzheimer's that are digital tend to be one- or two-dimensional, flattened and passive without the stimulus or immersion needed for experiential, embodied engagement. Although many of the more therapeutic tools are visual and aural, the sense of touch is employed in a purely functional capacity, such as pressing the buttons on a remote or handling pictures that represent objects or photographs, like the aforementioned RemPad, and Six Views in a Box. In these instances, touch is used as a control factor to instigate a response from a screen-based item. Digital interventions that are screen-based are not directly relational to the body that is actually experiencing the sense of touch. One example of this is the reminiscence therapy for PLWD developed by Bruno K. Kajiya (2007), which combines the presentation of old photographs and favourite music pieces of individuals, presented in personalised video channels via a television monitor. While this can be an effective means of engaging with past memories and experiences through visual and aural stimulation, the level of engagement with the body is minimal. The physical sense of touch is only employed to turn the device on or off. In other words, it is not explored as an immersive experience. More interestingly, it is devoid of human interaction. It often promotes sedentary distraction and there is no outlet for relational activity such as co-tellership, or discussion.

A number of purpose-designed interventions do exist that explore sensory responses where sight, sound and smell are stimulated as separate sensory elements through the use of designed games or interactive artefacts, such as the aforementioned 'E-textile pillow' or 'Le Loto des Odeurs', a game of scent recognition that comprises a set of scents, with colour cards to match. The game consists of aromas that correspond to cards that have a visual representation of a particular smell. The sense of smell promotes visual recognition and vice versa. This is a game that can be played with two or more people and as it focuses on smells from everyday life such as baking bread or the scent of flowers after a shower of rain, it triggers animated responses and is interactive.

In *'Sealing the deal? Irish caregivers' experiences of Paro, the social robot'* Share and Pender (2021) discuss the use of a technology, the 'Paro seal', as an alternative to pharmaceutical interventions, however they also outline the ethical implications of introducing a robot in a dementia care setting, and acknowledge that replacing or augmenting humans with technology is controversial. They cite Saetra (2020) who identifies issues such as 'the potential for deception of care recipients; the lack of authenticity in the 'relationship' between robot and user; the lack of recognition of users as unique individuals, which can only be developed interpersonally' (Share and Pender 2021: 4). The other issue which arose in the study was the lack of training in robot care for staff. This could apply to any intervention. If care staff are not able to participate in training, the intervention cannot reach its full potential in the community of care.

A considerable amount of research is currently underway in the area of music and dementia. One example is 'Singing for the Brain', which is a service provided by the Alzheimer's Society that uses singing to bring people together in a friendly and stimulating social environment. With the onset of Covid-19, singing for the brain has adapted to 'ring and sing', where the participants with the help of their carers either phone in or zoom in to sing together. Multisensory stimulation (MSS) is often employed in a number of research and real-life capacities, including the Snoezelen room at Queen's University, Ontario, Canada and Hacettepe Universitesi, Turkey and the Hamilton DOMUS room, University of Western Scotland, Glasgow. These multisensory rooms are designed specifically to target older people with varying degrees of physical and mental illness. They are calming spaces that are typically dimly lit and include many objects pertaining to the senses, including objects such as textured balls, a wall projector, different musical selections, fiberoptic cables, aromatherapy oils and a colour-changing water column (see Appendix 2 for more on the DOMUS multisensory room).

The Brigstow Institute at the University of Bristol has developed a project called 'Tactile Interfaces for Older People' (2017), which brings together a computer scientist (Kirsten Cater) and a social scientist (Helen Manchester) with creative technologists (Annie Lywood and Pete Bennett) to explore the potential for soft, interactive textiles and art to enable older people to access and manage their immediate environment and memories. This work aims to improve the quality of

life for care home residents, enabling independence, communication and social interaction to mitigate the early stages of dementia.

The work of Rebecka Fleetwood-Smith (2020, 2021) draws upon techniques borrowed from ethnography, such as observation and interviews and marries that with sensory, creative and embodied methods. This work addresses the need for research methods that do not focus solely on verbal expression and recall for data collection. It advocates the use of creative and sensory approaches when working with people living with dementia, while sharing the creative methods used that are 'malleable, relational and improvisatory' (Fleetwood-Smith, 2021: 2). Fleetwood-Smith's research sits within the realm of sensory ethnography and utilises garments while acknowledging the body as a primary source of knowledge (Fleetwood-Smith, 2020). Her study examines the significance of clothing to people with dementia living in a care home and addresses areas with a certain similarity to this research, such as the need to be adaptable and flexible in the mode of researcher.

The role of the researcher in this cycle of study drew parallels with that of an arts practitioner (Leavy, 2015), knowing when to 'step in' and offer support, distraction or to scaffold ideas, or when to 'step back' and allow for pauses or moments of quiet. These processes were inherently creative, through the ways in which the encounters were relational and shaped 'in the moment.' (Fleetwood-Smith et al., 2021: 8)

Another method using sensory ethnography techniques is work of Dr Jane Mullins (2018) and the 'Suitcase of Memories'. This is a specific reminiscence tool that focused on one couple's experience of recalling their shared holiday memories, culminating in the creation of a multisensory digital story. The use of sensory ethnography had not been used in tourism research prior to this. Mullins (2018, ii) states: 'These are examined as ethnographic narratives that exemplify the lived experience of the co-researchers alongside the identification of the themes of Holidays as Life; Freedom; View seen, viewpoint heard and strengthened self-identity with younger self.' Mullins extended this study into a pilot and from the pilot significant outcomes for the participants emerged, such as strengthened identity with former sense of self, re-enactment through revisiting holidays and their associated artefacts as well as 'the transition from a negative life view dominated by dementia to rekindling (their) relationship positively as a result of the 'Suitcase of Memories' intervention and sensory methodology' (Mullins et al., 2022: 1).

'Material Citizenship' by Lee and Bartlett (2021) at the University of Southampton is an ethnographic study exploring personhood through functional object-person relations in the context of people with dementia in care homes. The findings of this study showed that within care settings not only were object human relations overlooked but they were dependent on individual caregivers to encourage interaction. The study also found that functional object-human interaction was critical for the 'maintenance and cultivation of identity' (Lee and Bartlett, 2021: 1471). The concept of 'material citizenship' was developed from

this research to cultivate more practice and research around functional objects and that an ideal solution would be to combine existing care practice with material citizenship (Lee and Bartlett, 2021).

The 'MinD' project developed by Prof. Kristina Niedderer was an EU-funded design project that addressed the social needs of PLWD in the community. Through mindfulness and design-based concepts, this project supported self-empowerment and social engagement. A number of outcomes and tools were developed over the course of the project, which included: a life story board game called 'This is me' (Niedderer et al., 2022); a mindful reflective booklet; an interactive decision-making tool; and a digital platform for social interaction with chosen family or friends. The project began in 2016 and was completed in 2020; the activities developed over the course of the project are continued through the 'MinD network'. Niedderer and her team are tackling some of the challenges that PLWD face in their day to day interactions with people while maintaining their own sense of self and well-being. The MinD project uses the concept of embedding mindfulness in therapy and within the context of their daily lives (Niedderer et al., 2017).

Since the MoM research began, there has been a marked increase in research that acknowledges the importance of Thomas Kitwood's recommendations around care and on recognition of the individual, the right of every person to be active in decisions around their own care, the importance of relaxation and stimulation, collaboration and connection through celebration and particularly play for PLWD. Play is one of the main areas that the LAUGH research project based

at C, 2019 University explores. Here, they have developed a Compassionate Design toolkit for maintaining personhood and dignity for designers working with people living with advanced-stage dementia (Treadaway et al., 2018a, 2019). The work has been both informative and inspirational for the work of this thesis. While the methods and materials are quite different, there are similarities in the attention to personalisation, to sensory experiences and the importance of connection to another. These traits are particularly valuable for engaging with people who are non-verbal in the advanced stages of the disease.

If one were to observe the hand-held felt giggle balls from the LAUGH project at Cardiff and do a quick comparison with the aroma balls from Rompa, which are hand-held squeezable balls with a scent, they would appear to be similar: both are round multisensory balls. However, the aroma balls are not customisable and are a finished and closed product. On the other hand, the giggle balls were developed for a woman who had played bowls and was mostly sedentary. They were developed as a means to introduce fun and laughter. Each ball has embedded electronics that, when shaken, trigger the sound of a child laughing. The research revealed that responses to these balls were mixed. Some residents were amused and many of the carers often found the balls useful as catalysts for changing mood or relieving stress. Some were mildly disturbed. It is important to note that according to Kitwood, in a healthy ecology of care interactions, an intervention such as the giggle or aroma balls might be a catalyst for changing a mood or a stressful moment and then another small

intervention, like a short walk, could be introduced to guide the PLWD away from the feeling of anxiety or stress (Kitwood, 1997; Treadaway et al., 2019b).

One of the most sensitive and tender outcomes of the LAUGH project is HUG, which is a soft wearable, designed to emulate the sensation of being given a hug; it provides an experience reminiscent of nursing a small child. It is personalised with the favourite music of the woman for whom it was created. This woman showed benefits to her overall well-being within a short time of being introduced to HUG. (Treadaway et al., 2018a, 2019). These interventions illustrate that technology can act as a valid and important tool to be utilised, along with sensory and other important elements such as those mentioned above. Technology used in the traditional sense can confuse older people and unless it is interactive it can also lead to inactivity. Mobile phones, iPads and television screens are flat, two-dimensional and cold, whereas a soft textile wearable with a programmed microcontroller in its cavity with attached electronics that simulate a beating heart is a sensory manifestation of the loving kindness that lies at the heart of Compassionate Design.

2.2.2 Intervention potential for designing for dementia

This research sets out to address questions around the body, identity and personhood, and argues that clothing and textiles continue to be significant in the lives and well-being of people with dementia (Twigg and Buse, 2013). In short, it looks at the potential for textile artefacts to become agents for

reaffirming personhood in dementia care. The starting point of this study is of personal significance for the participants as it is an article of their own clothing.

Clothing and textiles are immersive objects and hold the potential for creating meaning embedded deep within the fibres, while also holding the lived experience of the wearer. Application of the principles and elements of 'personhood in a care environment' as defined by Kitwood (1997), Nolan (2001) and Dewar (2011) in the 'positive interactions', 'senses' and 'compassionate relationship centred care' frameworks to 'personhood enabled by textile artefacts and clothing' is a design challenge necessitating a novel approach. A gap has been identified between 'person centred' care and 'person centred' products or design as outlined in *Design for Dementia* (Timlin and Rysenbry, 2010). It is here, in the gap between person and object, that ideas around embodied personhood have potential to flourish. Personhood must first be defined as a separate entity embodying many elements but ultimately personhood has the potential to extend outside of its intangible 'being-ness' into a tangible or embodied 'being-ness'. Thus, the relationship through clothing, between projection of self to other and perception of self by other, is one in which personhood is enhanced through object–subject relations (Timlin and Rysenbry, 2010).

2.3 Memory, personhood and clothing within dementia care

2.3.1 Memory and the literature of memory

This section gives a short overview of the place memory holds in the ongoing evolution of self. It also looks at the art of memory and importance of the senses for binding memory. As discussed earlier in the chapter, memory has continuously played an important role in the establishment of sense of self and personhood. It is not within the scope of this research to give a complete history of memory and its systems. There is a brief overview below of the importance of memory and memory systems as they were developed in Europe and the key scholarly texts in this area. According to Yates, historically, we can see memory evolving from the anonymously scribed *Ad Herennium* (82 BC), which describes memory as being one of the five parts of rhetoric and of all five, it is memory that is the ‘treasure house of inventions, the custodian of all the parts of rhetoric’ (*Ad Herennium*, 82 BC), through to the present day where we have developed the mnemonic aid to an extent where we rely on external ‘mnemotechnics’ solely for memory.

Along the way, memory is pulled into focus by Cicero who described it as the ‘art of memory’ (Cicero 55BC), which was a technique essential for the ‘art of rhetoric’. Also, in *Institutio Oratoria* (1st C AD), Quintilian has left us with a rational critique and one of the only actual descriptions of the technique of the art of memory. It was generally held that there were two basic types of memory, artificial and natural. Natural memory could be enhanced artificially through the use of mnemonics or aids to help bind the memory. Giordano Bruno (1548–1600), who was known as the ‘artist of memory’, wrote extensively about binding

to memory. This required binding through the three gates of vision, hearing and mind or imagination to memory. He makes the point that it is through the senses that an experience can be bound to memory: 'if it happens that someone passes through all three of these gates, he binds most powerfully and ties down most tightly' (Bruno et al., 1998: 155). Bruno also held that to truly 'be' one needed to participate in being. He talks about 'being' as a process of participation that requires 'essence' or spirit to become – that there is nothing without participation in 'being', and without essence there is no being (Bruno et al., 1998). It is through the senses and imagination that a memory can then be bound to the self, allowing this participation in being to take place.

When describing the memory process, Francis Yates uses the example of digging into the memory for a word and looking for associations stuck in the memory to help dredge it up. She further makes the point that the classical 'art of memory' systematises that process of excavation (Yates, 1966: 14). Yates points out that this approach, although rooted in classical architecture, focused on irregularities rather than symmetries. It required human imagination and is full of human imagery of a very personal kind.

In the introduction to their compilation of historical and philosophical texts on memory, Carruther and Ziolkowski (2003) look to the early scholastic philosophers such as Aristotle, and his belief that memory involves some kind of emotion and therefore cannot be 'emotionally detached'. Aristotle looked at memory as being composed of two aspects: the likeness or image and the emotional resonance or intention. These work together to actively reinforce and

imprint the memory (Carruthers and Ziolkowski, 2003). Similarly, they present the idea that memory itself can never be a passive activity but involves human will and thought and participation in the mind. Storage and recollection were likened to a tablet upon which one writes. Cicero wrote down what he wanted to remember in places such as a wax writing tablet by means of images, just as if he were inscribing letters on wax, (Cicero, 55BC, cited in Yates, 1966). Or, as Carruthers and Ziolkowski (2003) illustrate, memory was a craft that was assigned tools and was designed to make a useful product. Memory therefore acted as a compositional tool that forged new ideas as well as being a tool for recollecting ideas from the past.

Yates quotes from the *Ad Herennium* when she speaks of memory as being triggered by unusual events or events of wonder: 'if we see or hear something exceptionally base, dishonourable, unusual, great, unbelievable, or ridiculous, that we are likely to remember for a long time' (Cicero, 55BC, cited in Yates, 1966: 9).

So too Yates (1966), again citing Cicero, maintains that through the use of emotional labels, the senses will commit or imprint something to memory thus forming comprehensive images. Cicero says that 'the most complete pictures are formed in our minds of the things that have been conveyed to them and imprinted on them by the senses' (Cicero, 55BC, cited in Yates, 1966: 10).

In the research on designing for positive emotion, Treadaway and the team at Cardiff explore different means of interpreting memory: declarative or explicit

memory brings to mind past experience and is the everyday meaning of conscious memory, describing such experiences verbally. Implicit memories are the deeper memories of emotion, such as are stored in the brain and provide a trace of unconscious response to experience. The brain subconsciously evaluates experience, deciding whether it is to be ignored or whether it should lead to some physical reaction such as sensing danger and then preparing to fight or flee (Treadaway, 2014). There is evidence that co-activation of conscious memory can be assisted by emotional memory systems during remembering (LeDoux, 1998: 213). Physical activities that have been practised over many years become encoded in the brain as procedural memory that is tacit and outside conscious recollection (Sennett, 2008). Treadaway suggests that it is possible that observation of these different memory systems may help to inform new ways of approaching designing for people with dementia (Treadaway et al., 2014).

This can relate back to the idea of binding memory to the self through the three gates expounded by Giordano Bruno: vision, hearing and mind or imagination. The other senses also act as conduits through emotion for memory to bind. These are laid down through the memory of what you have already experienced through the senses. Thus, paying attention to these methods of memory making, particularly when handling garments of significance, can inform the interactions and possible co-design possibilities whether it is experienced and sedimented in the body as procedural, or explicit in the daily realms of living, or implicit and

deeply committed – these are systems of memory that are embossed through lived experience and percolated through the senses.

Boncompagno da Signa (2003) outlines a number of the elements necessary for inhibiting and enhancing memory in his treatise 'On Memory'. While many of Da Signa's thoughts on women as being inhibitors of memory are highly questionable, when speaking of ways to enhance memory he talks of a need for the presence of pleasure experienced through the senses:

Let pleasure be taken in the form of the scents of spices and herbs... Let one's clothes not be too soft, rough or worn out with age... Stop now and then in pleasant or delightful spots in which one may hear nightingales or the sweet sounding running of brooks. (Boncompagno da Signa, cited in Carruthers and Ziolkowski, 2003: 119)

Da Signa is reinforcing the idea that something vital in lived human experience is cultivated through memory and vice versa.

Memory has continuously played an important role in the establishment of sense of self and personhood. Dementia is often perceived as a disease that affects memory and therefore also affects one's sense of self. Dementia is also a journey in which the sense of self is re-established in new ways over time. The area of difficulty lies in the fact that sense of self is not just perceived by oneself – it is also enhanced and supported through interaction with other people. As the

person with dementia is changing, the people around that person feel more and more the sense of loss of the person's self that they knew intimately.

It is important not to underestimate the importance of the senses for binding memory, the participatory nature of memory and the relationship of memory to the sense of self.

2.3.2 Personhood, identity and sense of self

A contextual literature review in the gap that sits between ideas, memory, self and personhood has been discussed. Historically, many of the ideas in this area have arisen from the human need to comprehend our existence on the Earth, as individuals, both within community and our environment, and also within consciousness. Plato and Descartes believed that the universe consisted of two fundamental kinds of matter: material 'stuff' relating to the body and the 'stuff' of consciousness (a substance associated with soul or spirit). The term 'consciousness', however, refers to experience itself. Rather than being exemplified by a particular thing that we observe or experience, it is exemplified by all the things that we observe or experience.

Descartes (1596–1650) sought to reorder the relationship between the mind, soul, body and memory in his endeavour to theorise a rational individualism (Katz, 2013). Descartes also famously believed that thought epitomised the nature of consciousness, and consequently defined it as a 'substance that thinks' (*res cogitans*), which distinguished it (in his view) from material

substance that has extension in space (*res extensa*) (Velmans and Schneider, 2007).

Paul Ricoeur, too, introduces a key distinction between two kinds of identity in relation to selfhood: *idem* identity is the identity of something that is always the same, never changing; *ipse* identity is sameness across and through change. Self-identity involves both dimensions; for instance, as a person, I can say of myself that 'I am and am not the person I was ten years ago'. It is the existence of *ipse* identity that indicates that a self is better thought of in terms of the question 'who is a self?' than in terms of the question 'what is a self?'

Ricoeur (1992) maintains that selfhood is constructed from the interaction of these two kinds of identity – the *idem* and *ipse* – both of which are distinctly different but necessary for a complete sense of self. The 'idem identity' (that which is always the same) exists in the now. It is unchangeable in the present and the 'ipse identity' (the identity of a character that remains identifiable as it changes and unfolds over time) is the relationship over time as one moves from the present into the future and therefore from the past – a running sense of self through time (Cohen and Marsh, 2002).

Wagner and Northoff (2014) attempt to bridge the gap between personhood and identity by relating a person's sense of identity to habitual behaviour within a familiar environment that moves backwards and forwards through time. By forging a link between conscious intent and habitual action, they link the synchronic and diachronic timescales of a person's life (Wagner and Northoff,

2014). Another means by which clothing plays an important role in the affirmation of one's sense of self is through the habitual act of getting dressed every day, which also involves conscious intent. An example of this in practice might hypothetically be a person who is the director of a corporate company and who consciously dresses themselves specifically for the role that they perform at that specific point in time along the journey of their life. In the same way, a person who is leading an active life on a farm dresses to reflect and support the daily activities in which they are partaking. This research for this PhD examines personhood and sense of self as ever-evolving and unfolding over time, as presented by Ricoeur (2012). It also, as Zeiler (2014) notes, looks at the human capacity for complex forms of consciousness to persist and develop over time. The PhD research seeks to establish whether an intervention such as a garment can help to reinforce the sense of self even if the perceived identity has changed and at that time is not recognised.

Being human can be seen as being a person in the sense that 'being' is what gives one a sense of personhood. Each human has arrived at their sense of who they are by taking a unique experiential journey through their life. In recent years, 'personhood' has been hailed as perhaps one of the most significant advances in understanding the complexities of growing older, and particularly growing older with dementia. We have seen an increased emphasis on person-centred care, which places the experience of the person with dementia at the heart of this practice (Wilkinson, 2002) and specifically on the growing

importance of the role of the social environment in supporting, or eroding, this (Kitwood, 1992, 1997).

If we consider personhood to be a state of being or consciousness comprising a diverse and modular set of both internal and external components, then the idea of personhood as solely linked to the individual person becomes less plausible. Kitwood draws on the work of Martin Buber, who fully maintains that relationship is as formative as person itself, saying that 'All real living is meeting'; therefore, 'I--thou' is an even more complete a way of being than 'I' in isolation (Buber, 2013). 'It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood, 1997: 8).

Offering care for people with dementia by considering them as a 'person with dementia' in isolation means that that whole notion of individuals' selves – or how people present themselves, interact with and are seen by others – can be overlooked (Nowell et al., 2013). Interaction allows meaning to be shared. It involves reflection, anticipation, expectation and creativity.

If personhood is constructed and maintained in a social environment, more of an understanding of the complexities of growing older, and particularly growing older with dementia, begins to take place (Nowell et al., 2013). These indicators of interaction are useful on another level as they can illustrate both the existence of and need for a continued ecology of care (Kitwood, 2012). According to Kitwood, if PLWD are seen as simply 'behaving' in a meaningless way, then an

essential feature of personhood is lost (Kitwood, 1997). As mentioned previously, Kitwood describes the type of interactions needed as being an ecology of interactions or care where many different types of intercourse are involved. Each enhances personhood in a positive way, for example, by nurturing an ability, or strengthening a positive feeling, or healing a trauma. The idea of situating the PLWD in an 'ecology of care' is a key ambition for this research. I have expanded this to also encompass personal ecologies that place the PLWD at the heart of their own ecosystem.

Kitwood (1997: 8) held that personhood is not only a personal state of being but one that is in constant interaction with another human being, 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being'. Thus, by its very nature, personhood also embodies the characteristics of being that can occur through contact and interaction with another. It is through relational, interactive traits such as recognition, respect and trust (Kitwood, 1997) that personhood becomes part of the unfolding of what it means to be human both as an individual and in the reflection of another.

In his book *The Feeling of What Happens: Body and Emotion in the Making of Consciousness*, Antonio Damasio (2000) sees consciousness as being the relationship between two players, the organism and the object. Thus, it is not a stagnant state but rather an ongoing organism–object interaction. Stanghellini and Rosfort (2013), in *Emotions and Personhood*, emphasise that emotions also play a crucial role in human engagement, enactment and attunement to the

world and therefore also for the development of consciousness and personhood. This idea is rooted, they say, in Ricoeur's theory of subjectivity that regards otherness as a part of who we are (Cohen, and Marsh, 2002; Stanghellini and Rosfort, 2013).

The idea of personhood as a reflective state, which is particularly reaffirmed when 'rooted in relationships with others', is echoed by Penrod et al. (2007: 64) and requires the 'presence of another human being'.

Goffman (1984: 7), in *The Presentation of Self in Everyday Life*, uses the metaphor of the theatre to describe human face-to-face interaction. When an individual comes into contact with other people, that individual is constantly attempting to portray an image of themselves by utilising the tools of appearance, environment and 'other'. It is thus a result of interaction with others that the individual can see his/her own identity, through an exchange of 'being' and 'being seen' and 'seen'. Although personhood appears to align with the individual and 'being' it is quite clear that, of equal importance, is the need to 'be' in the light of others' perception of who you are.

Damasio (2000) writes that one's sense of self is determined on a continual basis by what is happening to you and how your sense of being is 'modified by the acts of apprehending something'. He shows how our consciousness, our sense of being, arose out of the development of emotion. At its core, human consciousness is consciousness of feeling, experiencing self, and the 'very thought of' oneself (Damasio, 2000). He further shows that both the brain and

the body are affected by emotional states and that there are three steps that lead to an emotion being fully known or 'felt' by both body and mind. These are: engagement with the inducer of the emotion; processing the image/ sound/ smell/ taste/ touch of the inducer; and bodily engagement (somatosensory cortices, endocrine glands, viscera) triggered by intra-brain circuitry (Damasio, 2000).

The 'ecological self' can be seen as equivalent to what Schooler (2004) terms 'consciousness', and what Brown (1977) in Morin (2010) describes as the 'neocortical level' and 'sensorimotor awareness' or what Farthing (1992) terms 'peripheral' and 'primary' consciousness. The 'interpersonal', 'extended' and 'private' selves from Neisser's model reflect varying levels of self-awareness also captured by

's (Schooler et al., 2004) 'metacconsciousness', Brown's 'symbolic level', and Farthing's 'reflective consciousness'. What Neisser calls the 'conceptual self' refers to a higher level of self-awareness and is similar to 'iterative meta-representational self-consciousness' as described by Newen and Voegeley (2003).

In 'Studying the self in people with dementia: how might we proceed?', Lisa S. Caddell and Linda Clare (2013) describe Neisser's (1997) 'senses of self' as offering the advantage of specifying aspects of each component of self that are tangible and can potentially be observed and noted. In addition, this text considers the importance of time in experiencing the self, the significance of

which has been revealed through the research and documented. Neisser's conceptualisation of the self incorporates the main features of other salient models of the self, while also offering a number of advantages such as the potential for using this model as a basis for empirical studies and applying the results in a real-world context. Caddell and Clare (2013) argue that his model could be utilised to provide a much-needed clear, systematic and comprehensive theoretical framework that would be helpful for guiding future research regarding the impact of dementia on the self.

The next section examines Neisser's model in more detail in relation to existing research on the self for PLWD.

Therefore, a complete understanding of personhood would allow an individual to 'become' a person through cultivation of the experience of 'being' (Kitwood, 1997) through unity of soul, mind, emotion, memory, sensory perception and body and through heightened awareness of the object by the subject (Damasio, 2000). While investigating the paradox of the body, Shusterman (2008) notes that somaesthetics recognises the body as a perceptive living entity that is constantly undergoing sensory appreciation while also creatively self-fashioning itself (Shusterman, 2008). This higher state of consciousness gets reintegrated as the evolution of the person unfolds (Miller, 1987), further reinforcing the idea that the body is both a subjective sensibility experiencing the world and an object that is perceived in the world.

2.3.3 Neisser's framework of personhood and sense of self, with best practice nursing

In the area of best practice nursing, research undertaken by Caddell and (2011) in their study 'I'm still the same person: the impact of early-stage dementia on identity' suggests that the construct of 'self' is difficult to define. They found that the development of interventions to support self and identity for people with dementia highlighted significant methodological limitations. The interventions varied in terms of participant characteristics, content and outcome measures, making it difficult to draw overall conclusions about effectiveness.

Caddell and Clare (2011) highlight the difficulties created by approaching the subject of self, using such a wide range of concepts, models and methodologies. They go on to recognise that the disparity in models and methodologies means that it is difficult to draw any firm conclusions from the existing body of evidence, since many studies do not outline a clear theoretical framework. Their review of ten interventions supporting self and identity in people with dementia recommended that when designing the framework for a study that aims to improve sense of self identity or personhood, it is important to outline the desired effects of the process specifically, and to tailor the method to these effects (Caddell and Clare, 2011). For example, Cohen-Mansfield et al. (2006) report improvements in mood and enjoyment following their intercession, but few gains were observed in cognitive functioning, activities of daily living or self-care.

The model most commonly used to investigate the self in dementia is the social constructionist model (Sabat and Harre, 1992; Sabat and Collins, 1999; Li and Orleans, 2002; Sabat, 2002; Fazio and Mitchell, 2009; Caddell and Clare, 2011). This model holds language as a seat of fundamental importance in the creation of social reality, which also influences our experience and thought processes (Caddell and Clare, 2011). While language is undoubtedly an element that enables construction of our social reality, it is not an essential element – particularly if we consider that many might not appear to be cognitively present, and this calls attention to the issue of cognitive function. The placing of language in such a position of importance can potentially exclude people who do not appear to be cognitively aware or present as non-verbal. It diminishes the importance of the body as a receptacle of lived experience, which, according to Hughes (2014), is then sedimented as embodied knowledge. Although this study does look at language, particularly storytelling, as being pivotal to exploration of self, it is only one element that sits within many other elements. Bearing this in mind, Caddell and Clare’s recommendation to consider the model of ‘self’ proposed by Neisser (1988) as a theoretical framework on which one can base empirical research around notions of selfhood does open up the possibilities presented when the interconnectedness of all aspects of self along with the complexities of being human are acknowledged.

When Neisser (1998) describes the five types of ‘self-knowledge’ they are distinct from each other but not separate. They each establish a different ‘self’ but these selves are not experienced as being disconnected from each other, as

there is usually stimulus information that creates the feeling of unity as well as a sense of continuity over time, which also contributes to the overall sense of unity of self.

Figure 5 depicts a conversation between a PLWD and their carer or friend. They are discussing the items in the centre of the drawing. They are surrounded by the words of their lived experience such as habit, ritual and place, share, time, hope, personhood and intimacy. Neisser's five senses of self are mapped on to the drawing as present in the phenomenological moment.

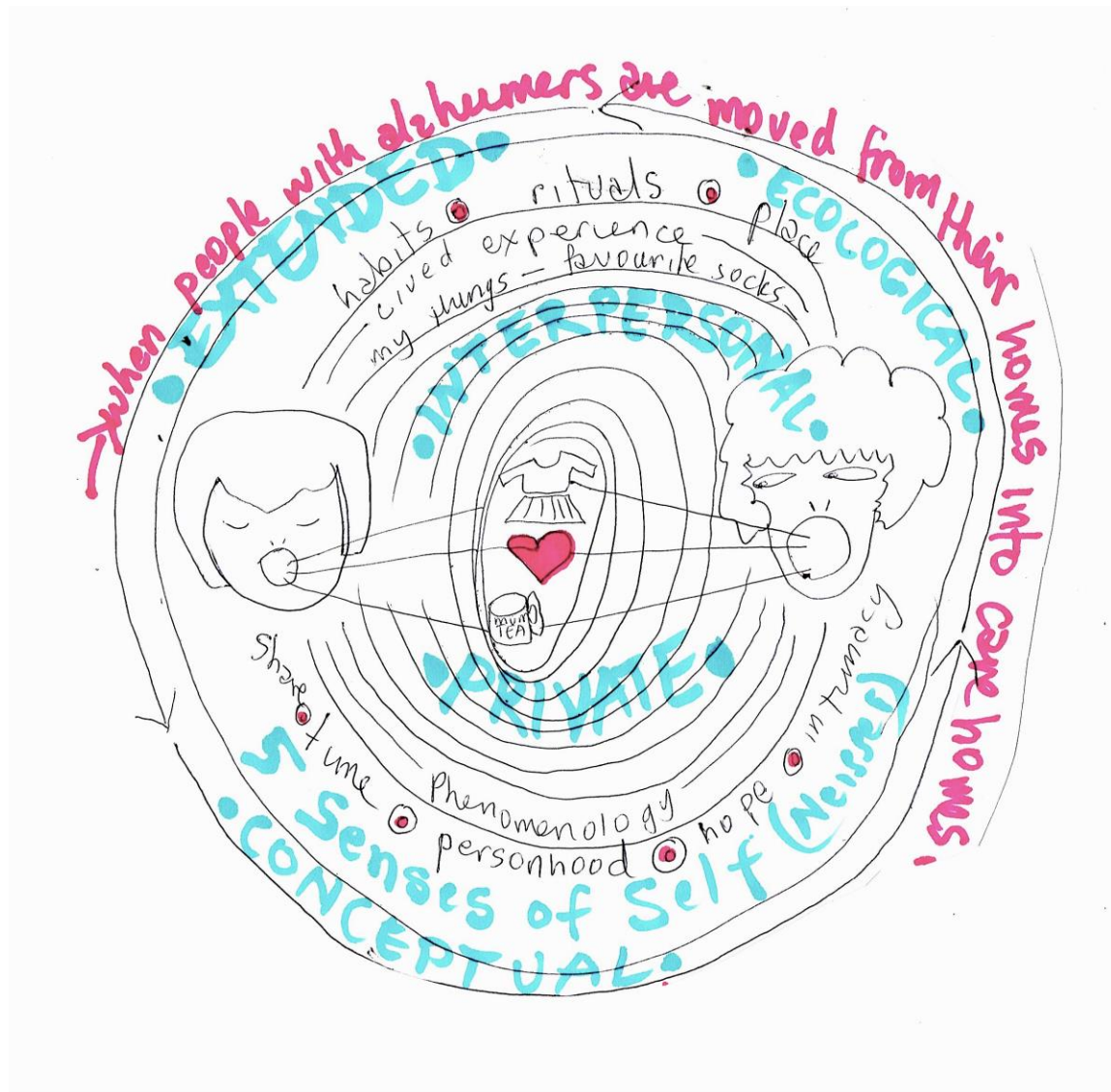


Figure 5: Ulrich Neisser's five senses of self: lived experience

This enables the researcher to link whatever is being tested to a particular construct of self and avoids the issue with some previous research where the component of self being tested (or the ability that is thought to be related to possessing a sense of self) has no obvious link to a specific model or framework of the self (Caddell and Clare, 2011b). This issue, according to Caddell and

Clare, is partly to blame for the difficulty in interpreting findings from previous studies, both from the perspective of the single study, and also when trying to integrate findings from different studies. A study by Morin (2006) compared levels of consciousness and self-awareness in the views of neurocognitive models proposed by nine experts in this area. In this study, Morin includes Neisser's five senses of self, which cover the levels of consciousness from the most basic ecological self through the interpersonal, extended and private selves to the overarching concept of self (Morin, 2006: 359).

This research has engaged with people living with mid-stage dementia using the five senses of self by Neisser as a framework on which to build the MoM intervention for an exploration of self. As the research is exploring the overall sense of self and lived experience of the PLWD, it stands to reason that the MoM framework can act as a forward planning intervention for when the participants are less cognitively present or aware. The MoM framework acts as a provocateur for lived experience and personhood. It also becomes a central repository where lived experience and personhood can be stored and accessed when needed later. Neisser's five senses of self has, over the duration of this research, shown itself to me and to the participants to be adaptable for the purpose of the MoM in that it moves through states of consciousness and self-awareness, starting with the ecological self, and ends up in meta self-awareness with the overarching conceptual self. At the beginning of this study, all of the participants living with dementia were at the mid-stage of the disease, were communicating verbally and were experiencing moments of clarity with their

carer/partners. As the study progressed and cognitive decline started to happen, the participants revisited their earlier lived experience. At no point did any of the participants stop communicating altogether over the course of this study. The senses of self and consciousness relating to minimal consciousness proposed by Brown (1977), Schooler (2004) and Farthing (1992) have not been addressed directly in this study, but the level of engagement and co-design input from the participants with dementia did contribute to the library of self, lived experience and personhood, which was then unlocked for the use of the PLWD and their primary carer and family members.

Below is an overview of the senses of self from Neisser. The 'ecological self' is determined directly through the senses. This is a situated self – a self that is perceived in relation to its surroundings. The 'interpersonal self' represents the self as engaged in social interaction and can also be perceived as interaction with another. The 'extended self' is the self as experienced across time, based on memories of our past self and anticipation of our future self. This self is more akin to the running sense of self across time. The 'private self' refers to our conscious experiences such as thoughts, feelings, intentions and pain, and is solely perceived by the person experiencing it. The 'conceptual self' represents a tying together of the other four components of self and reflects the way in which each person has a particular concept of him/herself, how they relate to their environment, relate to others and how they process their thoughts.

The **ecological self** represents awareness of the self as perceived with respect to the physical environment, through the processing of visual, auditory and

kinaesthetic stimuli. The continuous flow of optical information through the visual system means that the person (the 'ecological self') is constantly aware of their position, posture and movement with respect to the environment within which he/she sits. It is also thought that the ecological self is related to the self as an embodied 'agent'; that is, it is able to initiate movements and perceive the consequences in order to observe the effects of acting upon the environment. This specifies that the parts of the body that one is able to move and control are parts of oneself, creating a sense of embodiment (Cadell and Clare, 2011).

Neisser's conception of the ecological self aligns well with Kontos' theories on embodied personhood. In the past, body and mind, body and self, and the biological and social have been accepted as distinct entities, particularly in the area of dementia care (Kontos, 2004, 2005). The ecological sense of self challenges the idea that cognition or language are necessary elements for a sense of personhood or identity to exist.

The **private self** refers to conscious experiences that are not available to other people; it includes both aspects of perception and action, also phenomena that are not related to a person's present circumstances, such as dreams. It seems likely that many studies examining the self in dementia rely on the ability of the person to either report his/her internal experiences to us, or to act upon them in order to complete a measure or task, whether they are thoughts, feelings or other kinds of experiences. Studies that ask the participant to respond in some way – by talking to the researcher, answering questions in written format,

completing practical tasks, etc. – all require some underlying conscious processes (Cadell and Clare, 2011).

The **interpersonal self** represents the self as engaged in social interaction and can also be perceived on the basis of objectively existing information that signals that the self is involved in an interaction with another. Thus, we see that the Neisser model of the interpersonal aspect of self can be seen through interactions with other people.

The **extended self** is the self as experienced across time, based on memories of our past self and anticipation of our future self. It enables a person to experience a sense of continuity. Roles, identities, attributes and preferences have been viewed as components of self-identity in three studies, which have studied roles with which people with dementia identify (Cohen-Mansfield et al., 2006; Cohen-Mansfield et al., 2010; Cohen-Mansfield et al., 2015). The extended self requires the person to answer questions about his/her past roles as well as his/her present roles in life. It requires that the person has an awareness of his/her self in the past as well as in the present moment, which relies on a person's episodic memory, and therefore his/her sense of the 'extended self' (Cadell and Clare, 2011).

The **conceptual self** represents a tying together of the other four components of self and reflects the way in which each person has a particular concept of him/herself. It is made up of abstract representations of oneself, such as roles, traits, identity, personal characteristics and autobiography (Morin, 2006). This

aspect of self is based on what one has been told about oneself as a human being in general, and as a person in particular, as well as on what one notices about oneself. There are a number of sub-theories that make up the conceptual self. The first is 'role theories', which reflect our beliefs about how we fit into society. 'Internal models' reflect our beliefs about our bodies and minds, and 'trait attributions' are theories about the self that may be acquired from our beliefs about our roles and our internal models. These self-theories are distinguishable from the other four kinds of self because they tend to be based on socially established and verbally communicated ideas. Other kinds of experience are also likely to be considered, such as our perceptions of our bodies, our interpersonal communication, memories of what we have done in the past, and the meanings of our thoughts and feelings. Thus, each of the other four kinds of self are also represented in the 'conceptual self' (Cadell and Clare, 2011).

There are a number of advantages and also some limitations to using a theoretical framework such as Neisser's to clarify exactly what is being researched and discussed. This sort of model provides a way of organising research that ties it to a conceptual framework of self. This in turn allows one to link whatever is being tested to a particular construct of self and avoids the issue with some previous research where the component of self being tested (or the ability that is thought to be related to possessing a sense of self) has no obvious link to a specific model or framework of the self. Another advantage of having a multi-component model of self is that it enables the testing of different aspects or

specific components of self in an effort to establish whether the self is affected as a whole by dementia, or rather where specific components of self are affected independently of each other (Cadell and Clare, 2011). While this complex distinction is not the focus of this research, the distinction is relevant and important to this study because having a number of different components by which to define self provides some measure of flexibility in practice; for instance, where certain areas of cognition may be unavailable, others may yet prove to be present and relevant.

Many of the ideas discussed in this chapter reach beyond a simple literature review and indeed attempt to give a contextual framework with the specific aim of making complex and intangible concepts more tangible. Ideas around the self, personhood, thought, the meaning behind our existence and the relationship of the body within its environment, with other people and with its past are all discussed here by way of situating the key areas of concern of this thesis. Similarly, the aim of this thesis is to show the importance of and need for flexibility and collaboration in design approaches. If the design intervention/object is ongoing, relational and contingent on interaction with others then the design intervention/object cannot be fixed. This research therefore lends itself to the creation of an open intervention that grows with the person and accompanies them on their journey through the disease and beyond.

2.3.4 Designing for personhood in dementia care: using a person's name

This section considers the complex domain of personhood as applied to dementia care practice (which puts personhood at its centre). The research started and developed by Tom Kitwood (1995) posits that considering personhood as a core value in dementia care can directly improve the lived experience of someone living with dementia. Kitwood's (1995, 1997) work on person-centred care was a direct antidote to the 'culture of care' that he felt existed in the institutions that care for older people and persons living with dementia. Kitwood (1997: 8) examines the idea that personhood is bestowed upon one human being 'in the context of relationship and social being'. Kitwood (1995, 1997) observed that many people who were living with dementia were surrounded by a malignant social psychology that undermined personhood. It was the result of a hyper-cognitive culture that categorised those with severe dementia as 'non persons' (Dewing, 2008). He observed that many people who were living with dementia were inhabiting a social environment that depersonalised them. This approach to care not only puts personhood under threat but also reduces the capacity for meaningful lived experience.

One example of this depersonalisation was the lack of attention given to people's names. This pervades many aspects of patient/medical care and is a fundamental criterion of personhood. Naming someone is deeply embedded in sense of self. Kate Granger is a medical doctor in the UK who was diagnosed

with terminal cancer. Granger spent a number of weeks receiving care while undergoing treatment. She realised the importance of the gesture of giving one's name, stressing that 'it is the first rung on the ladder to providing compassionate care' (Granger, 2013). Calling someone by the name with which they are most comfortable immediately reinforces a sense of self. The person is acknowledged as a person because they become known by the name they prefer. It also opens up channels for interaction. Granger's (2013) national campaign 'Hello My Name is...' encourages all care staff members to call themselves by name when meeting a new patient and vice versa.

A study conducted by Cohen-Mansfield et al. (2000), which looked specifically at self-identity in older persons with dementia, found that only 70% of the 23 residents who expressed an opinion preferred the use of a first name. This contrasts with the staff reality that 96.2% of the residents were addressed by their first name, and 3.8% as 'Mr' or 'Mrs'. There is a gap of 22.6% illustrated in these figures, which clearly shows a deficit in one of the most primary routes to positive affirming interaction (Cohen-Mansfield, 2000). Consideration of something as basic as calling someone by their preferred name illustrates the need for a more human-centred approach to care generally.

In the next section I will look at some of the arguments around what it means to be a PLWD with an increasingly diminishing sense of self and personhood as experienced through both mind and body.

2.3.4.1 Personhood: body and mind

Personhood, as discussed, relates to the cognitive and the physical. The discussion below presents current research that focuses on the physical and gestural aspects of personhood as examined by (2017), Zeiler (2014) and Laitinen (2007) as well as by John Locke (2014). Locke's conception of personhood stresses the importance of cognition and the capability to remember past events and past actions, to think about and identify oneself as oneself. However, a focus on cognition alone fails to acknowledge the role of embodiment for personhood (Zeiler, 2014). Further, more recent discussions around personhood (Kontos, 2017; Zeiler, 2014) reveal the importance of acknowledging that both the physical self and gesture are crucial indicators of personhood. A number of types of personhood have been defined by Laitinen (2007) and are presented below. The first three draw on Laitinen's discussions around different concepts of self and personhood. These definitions can function alone as single entities, or they can function simultaneously or side by side.

Monadic cognition-oriented conception of personhood is where a person is 'an individual with a set of capabilities that necessarily involve cognition' (Laitinen, 2007: 6). John Locke's formulation in 'An Essay Concerning Human Understanding' exemplifies this. A person is a 'thinking, intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking' (Locke, cited in Zeiler, 2014: 268).

Mixed cognition-oriented conception is where a person is an individual with a set of capabilities that necessarily involve cognition and who participates in practices where s/he is regarded as a person by others (Laitinen, 2007); again, this can be seen as limited in that it emphasises the cognitive need for personhood.

Dyadic conception is where persons are individuals who stand 'in relations to others who regard them as persons; this is both a sufficient and necessary condition for personhood' (Laitinen, 2007: 6). The relation between the individual and the others is sufficient to enable personhood.

Monadic body-oriented conceptions, which opens up the idea of body-oriented selfhood, is where a person is an individual with a set of capabilities that reside on pre-reflective bodily levels of existence (Zeiler, 2014; Kontos, 2017); thus, even with cognitive impairment and or lack of mobility, the pre-reflective body would continue to be fundamental to the whole of selfhood. This points to a level of existence that is so deeply embodied that it illuminates the self, even with the degradation of the other indicators of personhood, thus enabling individuals to express themselves on bodily levels of existence and co-existence even while being incapable of verbal expression (Kontos, 2005). The idea of the body being a fundamental source of selfhood that does not derive its agency from a cognitive form of knowledge is central to the argument of Kontos.

According to Zeiler (2014), definitions of the different types of personhood, verbal language, reflection and memory are important indicators but they are not

necessary criteria for a whole experience of selfhood. She argues that while cognition certainly is important for personhood, it is unclear why actions that involve cognition should be a prerequisite for someone to qualify as a person. She states: 'What matters is that individuals can express themselves on bodily levels of existence and co-existence, in ways that are typical for them' (Zeiler, 2014: 139). Where Zeiler differs slightly from Kontos is in the interaction between the person with dementia and the people around them. Kontos maintains that an understanding of the body must include the interrelationships of the body with other elements. It needs to encompass environmental, sociocultural and even the 'broader socio-political landscapes that influence care practices and the experiences of persons with dementia' (Dupuis et al., 2012: 163).

Zeiler (2014), on the other hand, presents an 'inter-corporeal' conception of personhood and philosophically argues that others can 'hold one' in personhood. Because one can be held in personhood in interactions, then one can indeed qualify as a person also when not in such interactions. Zeiler gives the example of a sleeping person without dementia. Just because the person is asleep does not mean that they are not capable of interaction at other times. Similarly, if a person with dementia can be held in personhood by others, even for a very short time, this is seen as enabling personhood. This also means that others can act in ways that maintain personhood through interaction that enables someone to express themselves. So, while language and memory reinforce a sense of self, they are not necessary for inter-corporeal personhood,

which is possible even in interactions where others take the initiative to help them to express themselves (Zeiler, 2014).

Kontos claims that a social interactionist perspective 'relegates the body to a symbolic role, where it is understood as being representative of meaning rather than as a significant dimension of selfhood' (Kontos, 2005: 555). She goes on to acknowledge that for a long time the bodies of people with dementia have been 'denied their agency as social connectors' (Kontos (2005: 555). She critically questions previous work on personhood (Sabat and Harré, 1992; Kitwood, 1997; O'Connor et al., 2007) because, she says, it inadvertently resulted in the privileging of the social over the corporeal with its focus on interaction with self. This overlooks the self in the body, as rooted in a pre-reflective level of experience, which is fundamental to the manifestation of selfhood for persons living with dementia (Kontos, 2004). Body and mind, body and self, and the biological and social have been accepted as distinct entities, particularly in the area of dementia care (Kontos, 2004, 2005).

The MoM addresses the ever-increasing scope for personhood, particularly for both embodied and inter-corporeal experience. Importantly, the body can and often will respond when cognitive function does not, even if only in relationship or interaction with an 'other'. Gesture emphasises more than the natural expression of the body; it can also disclose social and cultural movements and physical cues that derive from an embedded sociocultural heritage (Kontos, 2017). Thus, through gesture and movement, even the sense of one's self as

defined by sociocultural criteria can be maintained although the cognitive recognitions of self may have fragmented.

2.3.4.2 Approaches to personhood within best practice nursing for dementia care

This section examines the culture of care that surrounds people living with dementia, and the interrelationships within the care environment and the ongoing developments that have evolved to support and nourish best practice in care settings.

Kitwood describes the type of interactive care that is needed as being similar to an ecological system where many different types of interaction are required to be truly involved. Recent research attempts to place the experience of the person with dementia at the heart of care practice (Kitwood, 1992, 1997; Dewar et al., 2011). This is coupled with an increased emphasis on relationship-centred care, and specifically on the growing importance of the role of the social environment in supporting or eroding this (Kitwood, 1993, 1997). Kitwood identified that the three main types of discourse around dementia in which the concept of personhood is to be found are social, psychological and transcendental. Central to all three is personhood (Kitwood, 1997).

PLWD become more dependent on others as the disease progresses. Practical difficulties with daily tasks such as dressing, washing and going to the toilet gradually become so severe that, in time, the person becomes totally dependent on others (Alzheimer's Disease International, 2020). Relationships are formed

out of necessity. These relationships are key to caring for people with dementia. In the same manner that designing with empathy considers the whole context including interrelationships and environment, so too the care of people with dementia must start from an empathic perspective. By its nature, empathy involves more than one person. By considering a 'person with dementia' in isolation, the whole notion of personhood or how people present themselves, interact with and are seen by others can be overlooked (Nowell et al., 2013).

Interaction allows meaning to be shared. It involves reflection, anticipation, expectation and creativity. During everyday conversations between people, a rich ecology of interactions is present (Kitwood, 1997). If people with dementia are seen as simply behaving in a meaningless way, then an essential feature of personhood is lost.

A healthy way of being in the world applies to our interrelationships with others, our status in society, how we are regarded, our sense of achievement, our spiritual nourishment, our ability to connect to one another emotionally and our ability to belong. When one considers ancient and indigenous methods of approaching the person with all aspects of health functioning in a positive way, we can see that health applies to more than just the physical and mental, particularly in regard to older persons. Tom Kitwood was not speaking of a new breakthrough when describing an 'ecology' of care; he was merely referring to a complete holistic approach to human health, which is an essential element of well-being. Certain indigenous cultural practices refer to their communities' integrated health practices in association with other aspects of living well (Mac

Coitir, 2017). In traditional Irish societies, old age was often linked with wisdom, and thus older people were considered to be valuable contributors to society. Older members of the community were called elders and as keepers of many knowledge types, great respect was afforded to them. (Kerrigan, 2020) Yet, as Jared Diamond (2014) acknowledges, in Western society, and particularly in North America, older people are not always treated very well. Diamond has undertaken a body of research on traditional societies and how they treat their elders and suggests that this might guide Western society on what to emulate and what to avoid.

He says that while older people in traditional societies can no longer spear game or battle enemies, they can still gather food and care for children. They are often experts at making tools, weapons, baskets and clothes (Diamond, 2014). In many societies they serve as 'tribal elders' in medicine, religion and politics. Diamond does not hold that this is the only way; he stresses that the important thing is to strive to understand the strengths and weaknesses of older people as they change with age. It is important to appreciate their deeper understanding of human relationships and their ability to think across wide-ranging disciplines, to strategise and to share what they have learned (Diamond, 2014).

As PLWD appear to lose their sense of personhood, so too the people around them are entering the territory of an unknown journey. The predominant experience of dementia is often understood in terms of progressive deterioration, loss and suffering. However, maintaining or having access to a

sense of personhood through the duration of the journey has potential to alleviate the negative aspects of the disease.

In 'The construction and deconstruction of self in Alzheimer's Disease', Sabat and Harré (1992) explain that the repertoire of selves, the personae that are socially and publicly presented, which require the cooperation of others in the social sphere in order to come into being, can indeed be manifested even in the later stages of the disease. They show that the threat of a loss of self for people with dementia is not directly linked to progression of the disease. Rather, it is related to the behaviour of those who are regularly involved in the social life of the person with dementia and go on to say that to react positively to such change requires persistence and dedication (Sabat and Harré, 1992). If personhood evolves with the person, as Kitwood has shown, then as cognitive ability changes, so too personhood changes. It does not cease but it evolves. Thus, relationships can still be created, communication can still take place and certain elements of Kitwood, Nolan and Dewar's interactions can still occur – but perhaps not as frequently or with the same outcome each time.

By studying existing best practice care in nursing environments for older people, this research will outline a number of key aspects of personhood, which can then be applied as a starting point to develop an empathic co-design forward intervention for exploring sense of self and personhood. While maintaining a 'running' or continuously conscious and fairly consistent sense of self may prove difficult in the face of the progression of dementia over time, by contrast, personhood, by its nature – defined and redefined – can, at many stages of the

journey of living, intertwine with the sense of self and can also exist independently of the running sense of self.

The following section presents the three frameworks from best practice nursing and care for PLWD. These frameworks have been assimilated into Neisser's theory on the 'senses of self'. This was a fundamental cornerstone which underpinned the MoM.

There are 12 different types of positive interaction that Kitwood describes as provisional and a starting point for meaningful interaction. They have grown out of a care system in need of change. These three frameworks have been chosen because they align with empathic relationship-centred care and each has scope for the type of adaptation that is necessary for the unfolding of personhood within relationships of care. The next section begins with Tom Kitwood's (1997) measure for Quality of Care, then moves on to the Six Senses Framework created by Mike Nolan (2006) as a development of the important work researched by Kitwood (1997) and finally considers Dewar's (2011) work on compassionate relationship-centred care, known as the Seven Cs. This technique was developed while undertaking her PhD research under the supervision of Nolan (Kitwood, 1997; Nolan et al., 2006; Dewar, 2011).

Each of Kitwood's 12 interactions enhances personhood in a positive way, for example, by nurturing an ability or strengthening a positive feeling or healing a trauma – all instigated at the particular moment. At times, they may be almost insignificant but rather than instilling a negative feeling they encourage positivity.

As personhood is often constructed and maintained in a social environment, more of an understanding of the complexities of growing older, and particularly growing older while living with dementia, begins to take place (Nowell, 2013). Kitwood's (1997) indicators of interaction are useful on another level as they can illustrate both the existence of and need for a complete ecology of care.

For relationships within a care environment to be positive and meaningful, consideration must be given not only to the medical needs of individual patients but also to their emotional and physical needs. So too the needs of carers, relatives and staff who are in contact with the PLWD must be considered. Of the 12 positive interactions, the first five relate to the person who is interacting with the person with dementia. These are positive interactions that are often instigated by a carer or 'other'. The next three are psychotherapeutic and the final two are focused on the person with dementia as the instigator of the interaction. Below is the observational framework of Dementia Care Mapping, developed and modified by Kitwood to be used as a measure for quality of care on a daily basis and built on the subjective factors relating to life circumstances originally developed by Clarke and Bowling as the 'Quality of Interaction' schedule (Clarke and Bowling, 1989; Dean et al., 1993).

Observational Care Mapping:

- Recognition: Acknowledgement of the person as a unique human being.
- Negotiation: Person is consulted about their care. There is a sense of agency over the care received.

- Collaboration: Two or more people are aligned on a common task with a shared aim.
- Play: exercise in spontaneity and self-expression.
- Timalation: Providing stimulation through the senses without making any demands, e.g., aromatherapy.
- Celebration: Any moment where life is experienced as being intrinsically joyful.
- Relaxation: Ability to relax in a social situation; lowest level of intensity.
- Validation: To validate the experience of another – acknowledge the reality of a person’s experience.
- Holding: To provide a suitable psychological space for expression/ exploration of vulnerability, emotional trauma, etc.
- Facilitation: To enable a person to interact/collaborate with meaning in a way that they may not ordinarily be able to do. This represents a form of care where the person with dementia is being actively drawn into the social world. Two typical types of interaction often emanate from the PLWD.
- Creation: A spontaneous offering of something to the social setting.
- Giving: The PLWD expresses concern, affection or gratitude, makes an offer of help or presents a gift. (Kitwood, 1997)

The Senses Framework developed by Mike Nolan and his team at Sheffield University (Nolan et al., 2006, 2008) focuses on developing positive relationships between older people, relatives and staff, as interdependence is

seen as an important ingredient of quality in care. Based on empirical research in long-term care settings, Nolan identified the Senses Framework as a potential framework for older care practice (Nolan et al., 2006). Nolan and his colleagues argue that each of these three groups of people in the care setting (older people, relatives and staff) need to feel each of these senses. These studies suggest that in the best care environments all participants should experience the following senses:

Senses Framework:

- Security: to feel safe.
- Belonging: to feel part of things.
- Continuity: to experience links and connection.
- Purpose: to have a goal(s) to aspire to.
- Achievement: to make progress towards these goals.
- Significance: to feel that you matter as a person. (Nolan et al., 2006)

Nolan and his team suggest that, through linking the experiences of older people, their families and staff, the Senses Framework has the potential to promote understanding of the feelings of others, and, as a result, to improve communication and the ability to work in partnership (Nolan et al., 2006, 2008).

Building on the work of Nolan, Belinda Dewar (2011), as a senior nurse and practitioner researcher, used her practice to evaluate processes that enhance compassionate relationship-centred care. While Nolan's work advanced older persons' care, by focusing on the relationships between the carers, families and

patients, Dewar opened up a space for a more developed type of relationship to develop altogether. Her findings, called the Seven Cs, proved that in conversations with patients, the carer needs to be conscious of particular states of mind and being in order to promote compassionate relationship-centred care.

This relationship, which is aligned with compassion, maintains that the skills of making personal connections with people can be developed within a relationship of care that is person-focused and empathic (Dewar, 2011: 148). This is a relationship that enables personhood through interaction and reciprocity, and that can help carers and staff find out what matters to people and to begin to use this information in shaping the way care is given and received (Dewar, 2011: 146).

The Seven Cs:

- The ability to Connect emotionally.
- The ability to be Curious.
- Collaboration.
- The ability to Compromise.
- The ability to be Considerate of others' perspectives.
- Courage.
- Celebration. (Dewar, 2011)

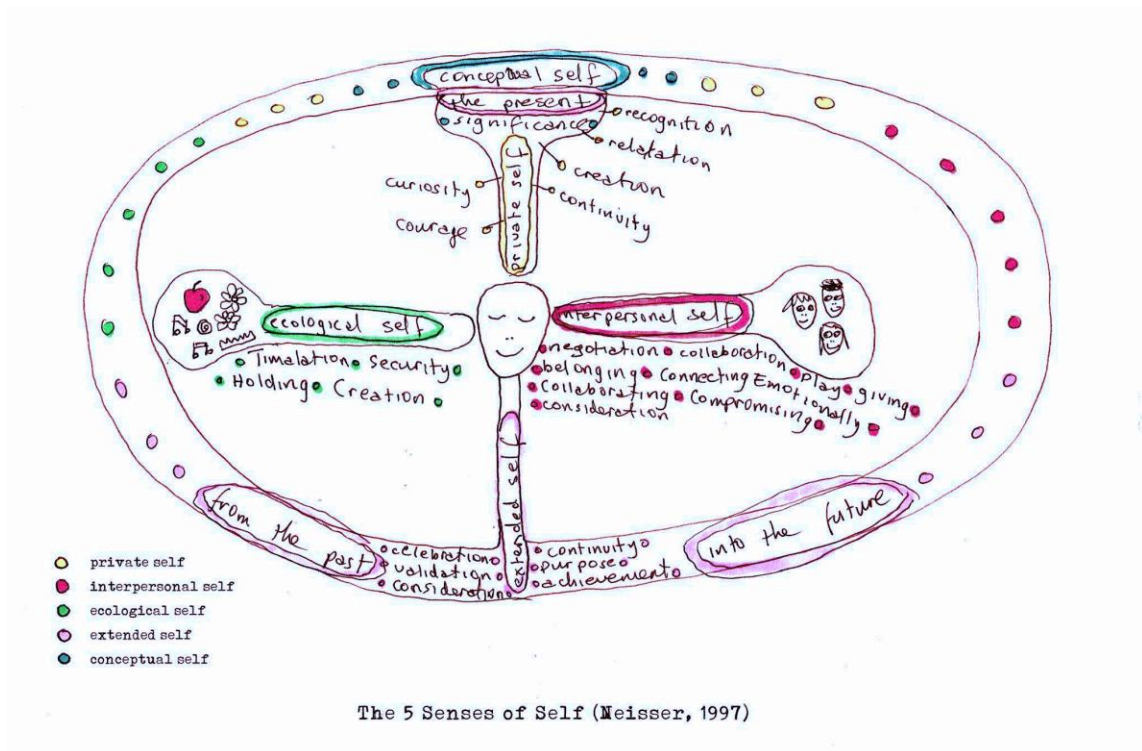


Figure 6: Neisser's (1988) five definitions of self with best practice nursing elements mapped from Kitwood (1995), Nolan (2006) and Dewar (2011)

Figure 6 is a drawing of Ulrich Neisser's five definitions of self with the three best practice nursing frameworks developed by Kitwood, Nolan and Dewar mapped and colour-coded to sit within Neisser's definitions of self. Illustrated are Kitwood's 12 positive interactions, Nolan's (six) Senses Framework and Dewar's Seven C's (Kitwood, 1995; Neisser, 1988; Dewar, 2011; Nolan, 2006, 2008).

2.4 Designing for personhood in dementia care

2.4.1 Clothing and textiles as an expression of personhood

This section considers and reviews literature relating to the emergence of the concept of self, identity and personhood through the wearing of, or interaction with, clothing. The evolution of self, identity and personhood through philosophy and theology has been outlined and discussed in the previous section. Traditionally, in philosophical discussion, as discussed by Wagner and Northoff (2014), there has been a separation between the criteria of personhood and the necessary and sufficient conditions of identity or sense of self. This is quite a different discussion to that explored within the arena of dementia and it is beyond the scope of this research. However, it is important to reference the fact that personhood has a long tradition, reaching as far back as Locke (1694), who famously regarded the concept of a person as a ‘forensic term’. Locke (1694: 335) says that a person is ‘a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places’.

In the 1950s, the renowned paediatrician and psychologist Donald Winnicott, in collaboration with his wife Clare, introduced the idea of ‘transitional objects’ to describe textiles such as blankets, toys and pieces of cloth to which young children develop intense attachments (Litt, 1986). Drawing from Bowlby’s (1988) ‘attachment theory’, which was designed to highlight the importance of infant–caregiver relationships for survival and personality development, Winnicott (1989) maintained that these transitional objects were essential for the development of a sense of self and that they enabled children to make the

transition from dependence to independence. The objects worked on a number of different levels, both as soft comforting objects and also as familiar objects within the environment of the child. Winnicott (1989) held that the idea of an individual or a child existing outside their environment was not feasible. Rather, he talked about a succession of psychosocial holding environments where the individual was embedded in the culture of their surrounding context such as peers, school, family (Litt, 1986). One of the functions of the transitional object was to soothe anxiety in the absence of the person to whom they were attached. Therefore, even if the caregiver was absent, if there was consistency in the presence of the object, the anxiety levels experienced by the child would not be as severe (Litt, 1986).

For a PLWD, clothing – which is a soft textile related to one’s sense of self – can act in a similar way to transitional objects, where emotional connection and familiarity are inherently present. Even in the face of cognitive decline or being moved to a care home from one’s home, it stands to reason that garments of significance can act as a type of transitional object.

Erving Goffman (1984) looked at how we, as humans, affirm notions of self in our lives through daily ‘performance’. As individuals, we utilise the tools of appearance, environment and ‘other’ to ‘perform’ our identity (Goffman, 1984: 7–8). Julia Twigg (2009) recognises the significance of clothing as being part of this performing of identity as objects ‘separate from the individual and their body’ but chosen by the person to represent their identity and expression of self. The practice of wearing clothes can be seen as central to the creation of one’s own

personal identity or personhood. It relates to appearance in how we perceive our own personal 'way of looking'. It relates to our environment in what we choose to represent through our dress on a social and political level, and it relates to the way we interact with others. The clothing we choose to wear can re-affirm our sense of who we are (Entwistle, 2000).

Twigg has identified clothing as a cultural object or artefact, embedded in personal, current and historical sets of meanings (Twigg, 2009: 13). In *The Meaning of Things: Domestic Symbols and the Self*, Mikhail Csikszentmihalyi and Eugene Rochberg-Halton (1981) discuss the need for humanity to look at the meaning of object representations as instigators of relations between the individual, their fellows and rhythms of the natural world. Clothing and textiles can also be seen as an interface between the subconscious being and the conscious being of the person as perceived by an 'other', often 'acting as an intermediary between the body and its public presentation' (Twigg, 2009: 13). Csikszentmihalyi and Rochberg-Halton make the connection between objects and the people that interact with them, 'past memories, present experiences and future dreams of each person are inextricably linked to the objects that comprise his or her environment' (Csikszentmihalyi and Rochberg-Halton, 1981: ix). The wearing of clothing is a situated body practice, part of the lived experience of people's lives (Twigg and Buse, 2013). It can be linked to both representation and misrepresentation of self, as determined by the wearer. Clothing, when placed in the category of 'objects', becomes the receptacle for memory to embed, experience to occur, and dreams to fulfil.

Daniel Miller in *Stuff* (2010) draws on the sociological and anthropological traditions that regard objects and things as representing who people are and who they want to become. People, he says, 'create themselves through the medium of stuff' (Miller, 2010: 99). It stands to reason then that people's situated body practices, such as getting dressed, become acts of self-actualisation and are an effort to bring together the self and the perceived self through the garments chosen. The body, according to Juhani Pallasmaa (2007), is the place of reference, memory, imagination and integration. According to Ashley Montagu (1983), all sensory elements can be traced back to the skin, the oldest and most sensitive of our organs. It was the initial medium of communication and most efficient protector. The body becomes the 'locus of reference, memory, imagination and integration' (Montague, 1986: 3). It is through touch that we integrate our experience of the world and experience of ourselves (Pallasmaa, 2005). As we recall certain experiences we also 'recall' the sensory feeling that helped to emboss this experience on to our memory. As mentioned in the foreword to this thesis, Sara Ahmed examines the body and its relation to space and objects as being elements that affect each other: 'bodies take the shape of the very contact they have with objects and others' (Ahmed, 2004: 53).

What makes bodies different is how they inhabit space: space is not a container for the body; it does not contain the body as if the body were 'in it'. Rather, bodies are submerged – such that 'they become the space they inhabit. In taking up space, bodies move through space and are affected by the 'where' of

that movement. It is through this movement that the surface of spaces as well as bodies takes shape (Ahmed, 2004: 54).

The sensory feeling strengthens this recollection just as the feeling is enhanced by the memory of the experience. It is almost like a mutual tagging or labelling that signposts the way to our inner sensorial realms, evoking emotive, empathic and physical responses. As artefacts, clothing and textiles inherently possess the multisensory qualities of touch, smell, sound and sight, and they have potential to trigger these responses.

Amy T. Holroyd also looks at fashion as 'the means through which people express their sense of identity and connect with others' through the medium of clothing (Holroyd, 2011: 3). According to Francis Corner, Head of the London College of Fashion, the term 'fashion' can refer both to physical garments and fashion culture. She maintains that although some make a distinction between fashion and clothing, clothing is usually engaged with fashion in some way – whether positive, negative, affirmative, indifferent, conscious or unconscious – and that this is an intractable part of dressing. Thus, fashion, well-being and clothing can be positioned within the discourse around notions of self, personhood and body image (Corner, 2009). In many cultures, 'fashion' garments and textile objects can act as a connecting link to ancestry, value, human interaction, emotion, self, ritual and the importance of tradition (Miller, 2010; Mooney, 2011). For example, in Western Christian culture, one of the most significant garments in use is the wedding gown. Often worn only once, and sometimes passed down through generations, the dress represents an

embodied human experience on two levels. It is the individual choice of the wearer and the treasured vessel of the collective family experience (Mooney, 2011). As clothing is allied with the body, the body then gives clothing life (Twigg and Buse, 2015). As long as the sense of the person is able to inhabit the body then the body can animate the clothing worn by the person. Throughout the following chapters, the research investigates the potential for clothing and textiles to trigger memory and narrative through the senses experienced by the body. Thus, forming an embodied experience where the senses are fully engaged in re-animating a sense of personhood.

2.4.2 Empathic co-design and the fashion ecosystem

Addressing personhood in relation to clothing and textiles may not seem to be immediately synonymous with ideas around sustainability and fashion; however, this research has partially originated from ideas relating to exploring the inherent embedded value in garments and textiles. Empathic fashion and textile design often falls under the umbrella term 'sustainable fashion and textiles'. The current fashion system does not tend to encourage long-term engagement between a fashion object or garment and its user. Researchers such as Tim Jackson and Amy Twigger- Holroyd explore the concept of a 'double dividend' (Jackson, 2005: 19), in which there is reciprocity between personal well-being and the general benefits of our environment (Holroyd, 2011).

As discussed in Chapter 2.3.8, there are many 'practices' associated with fashion and wearing clothing (including body, object, self-actualisation, skill,

attitude, storytelling and personhood) and sustainable fashion considers how to engage human intelligence in a broad field where everyday actions, relationships and material effects contribute to more holistic and empathic practices (Fletcher, 2012). In a fashion system fuelled by the production and consumption of ready-made objects, made uniform by mass production, finished, completed garments are designed to be replaced quickly by other new garments. Fletcher (2012) advocates for utilising empathy to support a more resilient design process. As design considerations shift from economic and rational issues to personal need and experiences Fletcher and Tham (2014: 241) believe that ideas around 'multi-voiced-ness and temporal awareness offer potential narratives for design that embody empathy, holism and connection'.

An empathic design approach starts with an exploration of the relationship between the person and the potential garment. According to Alison Gwilt (2014), this is a human-centred, process-oriented approach, 'instigated by a need for connection' and nourished by the community within which it sits, unlike the fast fashion design approach that is instigated by a need for acquisition and speedy replacement (Mooney, 2011; Gwilt, 2014: 56). Empathy is often considered to be a necessary quality for developing products or systems that meet customer needs (Kouprie and Sleeswijk, 2009). The designer works with an understanding of, and empathy for, both the user, the self and the social community within which the design process will take place. At the heart of empathic co-design lies the observation and interrelationships of people, conducted in their environment.

2.4.3 Empathic co-design, clothing use as craft practice

An empathic co-design process acts as an aid to becoming in and relating to the world in which we live. Co-designed objects become agents of sustained engagement between users, community, makers and producers (Chapman, 2006). Jonathan Chapman's (2006) book *Emotionally Durable Design* places responsibility on the designer to envision the emotional potency and durability of the product. Longevity is a necessary element to sustain all the myriad of sub-relationships held within the conception, design and making of an object (Chapman, 2006). The current culture of consumption often severs the fabric production and processes, garment design and making from the wearer of the garment and the context within which it is used (social community). This can often mean that a short-term inconsequential relationship can be the outcome. The ongoing work of Fletcher places garment 'use practices' in an active role as 'craft practices' that are dependent on both the wearer and that worn. Through her work with *Local Wisdom*, Fletcher (2016) gathers stories and images thus allowing a space for the 'craft of use' practices around clothing to be shared and to evolve. This is particularly pertinent for this project. As Fiona Hackney et al. (2020) observed through communal crafting in the AHRC project 'Stitching a sensibility for sustainable clothing: Quiet activism, affect and community agency', the separation between fabric process and end-object reduces the space to consider the easily overlooked amount of time and labour required in the making of fabric and garments. The project was multifaceted: it included several teams working in an interdisciplinary way, which encouraged the

participants to reflect on the potentiality held within the entity of the garments. The project set out to illustrate the capacity for garments to change through the craft of use (Fletcher, 2016; Hackney et al., 2020). Because clothing in particular holds such potential for a long-term relationship with the user, it is a rich vessel for exploration, in particular, the area of the wardrobe for the lived experience of a person with dementia and their primary carer where clothing of significance can help to support a 'durable' relationship with the person living with dementia, their primary carer and their environment.

In this study, through the empathic co-design workshops, profoundly meaningful responses around such garments were revealed and captured through the various means of storytelling, drawing, co-presence, co authorship, co-tellership, re-imagining garments from their original state and purpose to new states of being with new purpose through shapeshifting. The MoM revealed that an empathic co-design approach to cherished garments rooted in the 'craft of use' and habit could transform those same inanimate garments, often banished to the back of the wardrobe or contained within the dusty perimeters of the photo album and liberate them to embody the animated phenomenological experiences of their past users. Many of the garments handled and discussed in these rich sessions evolved materially to meet the emotional legacy held within their fibres in their interrelationships between people and their environment.

An empathic co-design approach is about reconsidering the meaning of value by identifying with embedded inherent value. Ultimately, it is relational, contingent on interaction with others and thus always open to adaptation. This research

necessitated a design approach that enabled this agency and ensured that the system or artefact was never closed or complete. The research makes a strong case for maintaining creative agency and self-activity particularly around the wearing of garments for PLWD.

2.5 Summary

This chapter has collated, reviewed and examined key existing design interventions for dementia that have been developed to address some of the problems associated with maintaining a sense of oneself and personhood. This has in turn highlighted some of the potential interventions for designing for dementia. The chapter has also reviewed the main literature and explored some of the key concepts in this thesis. The chapter has presented Neisser's framework of sense of self as a methodological framework for explorations of personhood, identity and sense of self. These concepts involve exploration and contextualisation of additional key concepts such as memory, personhood in relation to clothing, dementia and how both body and mind require investigation when exploring personhood within dementia care. With this broad backdrop the chapter has also discussed Kitwood's indicators of 12 different types of positive interaction, Nolan's Senses Framework and Dewar's Seven Cs. It has opened a discussion around clothing and textiles as an expression of personhood. Discussion of sustainable fashion and textiles considers where garments of significance lie in the context of value and worth. This is an important consideration for the empathic co-design forward intervention that is applied

throughout this thesis. Embedded within the empathic co-design process and particularly relevant for this study, is the idea of crafting care, through use-practice of garments. This approach enables individual agency and contributes to the broader narrative of community empowerment through collaborative pursuits.

Chapter 3: Methodology

3.1 Introduction to the methodology

This chapter looks at the preparation and planning behind the methodology, including concept development, methods of data collection, co-design intervention and data analysis.

To clarify the validity of the research to a broad interdisciplinary audience, this thesis takes a mixed methods approach to the research process. The study positions art-based research and qualitative research as the main methodologies, while applying some of the tools of qualitative research and methods of art-based research in the discovery process – workshops, observation, co-constructed narrative , drawing, interaction with garments, etc.

The mixed methodology encompassed art-based research and qualitative research (empathic co-design and narrative inquiry) with supporting areas of best practice nursing, dementia studies, ecopsychosocial supports for personhood, and personal ecosystems with ecosystems of care.

Empathic co-design was used to shape how the participants engaged with the project (Koskinen, 2003; Kouprie and Visser, 2009; Manzini and Rizzo, 2011). Art-based research (McNiff, 1998; Prior, 2018) was used to inform practice as well as enabling a deeper understanding of the subject and practice (Prior, 2018). Through drawing and garments of significance, a new way of understanding lived experience emerged (McNiff, 1998; Prior, 2018). Narrative

inquiry brought these together in knowledge synthesis (Ochs and Capps, 2001; Georgakopoulou, 2007). Finally, four amalgamated supporting frameworks acted as an underpinning upon which the study was formed: best practice nursing, dementia studies, ecopsychosocial supports for personhood, ecosystems (personal and ecosystems of care).

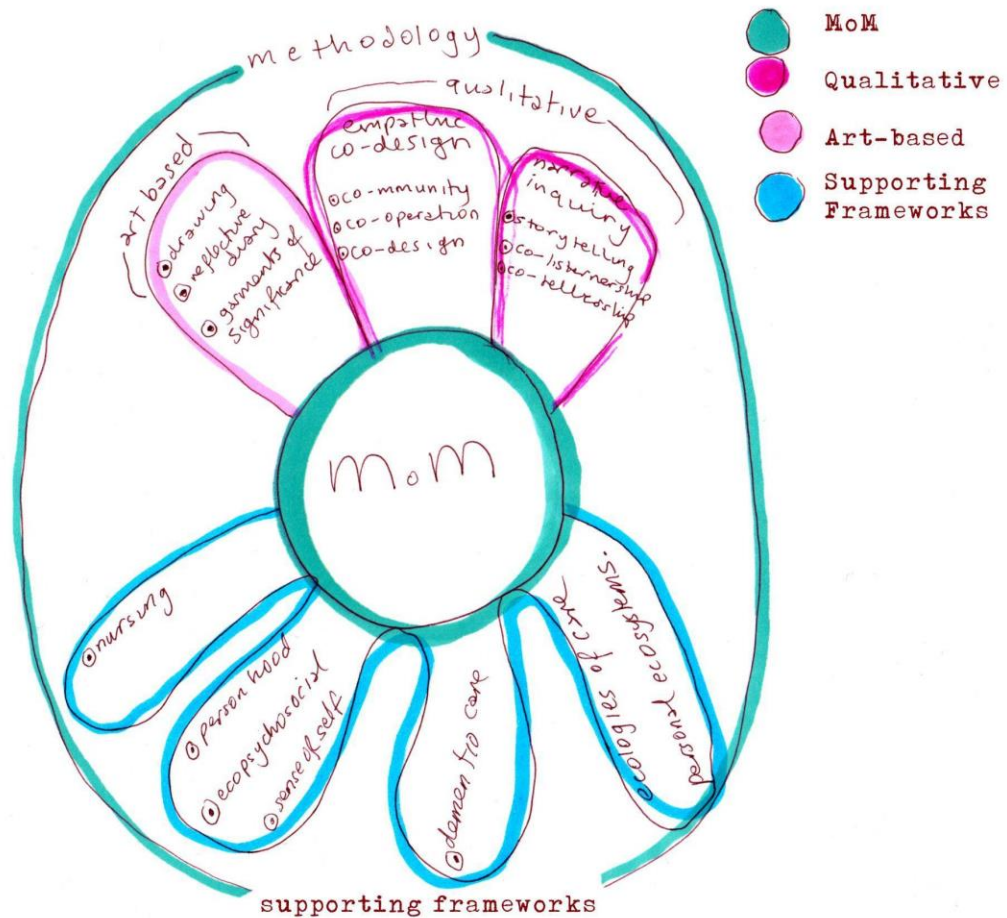


Figure 7: Knowledge domains represented as petals of a flower with the MoM at the centre

Figure 7 represents the domains of the work, each expressed as a petal of the flower with the MoM in the centre. The art-based research and qualitative methodologies (empathic co-design and narrative inquiry) 'petals' are on top as the theoretical underpinnings of the methodology, with four supporting frameworks and their theoretical underpinnings and 'petals' below.

The use of mixed methods addressed the inherent need for deep multifaceted engagement with participants. It also allowed for the unexpected, the real and the figurative to emerge, as it is often the art process itself that can tell us what has happened, through the creation of a space 'in which understanding is constructed and co-constructed with others' (Prior, 2018: 11). Creswell and Poth (2016) speak about methodology as the procedures of qualitative research and this they say, tends to be 'inductive, emerging and shaped by the researchers experience in collecting and analysing the data' (Creswell and Poth 2016: 21). In regards to this research, although the research questions, data collection plan and overall strategy was outlined prior to conducting the workshops, these all needed to be reconsidered and modified as the study unfolded. Shaun McNiff (2018), who coined the phrase 'art-based research', speaks of artistic outcomes as often emerging from the process of inquiry in an iterative and emergent manner. McNiff encourages researchers to be concise in developing their research questions and methods from the beginning of the work period. He posits that 'within a flexible and creative context, structure and spontaneity are reciprocal partners' (Prior 2018: 81). The initial design of the MoM was such that the structure was present in the 'senses of self' and best practice nursing

frameworks. The creative context and spontaneity arose through the actual MoM process. McNiff says that 'structure, supports and holds unplanned expressions distilled via the whole complex of the artist's history, thoughts, feelings, imagination, craft and aspirations in the present moment' (Prior 2018: 81)

Using art as research according to Prior, 'can bring together the known and the unknown, the planned and the unplanned the seen and the unseen' (Prior, 2018: 58). One example of how this manifested over the course of this study was in the drawings that were created during, and after the workshop sessions as well as prior to the period of the study in the months leading up to the sessions. The reflective sketchbook captured my unplanned artistic expressions that were often spontaneous responses without reflection. They were exploratory and yet in their manifestation became 'seen', 'planned' and 'known' as an integral part of the inquiry. Prior says that art can be the topic, process and outcome. A combination of these three, he shows us, is the 'three-fold primacy of Art and Research' (Prior, 2018: 57). In the introduction to *Using Art as Research in Learning and Teaching*, Prior (2018: 5), quoting Kossak, affirms that 'the phenomenological experience is represented though the creative act itself'. In a presentation on art-based research given to the doctoral college of University of Wolverhampton, Prior maintains that 'Art is the object of investigation and the method of inquiry' Prior (2021: 9). In this study, art is both a process and method of inquiry that invites a creative handling of the outcome of the investigation. The following example from the MoM is taken from one of the workshops with the VIOLET group. Violet created a label for her cape, which she conjured up from

her personal well of lived experience. The label was the outcome, co-created as process with her carer as shared lived experience. The process of this creative act was phenomenological: it was expressive and emotive, and it bound the cape to herself and bound herself to the cape in an embodied way .

Art then, became the expressive form where the emergent 'data' was both generated by and gathered through the creative act of Violet making her label for her garment(s) of significance. Because many of the participants' lived experience was still held in the embodied memory of the PLWD, and was captured through empathic co-design bearing witness to one another's lived experience. It married the creative process to their lives, which were then analysed or explored through narrative inquiry (the stories), gleaned and captured by the participants bearing witness to one another's stories (co-telling and co-listening emanating from interaction with the garments of significance). This is known during the study as the 'time frame of intimacy' within the MoM community.

The subject matter reflects the need for a co-created means of engagement that addresses the importance of dress and by extension, the personal wardrobe, for an ongoing continued sense of self/identity. Just as the wardrobe holds the garments that enable people to construct their identity daily, the MoM intervention taps into the wardrobe as a resource from which to explore sense of self. Textiles and dress can act as both the guardians of elements of embodied personhood and as a means to maintain continuity of self (Twigg and Buse, 2015), particularly as the site of the self undergoes some of the changes

associated with dementia. The garments within the wardrobe are embodied manifestations of the participants' lived experience and therefore become a conduit to explore past, present and ongoing sense of self and personhood.

There have been several developments in the area of dress and dementia research that specifically look at the significance of clothing in the relationship between people and their sense of self. Joanne Entwistle (2000) has examined how meaning can be created and negotiated through dress and clothing. The work of Buse and Twigg (2013) is particularly relevant. In their Economic and Social Research Council-funded study *Dementia and Dress*, the authors explore people's experiences of clothing for carers, care workers and people with dementia (Twigg and Buse, 2013). They highlight the importance of clothing as an element of the daily experience of selfhood for people with dementia and show that clothing can become an essential element of person-centred care. Building on this knowledge, the MoM research intervenes in the living system of embodied dress experience by maximising clothing as a signifier of both lived and living experience.

The MoM intervention was both developed and employed within this research project as a tool to gather and collate the lived experience of the participants' wardrobes and dress. This was done through the case study workshops with three PLWD and their carer/partners. In the workshops, participants were encouraged to construct the stories of their lived experience through narrative. Within the community of the MoM they then created their own resource set,

manifested through reciprocal narrative and triggered by interaction with the textile artefacts/clothing.

3.2 Art-based research and qualitative research methodologies

In this section, I will discuss art-based research as a methodology and in the following sections I will look at the qualitative methodologies of narrative inquiry and empathic co-design.

Art-based research is the use of artistic expression by the researcher, either alone or with others, as the primary mode of enquiry. (McNiff, 2018: xi)

In this statement, art-based researcher Ross Prior situates art-based research with reference to the foundational work of Shaun McNiff, by positing that art-based research is more than a field of knowledge, more than a method; instead, it is a methodology that sits as one of three broad research methodologies with quantitative and qualitative research. McNiff (2018: 80) speaks about artistic inquiry as corresponding to 'the variability of the creative process'. In other words, it is flexible and a lot like nature, in that it encourages 'infinite variation' (McNiff, 2018: 80) and encompasses the flow of fluid processes, as well as the results of cognitive and embodied, expressed knowledge in artistic form. McNiff contends that art-based research is neither inclusive nor exclusive of other research types that exist in social science. It has emerged as a 'practical

necessity to distinguish this approach from others'. Art, according to Prior (2018: 5), 'must stop trying to fit into methods and measures applied elsewhere'. McNiff (2018: 87) advocates 'letting art speak for itself as evidence' as it is the equivalent of data. Art is the evidence.

Prior (2018) builds a bridge to another form of research process and practice: The visual and figurative arts. Reaching beyond debates on the nature of research as necessarily replicable or repeatable and transferrable, in the sense that it must be researchable – that the journey, data and findings should always be discoverable for future scholars – Prior (2018) states that art praxis can itself be recognised as a distinct and informative practice upon which to base research.

In the introduction to volume 10 of the *Journal of Arts and Communities* (2018), Amy T. Holroyd and Emma Shercliff talk about the familiarity and flexibility of textile praxis as being key factors in the resurgence of creative collaborative practices specifically. This, they state, feeds into their potency as a means of inquiry within diverse research contexts. The ubiquity of textile making across cultures makes it a convenient platform for addressing self-development and social inclusion. The authors draw attention to some of the elements that can emerge during participatory creative textile making, such as gentle exploration of difficult to raise topics, an opportunity for communication and even, at times, contemplation. There is also an acknowledgement that other diverse data forms that are not solely based on words can also be generated – such as visual, tactile, oral, aural, emotional, experiential and temporal. In their study, capturing

data during the collaborative textile workshops meant that connections between doing, thinking and talking were simultaneously gathered. This enabled researchers to access knowledge in the moment.

In this study, it emerged that the ubiquitous nature of garments of significance made them an ideal tool for addressing sense of self. Over the course of the research period, it was found that participants were bearing witness to one another's stories and presence in a time frame of intimacy through interaction with garments of significance, and this was a conduit to connection, co-presence and co-tellership. Certain elements of this thesis are expressed in part through drawings, which represent the flow, feel and expression from the general engagement of the research participants and areas of study.

3.2.1 Empathic co-design to investigate personhood

Alongside art-based research, empathic co-design is the overarching approach to the design process. This was chosen primarily to encourage the participants to be active co-creators of their own MoM system that further feeds into the process. This way of working has grown from a need to understand what it is the participants are experiencing and how they are sensing their world. Koskinen (2003) speaks of the importance of experiencing the process in an empathic design practice to enable the designer to gain an understanding of how the user sees, experiences and feels objects, their environment or even a service, in the lived situation in which he or she is situated. The co-design element involves the participants themselves in the creation of the MoM. This empathic co-design

approach thus guides the development of the MoM framework and informs its use during the research process. This is extended by the researcher with participant observation that enables field researchers to gain a subjective or 'insider' understanding of social action from the actors' perspective.

Each session became a new opportunity for learning, reflection, discussion and generation of co-design practice in an iterative process between the person with dementia and their partner/carer, participants and researcher and practice and theory (Fals-Borda and Rahman, 1999). Each participant group responded differently and although the MoM was developed specifically to excavate stories of self through interaction with clothing and textiles, each of the co-design workshop sessions responded and adapted accordingly. Narrative analysis has been used as to assess the qualitative data (Ochs and Capps, 2001; Georgakopoulou, 2007).

3.2.2 Using narrative and narrative analysis

In this context, a narrative discourse approach has enabled insights from the data to emerge. The data is gathered through semi-structured interviews as part of the co-design sessions. The data exists in narrative and story form and is narrated directly from the participant's lived experience. According to Lindseth and Norberg (2004), both the teller and the listener take part in narrated meaning. Then they are both free to consider what the most important themes are and what the essential characteristics of the expressed meaning are. Over the course of the study, these moments of narrated meaning and 'tellership',

shared by teller and listener, were the basis of many of the workshop sessions. Meaning was expressed through storytelling, usually triggered by the garments, and was noted and built upon by the participants of the workshops. The essential characteristics of those lived experiences were that they were 'expressions of meaning' within which the empathic co-design process could take place. Ochs and Capps (2001) show that narrative is co-constructed, with the interweaving of text often creating a new co-authored work or way to work. Narrative is not consistent, but consistently serves the need to create selves and communities (Ochs and Capps, 2001). In *Life as Narrative*, Jerome Bruner (2004) looks at the nature of thought and, specifically, at how stories and narrative sit in the area of thought that is not necessarily logical. He goes on to reference Nelson Goodman who makes the argument that physics, painting and history are ways of world-making and so autobiography could be viewed as a set of procedures for 'life making' (Goodman, cited in Bruner, 2004: 2). 'Lived time', according to Bruner (2004), is often an event or multiple events that are chosen with a view to their place in an implicit narrative. The framework has been developed to facilitate the understanding and analysis of the expressed meaning. I have, as the researcher, a double role, where I am an active participant in the storytelling and also a passive observer in the analysis. Ricoeur (1976: 71–88) highlights that this type of research is an argumentative discipline that lies somewhere between art and science. We use our artistic talents to formulate the naïve understanding, we use our scientific talents to perform the structural analysis and we use our critical talents to arrive at a

comprehensive understanding. The MoM has been developed to facilitate the understanding and analysis of the expressed meaning.

In her paper 'The other side of the story: Towards a narrative analysis of narratives in interaction', Georgakopoulou (2006) presents a case for focusing on the ordinary narratives of conversation and moving away from linear past personal experiences that are often elicited in research interviews. One of the main points that she makes concerns the context within which these research interviews take place. She asks us to look at the types of social organisation and local context that might encourage or prohibit 'non-canonical' stories or, in the case of this study, co-constructs that do not always possess a linear structure. This was something that I was aware of over the course of the research study. Although the lived experience of the participants was the focus of the workshop sessions, because they were open and garment-focused, they were not linear. Also, visually representing moments of meaning in a drawing or photograph, making them into 2D objects and co-creating a visual representation of the lived experience enabled this to happen in a non-linear format. I discuss this in more detail in Chapter 4 when I present the drawing as enabling depictions of time and space outside of linear representation.

The stories themselves were part of the assemblage of an 'ecology of interactions' and, as such, contributed to the overall context of the narrative, determined also to a large extent by the context within which the narrative took place. By focusing on the garments of significance within the context of their use, the conversations were not directly focused on the participants. This

allowed a different kind of exchange to take place where the participants spoke about the garments' importance, which indirectly also gave autobiographical details about the participant. According to Ryan and Bernard (2003), this is an '*a-priori*' approach. The conversations were held with a focus on exploration of these ideas around personhood and sense of self through the garments. After the workshop sessions had been completed, I drew on their recommended methods of seeking repetition, similarities and differences (Ryan and Bernard, 2003) to enable the prioritisation and grouping of themes that were most relevant to the research as they emanated from the data. Thus, certain thematic ideas that were 'inducted' from the data became the most significant emergent themes and observations for this particular research study (Opler, 1945; Ryan and Bernard, 2003).

When one is excavating for lived experience, Walter Benjamin (2005: 576) stresses that it is important to 'return again and again to the same matter; to scatter it as one scatters earth, to turn it over as one turns over soil'.

Like soil, lived experience holds those memories. The MoM looks at that analogy and models it by using tactile 'memory markers' in the form of garments of significance and photographs, to act as sensory and embodied markers that show where to dig into the soil of lived experience and therein, slowly discover the individual and collective lived experience of the participants (Bullock et al., 2005).

3.3 Mapping the ‘MoM: Caring Through Clothing’

This section discusses the development of the design framework ‘MoM: Caring Through Clothing’ from the concept of personhood, which underpinned semi-structured interviews and co-design workshops.

The ‘senses of self’ framework (Neisser, 1988) provided a method that tied the research to a conceptual framework of self (as defined by Neisser). For the purpose of this research, Neisser’s ‘senses of self’ framework has been expanded to encompass certain elements of best practice nursing, as defined by Dewar (2011), with compassionate relationship-centred care with the Senses Framework outlined by Nolan (2006; 2008) and Kitwood’s (1995) 12 positive interactions derived from his ground-breaking work on the importance of personhood for dementia care.

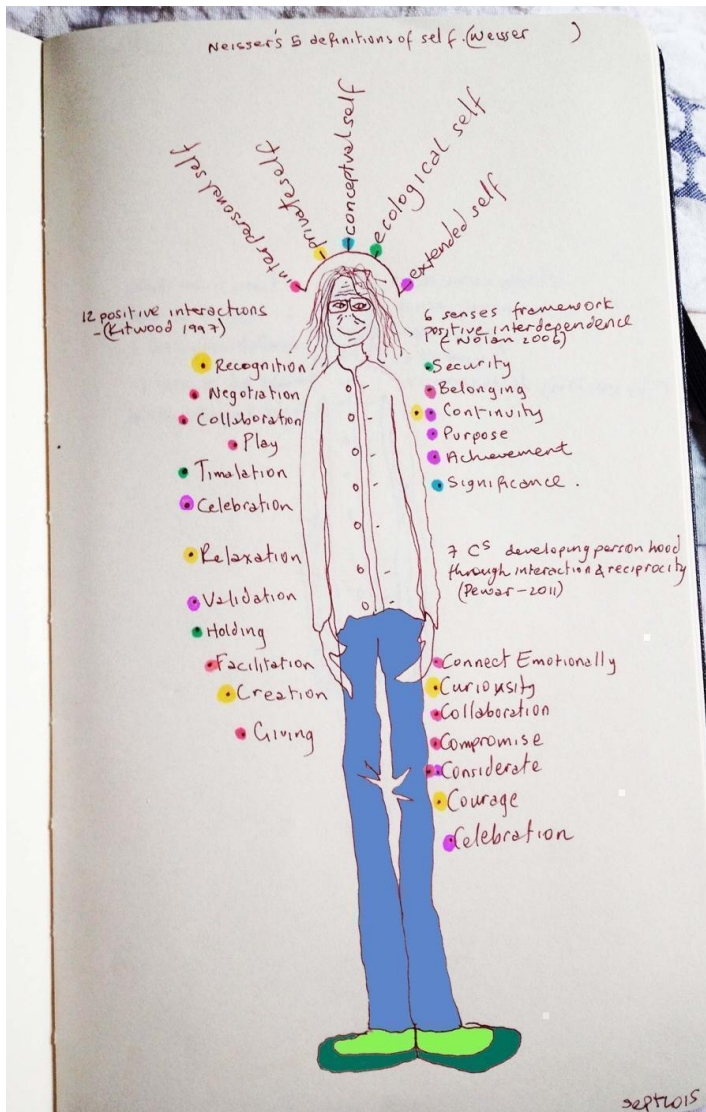


Figure 8: An early drawing from the reflective notebook

Figure 8 is an early drawing from the reflective notebook of Ulrich Neisser's five definitions of self with Kitwood's 12 positive interactions, Nolan's Senses Framework and Belinda Dewar's Seven Cs for reinforcing personhood through interaction and reciprocity. This drawing led to Figure 9 and was a key point of reflection that led to the design of the workshops for the MoM.

The 'ecological self' represents the self with respect to the physical environment and is determined directly through the senses. This is a situated self. When 'self' is perceived in relation to its surroundings it will impact on feelings and emotions, particularly around the senses, security and holding (Nolan, 2008; Dewar, 2011). The ecological self is the SENSORY self; it is the self as derived from and perceived in the physical environment (Neisser, 1988) such as 'holding', 'stimulation' and 'continuity'. It represents an awareness of the self as perceived with respect to and in the context of the physical environment. Neisser's definition of the ecological self aligns with ideas from Kontos on embodied personhood. In the past, body and mind, body and self, and the biological and social have been accepted as distinct entities, particularly in the area of dementia care (Kontos, 2004, 2005). The ecological sense of self challenges the idea that cognition or language are necessary elements for a sense of personhood or identity to exist.

The 'interpersonal self' represents the self as engaged in social interaction and can also be perceived as interaction with another. The interpersonal holds a particularly prominent place in the construction of self as it is often through interaction with another that we make meaning in such elements as belonging (Nolan, 2008), connecting emotionally, collaboration, compromise, consideration (Dewar, 2011), negotiation, play, giving and facilitation (Kitwood, 1998).

The 'extended self' is the self as it is experienced across time, based on memories of our past self and anticipation of our future self. This self is more akin to the running sense of self across time and ties in with elements such as

continuity, purpose, achievement (Nolan et al., 2006, 2008), celebration and validation (Kitwood, 1998).

The 'private self' refers to our conscious experiences such as thoughts, feelings, intentions, pain – and is solely perceived by the person experiencing it. It encompasses recognition, relaxation, creation (Kitwood, 1998), continuity and security (Nolan et al., 2006, 2008), and curiosity and courage – both of which can manifest as private or public elements.

The 'conceptual self' represents a tying together of the other four components of self and reflects the way in which each person has a particular concept of him/herself. How they relate to their environment, relate to others and how they feel that they are perceived. For example, the level of significance that they have – or feel that they have (Nolan et al., 2006).

According to Leonard and Rayport (1997) in 'Spark innovation through empathic design', empathic design requires unusual collaborative skills such as being open-minded, curious and observational. In order to develop an intervention around clothing, the study focused on empathic co-design. As a designer and artist, I strove to maintain an open-minded stance and was curious about the potential positive benefits of using clothing as a means to explore personhood. This led to a period of observation in which people living with dementia were observed in their surroundings in a silent and unobtrusive capacity to explore and discover what their experience was like and if and how an intervention might be developed. To enable the depth of reflection that this type of enquiry

required, this period of time was recorded in reflections and drawing as a means to capture unknown, personal and subconscious elements. I will discuss this in detail in Chapter 4.

The first stage of the design process was a period of discovery (Kouprie and Visser, 2009). As mentioned in the introduction, there was a long period of observation that led to questions around sense of self particularly pertaining to people with dementia. This period of discovery enabled me to look at the environment of the people with whom I was working. This led to a period of Immersion (Kouprie and Visser, 2009). Here, I as the designer remained open-minded and drew on the participants' experience without judging or influencing the situation. At this stage, the formal active interaction with participants took place. This was the data collection phase consisting of two sessions that ranged from an exploration of individual participants' habits around clothing through a series of semi-structured interviews loosely based around explorations of personhood and sense of self. These sessions were based around two simple elements: the first was the use of actual items from the participants' home and wardrobe; the second, utilised in the case study sessions, was the introduction to participants of garments that narrated stories from my own life experience and collection and a 'suitcase of stuff' (compiled over 18 months). This part of the empathic process was where a connection (Kouprie and Visser, 2009) with the participants began to take place. Here, possibilities around making meaning and emotional resonance through the narrated sharing of lived experience took place. This consisted of one to two sessions where design responses were

developed as interventions and possible prototypes. These design implementation sessions were followed by the semi-structured interviews with a loose questionnaire for exploring personhood. Finally, a short evaluation with participants took place. This period was concurrent with a period of detachment, as presented by Kouprie and Visser (2009) in which the researcher leaves the users' world and steps back into their role of designer. This is where synthesis and re-integration of the findings back into the process can take place.

A detailed discussion of the design tools is provided in section 3.5.5.

3.4 Methods of data collection: interviews and co-design workshops

3.4.1 Interview and co-design sessions – original plan

The following provides an overview of the case study workshops. Originally, a total of six sessions were planned with each participant couple (PWLD and their carer). The rationale for this number of sessions was based on having enough sessions to observe the participants in their environment, to build trust and to place a limit on the introductory phase of the workshop model.

These sessions are presented in the third person as a guide for future researchers.

Session 1. The first session is an introductory session: consent forms are signed; personal introductions take place and the researcher gives an overview

and explanation of what will happen throughout the course of the project. The 'About Me' questionnaire is delivered in an informal way as a means to relax the participants and exchange some information about each other (see Appendix for 'About Me' questionnaire). This is followed by a discussion around clothing in relation to self – specifically, clothing of significance from the past or present and photographs that have captured clothing of importance that may no longer be in existence. The preliminary questions act as an audit to reveal any clothing of significance in the participants' memory/wardrobe (see Appendix 3b). The researcher requests that the participants bring in any such items and photographs for Session 2 (one session of 60 minutes).

Session 2. The researcher informally asks in-depth questions of the participants around a specific item (or items) of clothing; either the item of clothing is brought to the workshop by the participants or a photograph(s) of the item(s) is presented. The questions were developed from two areas of importance: Neisser's outline of the five senses of self and best practice in person-centred care in nursing. The questions fall into sections that explore the 'sense of self' and personhood through clothing. These are the interpersonal self, conceptual self, ecological self, extended self and private self (see Appendix 3c) (one session of 45 minutes).

Session 3. This session sees the person with dementia and the carer/partner start to construct their own map of themselves through clothing. The MoM: Caring Through Clothing draws from the answers in the questionnaire and is enabled by the researcher by using templates, a sensory swatch library, and

drawing. Participants will continue (through physical engagement) to capture the MoM: Caring Through Clothing on to an axis that illustrates two concepts: 1) the running sense of self through time; and 2) personhood represented as points along the axis of time (one session of 45 minutes).

Session 4. Participants discuss the possibility of an advanced intervention for the future. How might the MoM: Caring Through Clothing be utilised in the future to explore the running sense of self through time? What elements of importance in the past and present could be revisited in the future? In this session we identify elements that need to be improved and changed. We discuss the last sessions and identify how the sessions might be improved and how the MoM could be further developed. Consent forms are re-introduced and signed again (one session of 45 minutes).

At this stage, there is a break for eight weeks where the design researcher withdraws from participation with the participants and evaluates the material from the case study workshops. All of the material that has been accumulated informs the re-designing of the MoM based on the combined experience of the participants.

Session 5. The researcher has a last meeting with the participants and asks them questions about the MOM process: how, if at all, did the relationship between them change? Did the participants feel that their sense of self had been explored? Has anything else of note come to light?

Session 6: This is a final debriefing session for all of the participants in which the research is presented. Consent forms are re-introduced and signed again. From the feedback and information that the log-journal brings up, refining and final development of the MoM will take place.

Figure 9 is an illustration that displays the theoretical underpinning for design of the workshop sessions. It depicts Ulrich Neisser's five definitions of self. Mapped on to this are Kitwood's (1997) 12 positive interactions, Nolan's (2006) Senses Framework and Dewar's (2011) Seven Cs for reinforcing personhood through interaction and reciprocity. Each of the 'senses of self' is colour coded; aligned with this, the corresponding elements from the three frameworks are also colour coded.

Neisser's 5 Definitions of Self

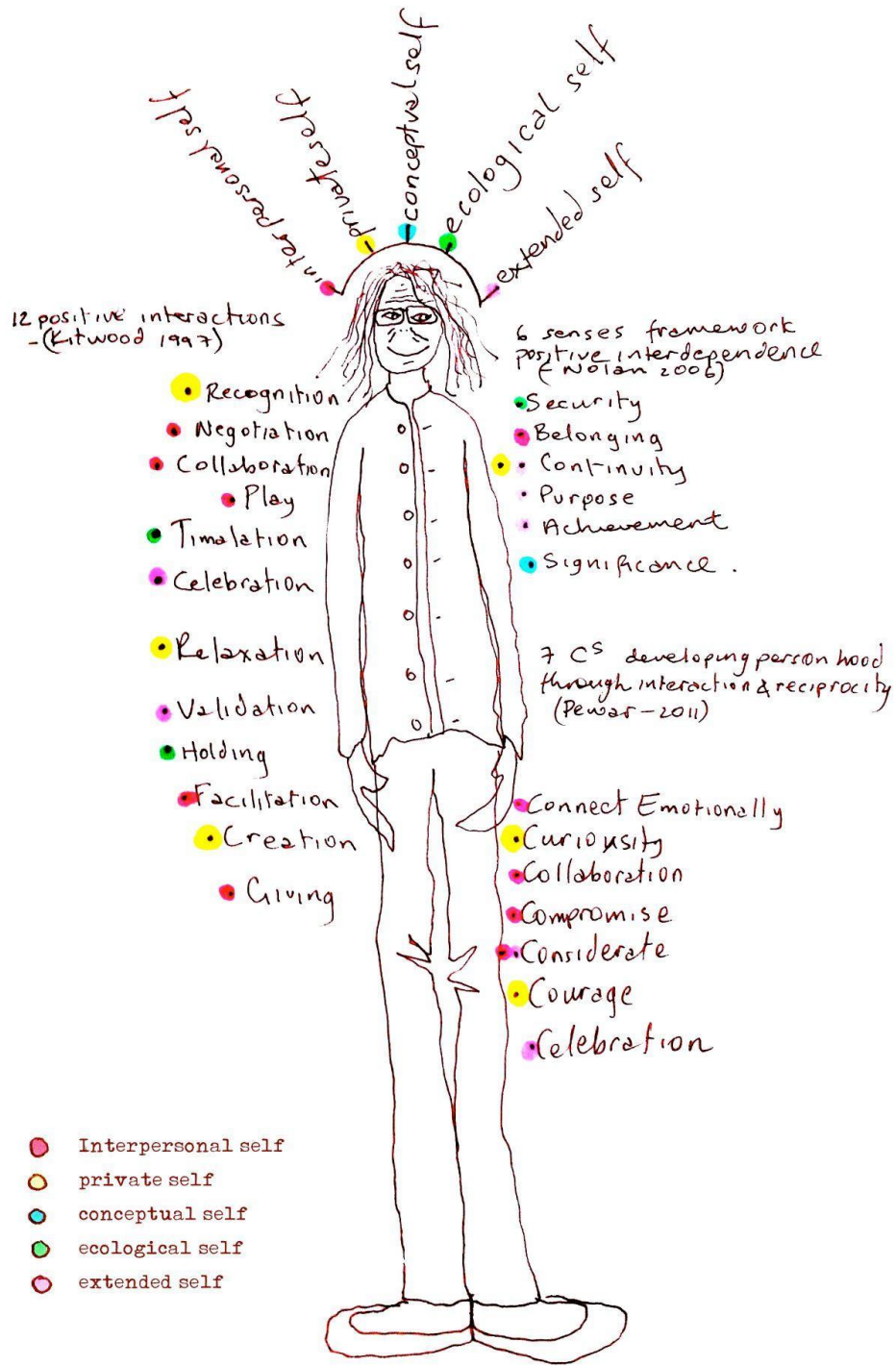


Figure 9: A drawing representing Ulrich Neisser's five definitions of self with Kitwood's 12 positive Interactions, Nolan's Senses Framework and Dewar's Seven Cs for reinforcing personhood through interaction and reciprocity

3.5 Changes to the research plan and reasons

This section looks at the journey from the planned methodology to the actual methods developed and used. It explains the different meetings, observation sessions and other sessions that took place. It looks at some of the reasons behind the development of the methods planned, including some of the sessions that led to the final MoM: Caring Through Clothing sessions.

During the development of and leading up to the co-design workshops of the main data collection, the researcher attended a number of informal observation sessions. From the end of June 2016, the researcher attended Alzheimer's Cafés in the UK and Ireland to familiarise herself with the context and systems for facilitating the study. Each of the different institutions required that the researcher acquire Garda clearance or undergo a DBS (background) check to work with the participants with dementia and their carer/partners. This process took between eight and ten weeks. In the meantime, the researcher was having regular meetings with the management staff, which led to observation sessions. The observations from these sessions were recorded in the form of notes and drawings taken afterwards. It was from continued meetings with management, initial notes and the observations that the pilot group sessions were developed in line with the 'Caring Through Clothing' workshop sessions. The pilot group sessions were not video- or audio-recorded; instead, the researcher made notes of observations and thoughts from the sessions immediately after them to capture the data. It was only after the pilot group sessions had been held that

the opportunity to work with couples from the sessions arose. Although connection and trust were being forged with people during and after the preliminary group sessions, only two or three couples showed an interest in partaking in the individual sessions for couples. In short, it took a long time to finalise the participants who took part in this study. A number of factors inhibited recruitment. For example, on a number of occasions, potential participants had agreed to partake but changed their minds about being part of the research study due to a number of factors outlined below:

1. The recruitment of participants required personal connection and a level of trust built up over time.
2. The MoM: Caring Through Clothing workshop sessions had to take place in a location and at a time that were convenient for the participant couples.
3. Participant couples expressed fear about trying something new.
4. The MoM: Caring Through Clothing workshop sessions were often cancelled at short notice due to illness or other unforeseen circumstances.

In the following text, I discuss these four points in more detail.

Recruitment of participants required personal connection and familiarity.

Although information was distributed to potential participants by the manager of the care home/ Alzheimer's Café/ day care centres, potential participants did not display any signs of interest in taking part in the research project until a face to

face session was held to explain the project and answer any questions. The information sessions generated a lot of interest and it was apparent that a preliminary group session could be a way to engage potential participants with the Caring Through Clothing method. This would also facilitate the growth of familiarity and would open channels for communication both within a large group setting and smaller sub-groups. Participants who were interested in joining the research project could then approach the manager to express their interest.

The Caring Through Clothing workshop sessions had to take place in a location and at a time that was convenient for the participant couples.

The participants were not able to commit to a set time schedule. Illness, changes in circumstances and reliance on the presence of the carer/partner at all times meant that scheduled meetings were often cancelled with little notice and were not rescheduled for quite some time afterwards. The amount of strain and effort required from the carers to bring their partner to the sessions was too much to warrant a special trip outside of their normal routine. *Therefore, the MoM: Caring Through Clothing workshop sessions needed to slot into the couples' existing schedule.*

The researcher also found that it was difficult to reschedule appointments particularly because the workshop sessions were often taking place after an Alzheimer's Café or day care activity that might only occur once every four weeks. The researcher needed to be flexible enough to accommodate this uncertainty in scheduling, while also extending the projected timeline.

Participant couples expressed fear about trying something new.

A lot of fear was expressed about trying something new. Many of the couples were experiencing ongoing traumatic shifts in everyday realities due to the onset of dementia. Everyday routines became less fluent for the people living with dementia, which impacted the carer/partners as more time and care was required to complete these tasks. For example, E's daughter explained to the researcher that as dementia progressed, it was taking her longer to help getting her mother dressed and ready in the morning. She needed to allow more time to help her mother into the car. J's wife M told the researcher that it was taking M longer to get ready to go out because she would mislay certain items and could not recall where they were.

This meant that although the couples were positive and seemed interested in the research project, some of them (the PLWD) were also fearful of forgetting the details of when to meet and what to bring to the sessions. Others (the partner/carer) prioritised the needs of the person with dementia when illness or unforeseen circumstances occurred.

Caring Through Clothing workshop sessions were often cancelled at short notice due to illness or other unforeseen circumstances.

Many of the potential participants contracted illnesses and were out of circulation for at least two to three weeks. Some of them went into respite care and many had appointments with doctors or nurses that clashed with scheduled times for the workshops. Two of the couples that had been identified by the

management in the Dunally Day Care Centre never made it to the first session. One passed away due to an unrelated illness and the other became very ill suddenly and needed permanent residential care. At the Alzheimer's Café, Molyneaux, after the two group sessions, two couples approached the facilitator/researcher separately to discuss joining the Caring Through Clothing sessions. Both couples told the facilitator/researcher (separately) that they would prefer to be engaging with this conversation with another couple rather than being alone and engaging with each other. Both the PLWD and the primary carer expressed concern about holding a session based on both of their experiences. They felt that another couple's perspective might make the experience more interesting for them. As it happened, one of the couples fell ill and was not able to continue with the sessions so the workshop session continued as first intended. The family taking part was very enthusiastic in spite of losing their co-participants.

These incidents delayed the interview and workshop process and presented as challenges that then needed to be built into the timeline of the project. The challenges outlined highlighted that the most important thing to facilitate was enabling both parties (PLWD and their partner/carers) to both 'be there' and 'want to be there'.

Outside the hours of a regular appointment or need, logistics prevented the possibility of people coming to attend or commit. Because of these issues and the need to re-recruit and the time involved in this, the original session plan had to be amended, and it became clear that the number of sessions needed to be

reduced to suit the participants. Sampling is described and explained in the following section.

3.5.1 Sampling

For the purpose of this research, the study worked with three people with early to mid-stage dementia and their partner/carers. As this is a qualitative piece of research, the sample size is small and each participant was chosen based on certain criteria. Some of the research studies that I have used as a reference during the research study had few participants taking part. One of these was 'The construction and deconstruction of self in Alzheimer's Disease' by Stephen Sabat and Rom Harre (1992), which involved three participants. Another was 'Crafts as memory triggers in reminiscence: a case study of older women with dementia', which used three female participants (Pöllänen and Hirsimäki, 2014)

The study by Ward et al. (2014), 'Once I had money in my pocket', involved 12 PLWD. This was a large study with many more participants, which was beyond the scope of the MoM: Caring Through Clothing study.

The participants with dementia who eventually took part in the Caring Through Clothing research project were three women. The carers and family members were of mixed gender. All participants with dementia were between the ages of 70 and 84. The carer/partners ranged in age from 53 to 70. The participants with dementia had all retired and their work had ranged from full-time singer to nurse to mother working in the home. For the purposes of this study, the first participant group will be referred to as (ROSE) – consisting of Rose, who was

living with mid-stage dementia, her husband and their daughter, who gave up her job to become their full-time carer. The second group will be referred to as (IRIS) and it consisted of Iris, who was living with mid-stage dementia, and her two daughters. The third group will be referred to as (VIOLET) and it consisted of Violet, who was living with early to mid-stage dementia, and her husband, who had become her full-time carer.

Participants were required to speak English fluently. They were recruited from Alzheimer's Cafés and day care centres in the UK and Ireland and a residential care home in Ireland. The researcher worked closely with the managers and staff of these facilities to ensure that the criteria were met for each potential participant before they approached them about the study. The PLWD were in a mid-stage of the disease with capacity to make decisions around consent and ongoing consent; also important was the fact that each of the participants with dementia had a primary carer who was also willing to partake as a participant in the study.

The first session was an open session at an Alzheimer's Café clinic specialising in early-stage dementia care. Information about the study was given to both the PLWD and their primary carer beforehand. The Irish sample represents a typical profile of people in the early to mid-stages of dementia, either living independently or with a carer/partner and attending Alzheimer's Cafés in the area or living in residential care. The UK sample represents a typical profile of people still residing in their home with a carer/partner and making regular visits to Alzheimer's Cafés in the area.

3.5.2 Original and new list of interviews and co-design sessions

The initial plan for the research sessions was as follows:

- One meeting with management session (to identify potential participants)
- One observation session (to immerse myself in the world of the participants)
- One introductory group session (where I explain the project to the potential participants)
- Phase 1: Four informal workshop sessions (where I gather data pertaining to self and personhood)
- Phase 2: Two workshop sessions (where I co-design the MoM with each participant).

The actual sessions that were developed as part of the methodology (for the reasons explained above) were as follows:

- One to four meetings with management
- One observation session
- One introductory group session
- Pilot group session(s).

3.5.3 Explanation of the sequence of events that informed the journey

The following sections are written in **the** first person. During this research process it became apparent that I had a responsibility both to the participants and to the project. I needed to understand the deeper nuances of their daily interactions, to look behind the co-relationship between the carer and cared for and to get a complete picture of who these people were within the context of their lives. To do this, it became necessary to spend more time with the participants than had initially been allocated for the study.

Kathy Charmaz (2004, 2006) speaks about the importance of spending time with participants during the research process. She notes that taking time to visit and interview participants provides a deeper and more complete understanding of the person's life than single or solely informational interviews can provide (Charmaz, 2004, 2006). Certainly, in each of the three case studies, there were a number of unscheduled meetings that took place because the researcher relationship was being reciprocated, with the participants providing ample cause for reconsideration of my own commitment. It was necessary to take extra time. This meant that my continued presence was necessary. Many potential participants were slow to take part in the project, therefore, we created a set of 'preliminary-pilot' sessions to encourage an environment of trust where co-creation of narrative could take place. These 'preliminary-pilot' sessions are outlined in Appendix 2 along with the actual Caring Through Clothing sessions.

Meeting(s) with management:

After initial contact was made, a one-page information sheet and guide for sheet was sent to the management. The second stage of the process was meeting the management to discuss the details of the research project and to identify potential participants whom the management might recommend as likely to fulfil the criteria for the research project. However, it was found in practice that the meetings were ongoing because working with this vulnerable group required close communication with the manager of the residential care home, the day care centres and the Alzheimer's Cafés and this needed to be built up over time. Ongoing meetings needed to take place particularly as a number of the participants became ill and two were not able to continue for various reasons. The logistics of potential participants' involvement with their carers required flexibility in choosing appropriate times and locations.

Observation session(s):

These proposed sessions were where the first introduction to the group took place. Each person introduced themselves and the regular daily activities of the group continued, with the facilitator taking an observational role. It was found, in practice, that although only one official observation session was necessary, many of the meetings with management became short observation sessions themselves as the researcher usually trailed the different managers on their daily rounds.

Pilot – Introductory Group Session 1:

The Introductory Group Session 1 was developed as a way of introducing the ideas behind the Caring Through Clothing research project to the group. I presented the project and introduced a story based on a garment from the collection of garments of significance. I also brought a sensory swatch library to the session and invited the group to pass the different fabrics with sensory elements around. Finally, the participants were asked to see if they had any items of significance in their own wardrobes and to bring an item of clothing with them for the next session (Group Session 2). This session took place as planned but it was noted that the participants did not come forward to take part in the study. The managers in both the Carrageen Centre and the UK Alzheimer's Café suggested that a group session that demonstrated the MoM to the group might be a good way to garner interest. This led to the creation of a pilot group session.

Pilot – Group Session 2:

Group Session 2 was developed as a follow-on session from the Introductory Group Session 1 and acted as a platform from which to explore the lived experience and sense of self of the different people in the group. This was done by using the garments that the participants brought to the session themselves as a starting point for narrative and storytelling. These sessions enabled the potential participants to narrate stories around their lived experience triggered by an article of clothing or a photograph of the same clothing.

Caring Through Clothing Workshop Sessions 1, 2, 3 and 4:

The Caring Through Clothing Workshop Sessions that were developed in the first part of the methodological journey began after the preliminary-project sessions had taken place.

3.5.4 Actual content and method of recording the preliminary group sessions

The sessions were not video- or audio-recorded. Notes were taken immediately after the sessions to capture the data. Quotes, moments of personhood and sense of self, stories and moments of importance within the group sessions were captured. This reflective text was the basis for making changes to the proposed sessions. The notes were reviewed by the manager of the day care centre/ Alzheimer's Café/ residential care home to ensure that the material and interactions had been documented accurately. The participants gave their permission for the notes of the session to be used as data. Confidentiality was guaranteed. All participants shared their first name with the group and these have been changed to preserve anonymity. Within the study the three participants are named Rose, Iris and Violet. Their workshop groups have the same names. The sessions were conducted using the preliminary MoM questions in an open-ended manner, which enabled participants to listen to and talk about their lived experience openly.

The 'in-depth' questions around clothing related to self were introduced in a loosely structured and iterative session that used some of the elements that the researcher had created including a suitcase of vintage garments, a sensory

swatch library, personal garments from the researcher's lived experience, hats, ties, scarves and gloves. These were then used as a starting point for storytelling relating to personhood, reminiscence about self, and interpersonal exchange.

3.5.5 List of materials

The materials that were gathered for the design process were chosen to provoke a narrative or response. Below is a list of the various materials that are discussed in more detail in Chapter 4. The MoM was a development from my reflective drawings, which were made during the whole process as a subconscious way to process what I was experiencing. Drawings and photographs in the case study sections were illustrative and used to illustrate the case study groups. Lucy Lyons (2012) talks of drawing objects as initiating the act of looking as well as being dependent on the act of looking. It, she says, 'engenders dignity as it involves investing time in the presence' of the drawn entity (Lyons, 2012; 1). The drawing was used in different ways, as a 'way in' to understanding the participants and as a means to 'reveal the unexpected qualities not previously noticed' (Lyons, 2012: 1).

- **Drawings:** Drawing was used as reflective practice in both the theoretical and practice-based research activities.
- **Curating garments of significance:** A garment of significance is a garment that has meaning for somebody. There is usually a story attached to such a garment. Hence, a garment with no connection to

someone can become significant through its connection and the ensuing story to another as a conduit to storytelling: I collected garments of significance from my own life story to use as a means of exploring personhood, narration of stories and co-construction of lived experience in the workshop sessions.

- **Wardrobe and photo album audit:** I conducted a narrated audit of the items of importance by asking questions and looking at photographs, also by handling garments of significance. I also asked questions around family occasions and conducted a virtual excavation of potential items of importance.
- **Swatch and sensory library as physical triggers:** A curated collection of sensory items, which included swatches of fabric with various colour schemes, designs, textures (buttons, small trinkets, netting, etc.).
- **Templates for co-creation of the MoM:** A set of silhouettes, which participants used to draw their own representation of self.
- **Photography for co-creation of the MoM:** The use of photography as a way of capturing images and data to reuse later as a design tool.

3.6 Data analysis

The data were contained within the narrated discourses that took place with the participants during the case study workshop sessions. The transcribed interviews from the workshop sessions comprise an enormous source of data.

Included in Appendix 4 are examples of some of the transcriptions. Please note that the transcriptions are available on request.

The research on narrative by Ochs and Capps (2001) proposes that narrative displays a set of dimensions that are all relative to the narrative. These dimensions are realised in narrative performances and in life events that are structured through narrative form (Ochs and Capps, 2001). These narrative dimensions are:

- (i) Tellership – one or multiple tellers.
- (ii) Tellability – whether it is a highly tellable account, moderately tellable or has a low tellability level.
- (iii) Embeddedness – whether the story is embedded or detached from surrounding activity and discourse.
- (iv) Linearity, temporal and causal organisation.
- (v) Moral stance – certain or uncertain moral stance, constant or fluid.

The data has been transcribed using narrative analysis (Ochs and Capps 2001; Georgakopoulou, 2008) as a guide. The aim of this analysis was to both extract new themes and extract themes relating to the MoM theoretical framework. Interviews were first analysed individually using margin notes, reflection and drawing. These were then grouped into themes. Each of the themes from the different interviews was then grouped together to create clusters of themes,

which were then compared with and, when applicable, mapped on to Neisser's five senses of self.

The themes around self in relation to garments and textiles that emerged from the data were manifested through personal storytelling, co-construction of narrative, physical engagement with the garments and attention to the drawing process. Sabat and Harré (1992) claim that selfhood is 'publicly manifested in various discursive practices'. They go on to name some of these practices as telling autobiographical stories, taking on the responsibility for one's actions, expressing doubt, declaring an interest in care, decrying the lack of fairness in a situation, and so on. The themes that emerged from the research were then evaluated using the MoM framework (see Figure 7).

3.7 Ethics, DBS and Garda clearance

Ethical approval was processed by the Ethics Board at the University of Wolverhampton (Appendices 9 and 11). The ethical approach was developed in line with the ethical guidelines of Alzheimer Europe, which is a primary research institution that gives past and current ethical debates about issues linked to various aspects of dementia research.

Relevant participants were invited to participate in the research as co-creators. They partook in the project based on the following criteria:

Participants were all living with mid-stage stage dementia. This included both vascular dementia (from stroke), Lewy body disease, and Alzheimer's dementia.

All participants started with mild-stage dementia with an MMSE score (Mini Mental State Examination) of 20 or above (bearing in mind that mild-stage Alzheimer's disease is scored between 20–26.)

Participants needed to have carers and or immediate family members who were willing and able to participate in the research project on a regular basis for the duration of the project.

A number of exclusion criteria were also identified. These included anything that might deem the participant unsuitable for the study such as Parkinson's Disease, young onset dementia, and anyone having a moderate to severe dementia classification (anyone with an MMSE score of 20 or lower). It is important to note that measuring according to the MMSE scoring is not a definitive method for identifying a particular stage of the disease; it is a guideline only. The participants and their primary carers came forward as possible candidates with the understanding that they were not severely impacted by the disease.

The research encompasses a set of three unique case studies, each defined in accordance with ethics guidelines for such research with vulnerable communities. Because the research took place both in the homes of vulnerable participants and in a day care environment, informed consent has been given by all participants living with dementia and their primary carer(s). The researcher worked with experienced clinicians in the case of all three case studies to ensure that the people who were chosen had capacity to give consent. Consent

has been monitored throughout the project and participants were invited to revisit consenting to take part in the study at two stages during the duration of the project: at the start and at the end. An assent form was also prepared. All participants were given the opportunity to withdraw if they so wished at any time during the process of the study. Please refer to the ethics document in Appendix 11.

3.7.1 Garda clearance and DBS check.

Garda (Irish police force) clearance was required. The day care centres and nursing homes working with the Alzheimer Society of Ireland required that the researcher acquire Garda clearance to work with the participants with dementia and their carer/partners. This process took between eight and ten weeks.

Working with the Alzheimer's Café in the UK, I received DBS clearance and was working under the University of Wolverhampton's ethical guidelines.

3.7.2 Safeguarding, building trust and working with vulnerable adults

Working with vulnerable adults means that all safeguarding issues must be in line with Alzheimer Europe's ethical framework.

All faces have been blurred and all names have been changed to preserve the identity of the participants and their families. Any short clips of recordings or photographs used when presenting the work at conferences, workshops and seminars to highlight key points will be rendered anonymous through facial

blurring and changing names. The transcripts from the research process are held by the researcher along with the photographs and all other materials from the study. Appendix 4 gives an example of the transcripts with the initial notes of the researcher from the three case studies: ROSE, IRIS and VIOLET.

The ethics document in Appendix 11 contains the information pertaining to confidentiality, consent, distress and safeguarding.

Confidentiality: After each session, the recorded material was downloaded on to a password-protected computer and the camera was wiped of all data. The data was transferred to a password-protected external hard drive and also a cloud-based storage system for safety reasons. Participants had the right to opt out of having their sessions recorded but could still take part in the study as normal if they wish.

Consent: According to the participant's level of need, each person with dementia and the partner/carer required different documentation. Three separate documents were created. Please refer to Appendix 1a, 1b and 1c for revised consent and assent forms

Participant 1a. Consent form for the person with dementia.

Participant 1b. Consent form for the carer/partner.

Participant 1c. Assent form for the carer/partner.

The guidelines for assessing capacity as outlined by Alzheimer Europe were followed (Alzheimer Europe, Mental Capacity Act 2005). Informed consent was

obtained at two intervals throughout the study in the first and final sessions. This provided participants with the opportunity to withdraw from the study, which is in line with Alzheimer Europe's (2014) guidelines on informed consent, in that it should be seen as an ongoing 'process rather than simply one fixed document'.

Distress: Because of the nature of the study and its relation to memory, there was potential for emotional responses to some of the garments of significance and other items. All participants were treated with utmost sensitivity. Due to the nature of this study, the risk of distress remained low but was possible. This could have ranged from mild discomfort to more severe upset; however, it should be noted that participation in this study also benefited the participants' overall emotional well-being.

Had I been made aware of abuse or self-harm during an interview – indicating that the participant needed support – I would have verified what the participant had said and terminated the interview calmly, keeping any recording devices running. I would have explained to the participant that I had a duty of care to inform someone that this was taking place, and why. If necessary, I would have invited another researcher or support worker into the interview in case of participant distress. The participant would then be debriefed for the interview as normal and offered the opportunity to ask any questions. A relative or support worker would be invited to meet them from the interview if needed. Beyond the appropriate contact, no further breach in confidentiality would have been taken (such as other personnel not part of the named research team). No information about the results or incident would have been given to relatives or third parties

whose identity or relationship to the participant could not be verified as that could breach assurances of confidentiality. All of those records would have been passed on to the appropriate contact and would not be held by this researcher.

3.8 Summary

This chapter has discussed the preparation and planning behind the methodology, including the concept development, the methods used for data collection/intervention and data analysis. The original plan was presented, and the actual plan as events took place with a discussion around the reasons for the changes that took place over the course of the data collection phase. The primary ethical concerns of doing such research have also been considered and discussed along with the design elements used throughout the process.

Chapter 4: The Design Concept and its Development Through the Co-Design Process

4.1 Introduction to the MoM and its development

This chapter explains the design idea and process for the development of the concept of the Map of Me: Caring Through Clothing study. The MoM was developed as a loosely structured framework for the exploration of personhood and sense of self through the excavation of lived experience, using garments as triggers for storytelling and memory. The MoM is an interactive ensemble of elements that convene to highlight the existing ecosystems within which the lives of the participants are lived.

The idea of the MoM emerged as a means of exploring personhood and sense of self for a PLWD and their primary carer, while also supporting a 'running sense of themselves' over time. The running sense of self is an overview of the many elements of self that exist within a person. This definition of self follows Neisser's multifaceted concept of self in which all five elements of self exist within the person both independently of each other and with each other (Neisser, 1988; Cadell and Clare, 2011). The five types of 'self-knowledge', although different to each other, unite and create a sense of continuity over time, which contributes to an overall feeling of unity.

The MoM was developed in a series of empathic co-design workshops with three participants with early to mid-stage dementia and their primary carers over a time period of 11 months.

Over the course of the project, the strong relationship between lived experience and clothing, and the importance of clothing for exploring and supporting one's sense of self, emerged. This research investigates how a sense of one's self and personhood can be supported and sustained through clothing, in particular, it explores the ways in which clothing can draw attention to moments of personhood constructed by the person's lived experience. The research project seeks the potential held within that construct, to further deconstruct and reconstruct personhood through the stories of lived experience attached to their sense of self. This correlates with ideas of existence and self that are both constructed and deconstructed by the clothing that people wear (Twigg, 2009; Miller, 2010; Fletcher, 2012; Twigg and Buse, 2013).

To facilitate this research, an empathic co-design approach has been utilised (Fals-Borda and Rahman, 1991; Koskinen, 2013), which includes a number of different aspects such as storytelling through narrative, drawing and items of textiles and clothing in form of the 'suitcase of stuff', which was assembled to facilitate and support the co-design process with the participants.

Storytelling, according to Mishler (1986: 53–59), in the form of loosely constructed narrative interviews is one of many methods for exploring the sense of self. In linguistic studies, the diachronic is the study of language development

over time. The synchronic is the study of language at a given point in time but does not concern itself with the passage of time (Wagner, 2014). This study further develops this idea of a diachrony and synchrony of lived experience and time to illustrate that personhood can co-exist as isolated, specific moments in time, with an overarching sense of self, over the whole lifetime of the person.

Drawing has been used throughout the entire research process both as a research aid and a reflective aid. Deanna Petherbridge (2010) shows an ongoing commitment to the primal importance of drawing in generating ideas and problem solving, both in her practice as an artist and illustrated in her book *The Primacy of Drawing: Histories and Theories of Practice*. Drawing has enabled me to uncover particular moments of knowledge that occurred during all stages of the research process, which were often intangible or hidden until visually represented through drawing.

The 'suitcase of stuff', comprising a collection of textile garments, artefacts, templates, swatches, photographs and illustrative drawings, acts as a means of eliciting and reinforcing participants' narratives. The 'suitcase of stuff' was the physical starting point for the MoM intervention. The MoM taps into and uses two readily available resources in most people's lives: firstly, *the wardrobe*, through people's own clothing; and secondly, *the photo album*, through photographs of people wearing their clothes. This intervention partially occupies the space between these sources. The MoM is likened to a process of excavation where tactile engagement with clothing plus interaction with photographs that have captured the wearing of the garments at a particular time

and place along with co-constructed narrative with the participants unearths information around lived experience from these two resources.

The concept of the MoM is developed in section 4.2. This is followed by a description of the 'suitcase of stuff' in section 4.3. In section 4.4, the set-up and co-design format for the case study sessions to enable the co-creation of the MoM are explained. This is followed by the discussion (section 4.5) and conclusion of the chapter (section 4.6).

4.2 Developing the concept of the MoM

This section discusses the importance of clothing as a representation of self and personhood; the use of drawings in the development of the MoM; and how the integration of clothing with drawing has led to the co-design intervention for developing the MoM.

4.2.1 Clothing as a representation of self and personhood

In her research on clothing and personhood, Julia Twigg (2009: 1) acknowledges that clothing is 'separate from the individual and their body' but is still chosen to represent identity and expression of self. Neisser proposes that it is the conceptual self that unifies abstract representations of oneself. For example, fashion and clothing are tied into representations of self through roles and identity. Roles can be defined by clothing in the form of a uniform. People present themselves and their characteristics through clothing, like a second outer skin, which is determined by our fashion and garment preferences. The

practice of wearing clothes can be seen as central to the creation of identity and personhood. It relates to appearance in how we perceive our own personal 'way of looking' (Twigg, 2009: 21). We can also choose to represent our social and political associations and beliefs or our relationships with others with the clothing we choose to wear, and we can reaffirm our sense of who we are (Entwistle, 2000).

Human interaction with fashion and clothing is ongoing. It is consistent and it is conscious. It engages our conceptual being to support our sense of self. From the moment that a garment enters the lived experience of its user, it is part of the user's ecosystem and thus enters the most potentiating stage of its life cycle, for it is during this 'user phase' of a garment's life cycle that garments become animated by the wearer. Fletcher's research (2016) during the *Craft of Use* project exposes and draws attention to the 'user phase' of a garment. Here, Fletcher demonstrates that the garments themselves often lie dormant until owned and worn. This research shows how garments can also lie dormant after they have been worn until ignited to become provocateurs for storytelling, at which point they also engage the user in a deeply imaginative interaction, which reinforces the wearer's sense of self. The user phase of a garment's life cycle is the most active, for within this phase lie the possible elements of care, wear, share association, reminiscence, empowerment, imagination, entrustment, interaction and creativity. Fletcher's research demonstrates that fashion garments that enable us to engage, connect and better understand ourselves, each other and our world are by their nature and existence facilitating ecologies

of interaction and deeper, more long-term, sustainable relationships (Fletcher, 2016). In many of the workshops with participants, there were moments where interaction with the garment reinforced a sense of self.

Figure 10 depicts Iris from the IRIS group. She is feeling the edge of the garment and reading the information pertaining to the construction of the garment. This is one example of a garment acting as a way in to a story or a moment of lived experience.



Figure 10: Feeling the edge of the garment and reading its construction

If the user phase of a garment is related to one's sense of self, then one's sense of self can be explored by interaction with or focusing on a garment. The connective ideas around clothing and identity are particularly useful for working with PLWD. According to Sarah Ahmed (2004), if objects can take on the feeling of an interaction with a person, then the touchable sensory nature of garments makes them appropriate objects for the transfer of feeling and discussion of lived experience (Ahmed, 2004). This opens up the possibility for clothing to act as a trigger for memorial discourse, where the drawing process, talking about and sensing clothing through touch, sight, smell and even sound all operate as memory prompts to harvest this lived experience. Hence, this study focuses on the user phase of a garment as an effective intervention point wherein one can affect change in the lives of PLWD and their primary carers.

Fletcher (2016) holds that many garments that have been mass-produced are presented as closed and have a completed and therefore 'untouchable' status. This element of open-ness and 'touchability' are at the heart of the research and have strongly guided the design process during the course of the research.

4.2.2 Drawing and its role in defining the concept of self and personhood

During the research process, illustrative drawing has been used as an agent to better comprehend different ideas around personhood and sense of self. Drawing has also been used to map moments of personhood on to the MoM in order to visualise the concept and thereafter share it with the research

participants. Petherbridge (2010: 7) states that drawing is the primal means of symbolic communication, which predates and embraces writing, and functions as a tool of conceptualisation parallel with language. Throughout the research process, reflecting on the theoretical concepts has taken the form of illustrations to capture information and interrogate the data material. Petherbridge (2010: 2) speaks about drawing as being a response to the external physical world, as well as combining the private signs of the subjective and emotive creative self. Lucy Lyons (2012), in *Drawing your way into understanding*, considers the richness of the interrelationship between that which is drawn and the drawer. She points out that the activity of drawing could be seen as a catalyst, acting as a method for remembering and communicating back and forth between drawer and object (Lyons, 2012: 20). It also requires a 'commitment to time, focus and concentration' (Lyons, 2012: 22).

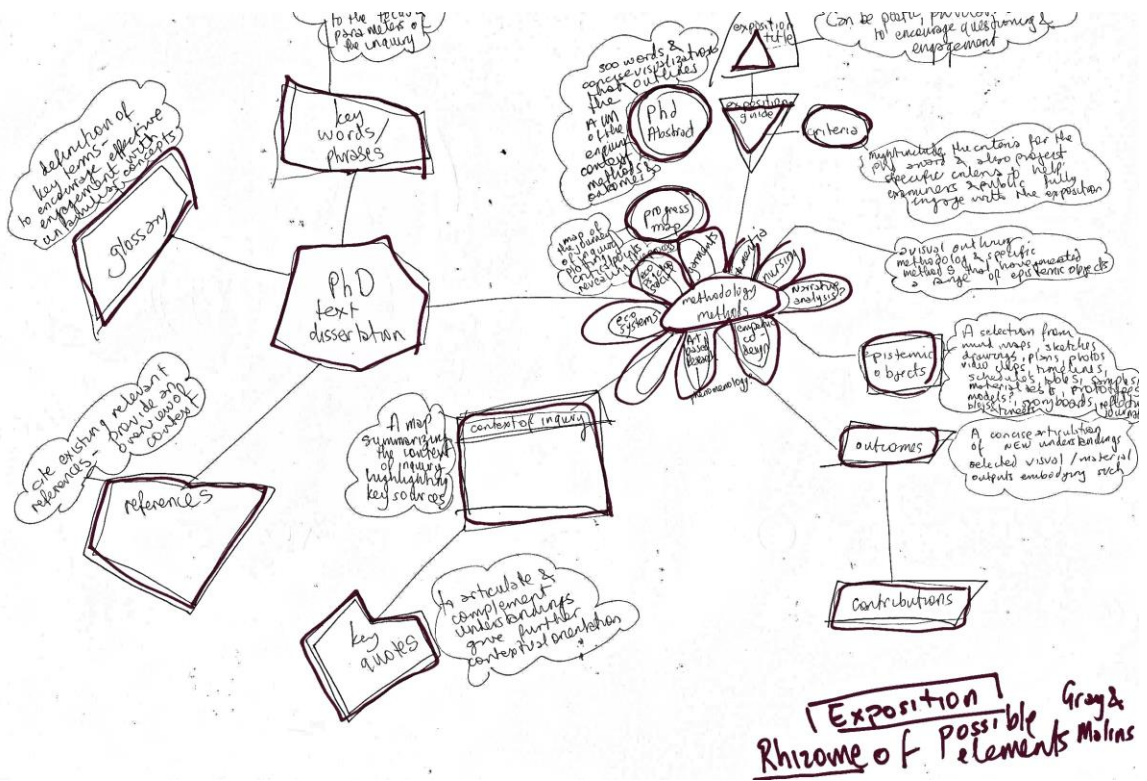


Figure 11: Page from the reflective journal

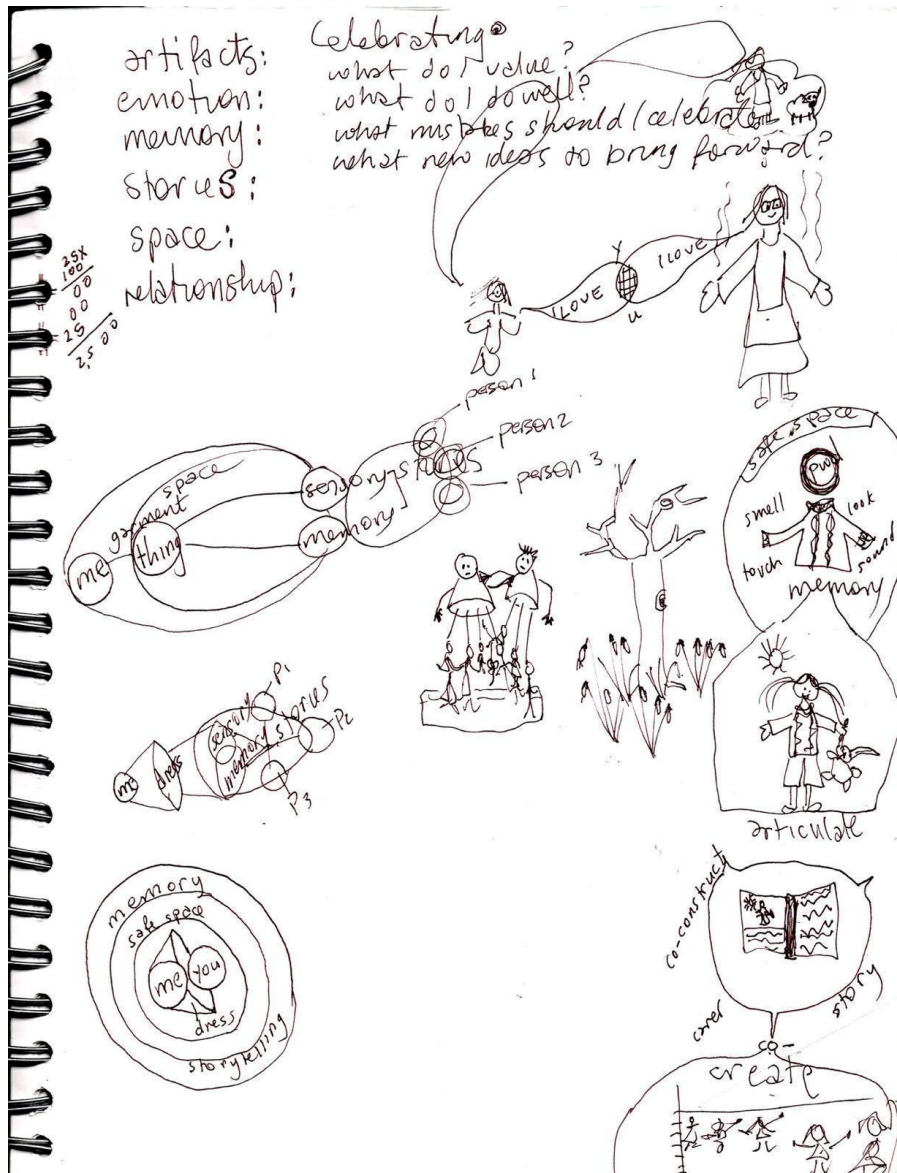


Figure 12: Working diary that uses drawings as provocations from the workshop sessions

The insights acquired through the use of illustrative drawing were integral to the design of the MoM intervention as a whole. Above in Figures 11 and 12 are examples of pages of interactive drawing that I created and then used to understand and extrapolate elements of the study as I was encountering them.

For example, by visually representing the problem of residents' clothing going missing in the care home, it prompted me as the researcher to start an investigation into the laundry practices of the care home and how to proceed with solving the problem of safeguarding the residents' garments (see Figure 55 *These are not my clothes*).

Another example was in the physical act of drawing Neisser's five senses of self. This enabled the researcher to note and comprehend the non-linear nature of self and cognitive decline. Lyons' research demonstrates that drawing can make complicated philosophical ideas more concrete and bring them closer to lived experience (Lyons, 2012: 14). By visually representing the MoM for each case study group, participants were enabled to engage with their own lived experience in a renewed and exploratory way.

The reflective sketchbook kept throughout the research journey became, over time, a living document that formed and informed the artistic research process throughout. Ross Prior correctly observes that in many academic fields, 'linguistic communication systems' have often been favoured and prioritised as 'more effective' than other 'non dominant communication' systems; however, he goes on to say the reflective sketchbook allows the researcher to track their own processes and thoughts on the study (Prior, 2018: 165). My experience was precisely this and more. Through the various sketchbook and drawing sessions, the researcher came much closer to understanding and sometimes capturing hidden 'findings' held within the research. Thus, knowledge and creative

responses, in various iterations over time, revealed more than any of the 'objective analytical' observations could ever do.

Figures 13 and 14 are two illustrations: One is of a woman wearing her favourite blue woollen scarf; the other is of a man wearing his favourite pink hat. Neither of the people represented took part in the study but I had frequent encounters with both over the period of the research. I did drawings of both in the reflective sketchbook and those drawings were important for development of the methodology. They enabled me to observe and record the importance of specific garments in people's lives.

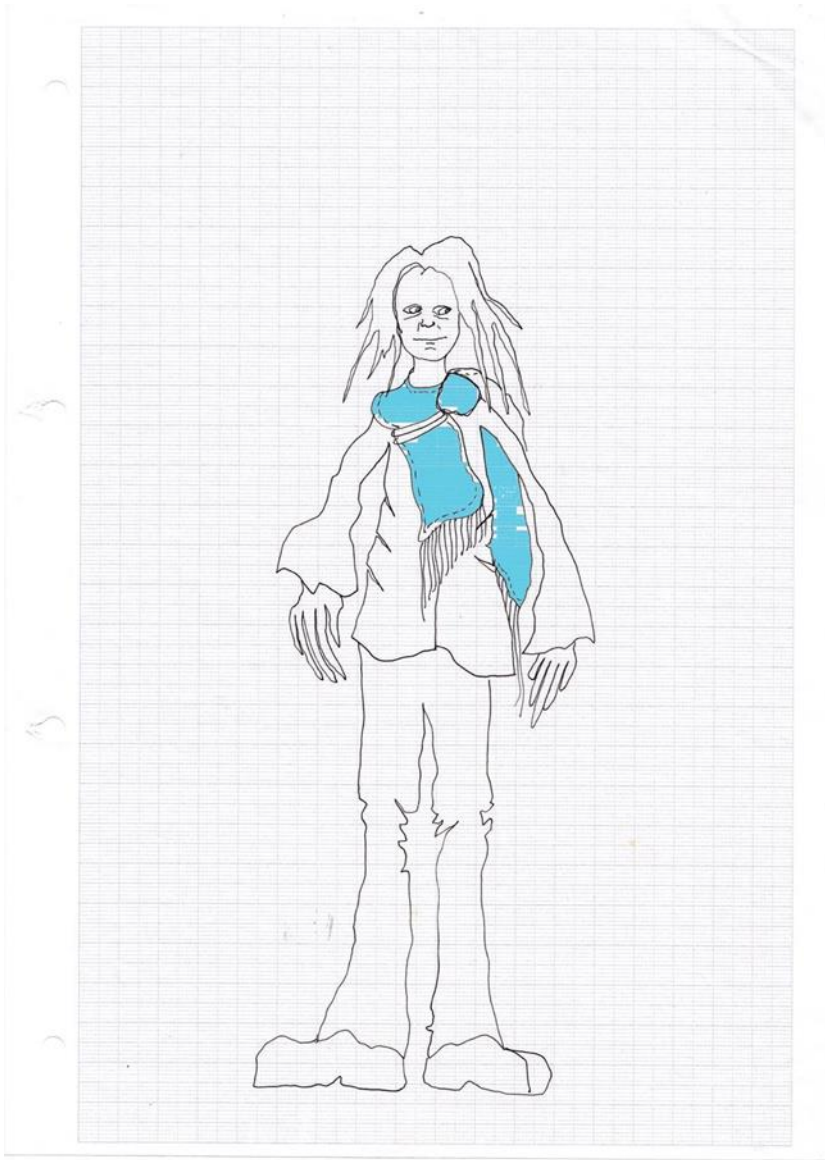


Figure 13: Wearing my blue scarf

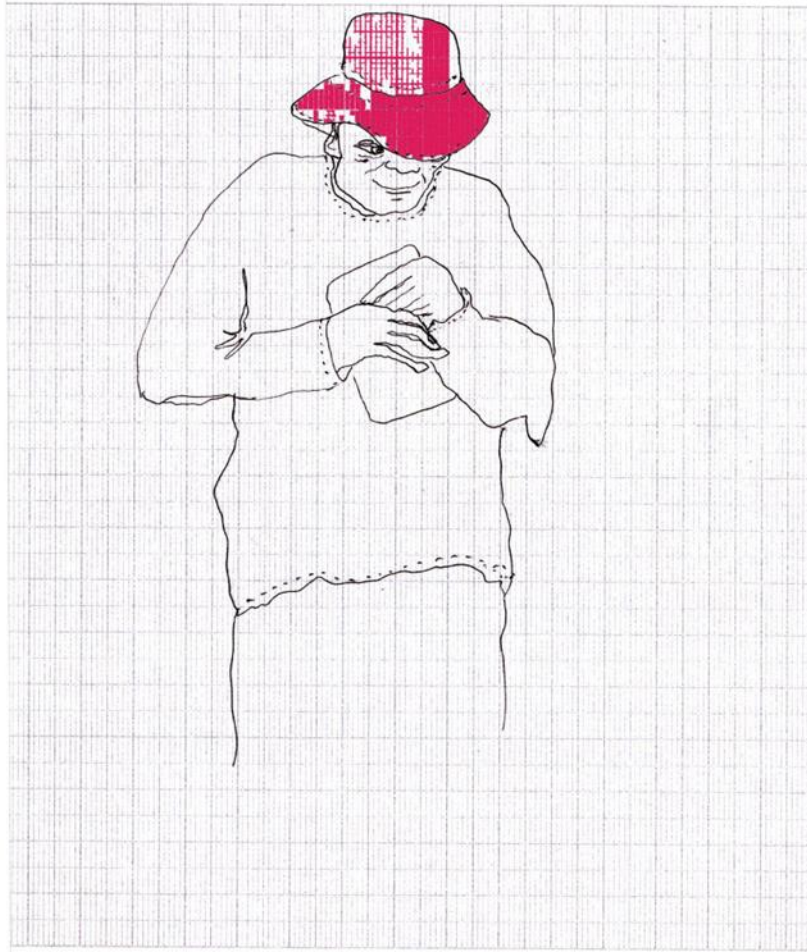


Figure 14: Wearing the pink hat

In Figure 15, I have visually represented my own wardrobe of significance, curated from my past and present lived experience. This exercise was part of my immersion and observation stage – the empathic and co-creation process. This enabled me to prepare for partaking in the co-construction of the participants' lived experience. This further prompted me to reconsider my own

relationship to fashion and clothing; my attention to dress through memory; and my self-construction of the image of myself. In this drawing, I have included among other things, my first party dress, my mother's wedding dress, a pair of woollen socks and a collection of silk scarves.

My response to gathering these important garments of my own around me was revelatory. When I entered into the exercise of highlighting my own garments of significance, I found that I experienced strong emotions as a response to this. It felt to me that the garments had lain dormant until I had 'unlocked' them. This feeling of 'einfuhlung' or entering into the exact feeling empathically of understanding the patina of lived experience through my own garments of significance is what enabled me to carry out the research and co-design sessions in the way that I did.

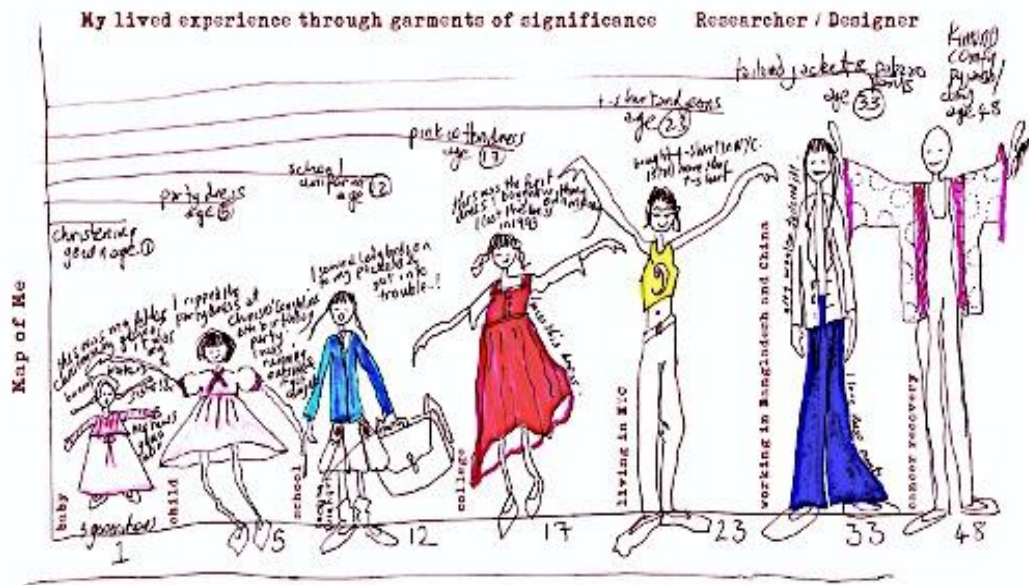


Figure 15: My lived experience through garments of significance

4.2.3 The MoM: Caring Through Clothing final template

The MoM intervention draws on the ideas and materials that emanate from the photo album and the wardrobe. Combining drawings and the creative ‘suitcase of stuff’, the MoM provides a loose template as a means for the participants to explore their sense of self and personhood in a suitable and safe, active and creative environment. The MoM begins as an illustrated drawing, of a person with their clothing of significance positioned around them. The idea was for the researcher to co-construct this drawing with the person with dementia and the family members and/or the people caring for and interacting with them. It offers the idea of a non-linear timeline; it places the person with dementia at the centre of their own ecosystem and life experience through their own wardrobe.

Figure 16 is a representation of the garments of significance. The audio and visual information that emanated from those sessions initially presented as small, seemingly insignificant elements of the participants’ lives that, when placed in the overall context of their lived experience, became the structure around which the overarching life story was built.



Figure 16: A visual map of 'garments of significance'

The MoM template was therefore designed to enable the participants to map isolated incidents along the 'axis of self' to create a 'running sense of (my)self through time' and 'moments of personhood'. This draws on two concepts: the first is the running sense of self through time, or the diachronic sense of self; the

second is personhood represented as a number of points along that axis of time, also called the synchronic self at isolated point(s) (Wagner and Northoff, 2014).

Figure 17 shows the illustration of the template that constitutes the axis of the MoM 'lived experience through my clothing' with the 'points of personhood' axis signifying the synchronic self, which relates to the idem identity, and the running sense of self axis signifying the diachronic self, which relates to the ipse identity (Ricoeur, 1992; Wagner and Northoff, 2014).

It offers a common starting point for the co-creation work as the first step in the subsequent design process. It presents an overview of the person's life on one page and aims to give an overarching sense of who the person is and was throughout their lived life from looking at the MoM. Although it presents itself as an ordered timeline, it does not require linear completion. The elements came sporadically and over a number of workshop sessions. Some of the elements of lived experience came into being through storytelling and were then re-presented as fundamental components of the story through drawing.

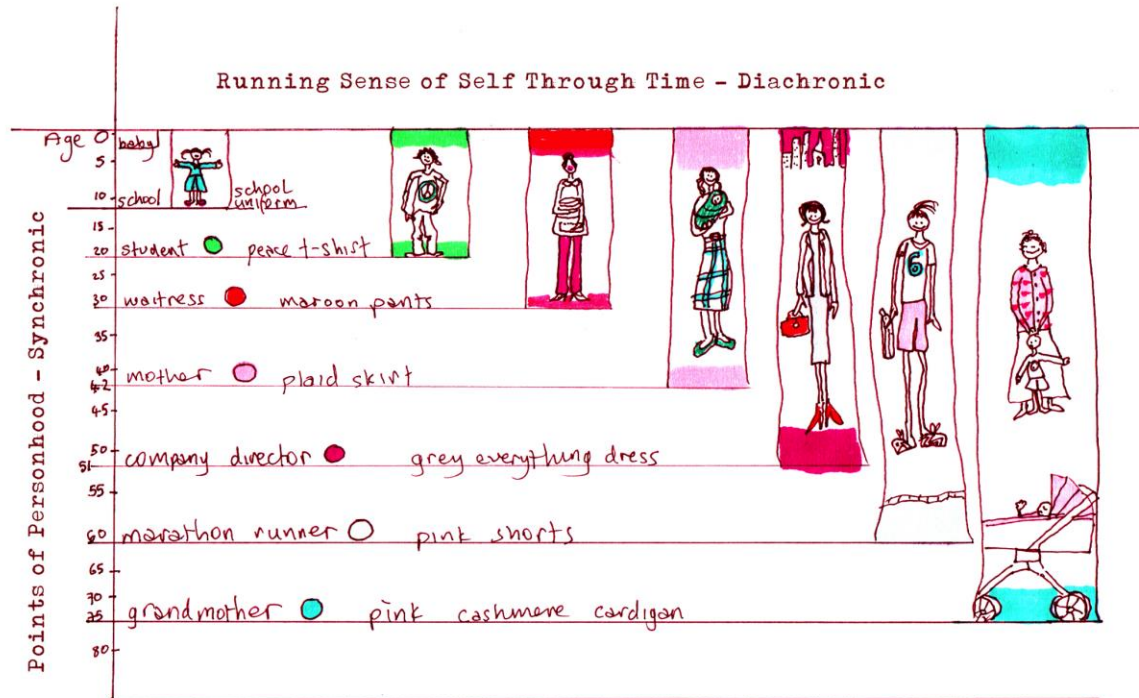


Figure 17: 'The MoM: Lived experience through my clothing' with the 'points of personhood' and the 'running sense of self' axis

The creation of a template for the participant intervention based around clothing could only work if it was an open and accessible template that enabled participants to identify with and add their lived experience. It also needed to have the capability to be re-organised, assembled, disassembled, reassembled in order to enable elements from the collective lived experience to be gathered and juxtaposed. Using drawings to represent them, Neisser's model of the five interpersonal aspects of self was used as a framework to identify moments of self throughout the study. The plan was to present the templates to, and work with participants through, four workshop sessions. The workshops were designed around interpersonal narrative activity through the sharing of stories

and co-construction of lived experience using the templates. Garments are used as the focus, as they importantly represent aspects of the sense of self and personhood in time. They also can be used to enable more person-centred interactions.

During the research process, it was found that 'The MoM: Caring Through Clothing' moved beyond triggering memories, moved beyond the isolated garments, and beyond the photo albums. It needed to elicit the tacit experiences between these elements. Treadaway's research advocates an approach that focuses on haptic and tactual experience rather than cognitive. She also goes on to say that when activities are shared it can lead to a more 'person-centred relationship' between the person with dementia and their family and carers (Treadaway et al., 2016: 6). Memory was integral to the process as part of lived experience but so too was the cumulative experience of touching the garments, sharing the space physically and co-constructing the narrative. In order for the participants to actively contribute to that shared lived experience, the use of the templates and garments were complemented by a further set of creative elements 'the 'suitcase of stuff', which was designed to enable people to explore and express their lived experience through creative means.

4.3 Development of the 'suitcase of stuff'

The following section presents the various elements that became part of the 'suitcase of stuff', as it was developed to support the MoM intervention. The 'suitcase of stuff' is reminiscent of the Liverpool-based 'House of memory'

project based at the National Museums of Liverpool, which allows participants to explore objects and memories held in a suitcase. These suitcases were specifically developed to trigger memory through photos, memorabilia and other objects.

In the 'suitcase of stuff' for the MoM, a curated suitcase of elements, including multisensory textile and photographic objects, was used to work with participants within the interview and workshop sessions. These are described below:

Drawing: Making the unseen visible

Photography for co-creation: Excavating and co-creating

Using and curating garments: My personal mobile wardrobe

Storytelling: Co-constructing moments of lived experience

Virtual wardrobe audit: Excavating through narrative

Templates: Co-creation and swatch library



Figure 18: The 'suitcase of stuff' closed and open



Figure 19: Box of vintage gloves

4.3.1 Drawing: making the unseen visible

The following section is written in the first person.

Drawing and drawing techniques were subsequently introduced as part of the 'suitcase of stuff' to tease out hidden elements of information, object, personhood, sense of self and lived experience. Drawing was used, for example, as a means to capture participants' memories or ideas of themselves that were not available – for instance, in the form of photographs. Drawing also allows a placement of time and space outside of linear representation. Petherbridge (2010: 90) talks about drawing practice as a means to prolong ideation or 'thinking-looking', and that throughout Western history drawing has been linked to idea, as the moving hand of drawing registers the movement of the 'thinking eye'. Drawing was chosen as a lens through which to process many of the elements encountered. It became a tool for excavating and discovering elements that may otherwise have lain unwitnessed or dormant for many years. Drawing was used to bear witness to others' past lived experiences, and in so doing was used to re-validate their experiences for themselves in a different time context with different focal points (Lyons, 2012).

To start with, for myself, the drawing process was a means to extract my own sense of self in relation to personal garments – past, present and future – to understand better what I as the researcher would be seeking in relation to the garments of others. I needed to have a deeper understanding of how their sense of self was reinforced or potentially de-stabilised through the clothing worn on a

daily basis. In line with the 'suitcase' metaphor, I focused on the clothing taken while travelling between Ireland and the UK at that time of the PhD research and tracked the frequency of use of items within the 'Travelling Wardrobe'. Thus observed, and documented, the Travelling Wardrobe soon manifested as my visual repository of lived experience, a visual diary of my own garments of significance. This is illustrated in Figure 20.

Drawing was subsequently used by me, during and after the workshop sessions, to enable a subconscious response to the garments being handled, the participants who were taking part, and to partake in the co-creation process by representing and substituting missing elements that had no visual or sensory representation. For example, in the ROSE group, the red shoes and the woollen bathing suit were represented through illustrated sketches. (See figure 21) For the IRIS family, drawing drew attention to elements of the knitted topography of Iris' sense of self as revealed through her extraordinary talent with knitting and sewing. Joseph Beuys' description of drawing is that it is the first visible thing of the form, of the thought – the changing point from the invisible powers to the invisible thing. But Beuys is not only describing the thought; he aligns the senses of balance, vision, audition and touch with the drawing practice (Beuys et al., 1993).

Every human being is an artist, a freedom being, called to participate in transforming and reshaping the conditions, thinking and structures that shape and inform our lives. Drawing is the first visible form in my work. The first visible thing of the form of the thought. The changing point from the invisible powers to the visible thing. It is really a special kind of thought brought down onto a surface be it flat or be it rounded. (Beuys et al., 1993: 73)

Drawing has been described by the poet Seamus Heaney (1971) as an art form that occupies a placeless heaven, freed from the literal. Thus, the drawing facilitated the bringing forth or visualisation of ever-present meaning that was

embedded within the lived experience of the participants. Within the contexts of each of the three case studies it thus enabled, in different ways, that meaning to become established within the broader context of the individual family journey/story.

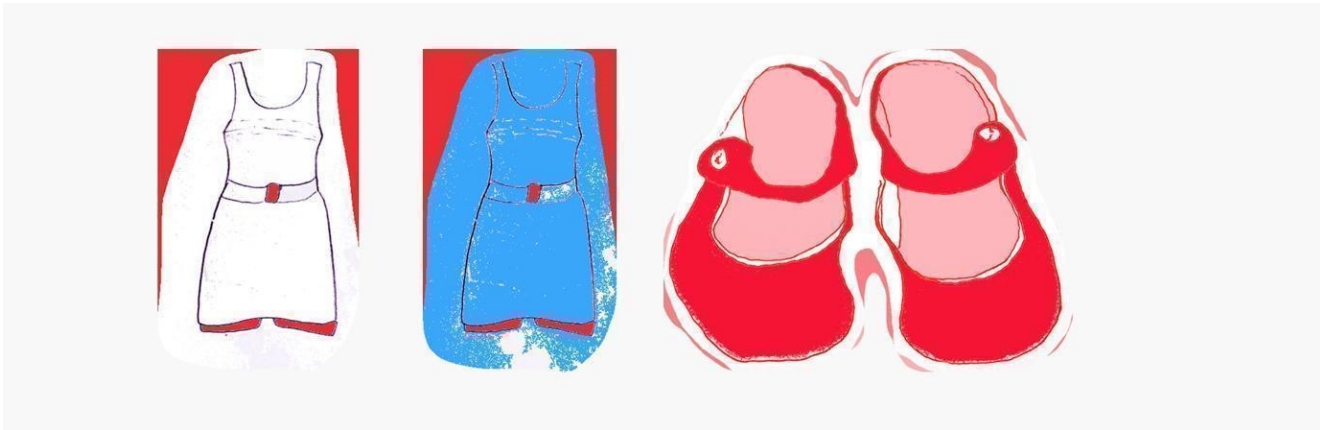


Figure 21: The woollen bathing suit and the red shoes from the ROSE case study group

Over the course of this study, drawing in my sketchbook was an effective reflective practice. In addition, I used drawing as a means of understanding complex ideas and representing missing elements.

4.3.2 Photography for co-creation: excavating and co-creating

Photography was included in the 'suitcase of stuff' as a way to capture important moments during the course of the semi-structured interviews. All of the participants had photographs of themselves wearing garments of significance from their lived experience. The photographs were an effective bridge between the participants' wardrobe and the photograph album in that they were used to

document the artefacts and to reproduce existing images from the past, particularly when the artefacts were featured for inclusion in the MoM. This was significant for two reasons. It became a means to visually document the participants as they handled the artefacts in the present. It also reinforced the participant's ability to enter into their own lived experience by constructing their own stories about how the garments were used in the past. The photographs were instigators for creative storytelling around the garments of significance as well as the events with which the garments were associated.

Brockmeier (2009) insists on placing the focus of representation of self on the process rather than the outcome. He talks about the world of humans as being 'in a constant state of flux or evolution' (Brockmeier, 2009: 214). My experience over the course of the project has been one of bearing witness to an ever-evolving representation of self. Memory is reinforced by the co-constructive telling and the story is further embossed in a place for retrieval. The story never stays the same for it is the result of multiple interlocutors.

For understanding and appreciating the human condition, it is far more important to investigate the ways in which human beings construct their real and possible worlds ... than it is to establish the ontological status of the products of these constructions.

(Brockmeier, 2009: 214)

The photographic albums that participants brought along represented part of the harvest of producing a life story. The albums were a representation of lived

experience and represented captured moments of personhood. They were present, but as an entity unto themselves, and they did not facilitate the process of co-construction. For the photograph albums to contribute in an active way, the items that they contained needed to be re-contextualised. This was done by removing the photographs from the confines of the album by photographing them in a new context, allowing the images to be altered. The copies could be cut out, placed in a completely different context or collaged with other elements such as drawing. Treating photographs as elements of the drawing process brought a fresh, unfettered interrelationship with the photograph. By tracing and cutting out the elements – and releasing them from their frame – certain relationships within the frame ceased to be spatial and were in effect liberated from the borders that contained the photograph. Figure 22 demonstrates this process. The family co-constructed this collage of the families' lived experience using photographs, drawings, and other elements. Petherbridge (2010) speaks about the inherent potential of shifting or altering the border, frame or outline of a drawing, which can then through spatial or compositional organisation change the very status of the drawing. Adding a border or frame can both isolate the enclosed area (the drawing space) and can bring attention to the 'particular moment in time in the development of the practice' (Petherbridge, 2010: 165). By treating the photographs taken during the sessions as 'elements' of a journey/story rather than fixed representations within time, it was possible to shift the 'finished-ness' 'linear-ness' and 'contained-ness' of the life story into a more open, multi-dimensional iterative story, which held potential for evolution within the family narrative.



Figure 22: Co-designed and co-assembled collage of elements of lived experience from the ROSE case study group

4.3.3 Using and curating garments: my personal mobile archive

The researcher has written this section in the first person.

I have been gifted and have collected vintage garments, textiles and related artefacts for many years. These include hand-knitted, sewn and woven garments and textiles of different weights, fibres, styles, making technique and colour and pattern; they constitute my own personal archive. This small, mobile personal archive represents my own MoM, developed over years of interaction

with garments of significance. Each of these items has some personal significance for me that has attached me both to them and to the experiences embodied in them. For this project, I curated a small collection of items taken from this archive and used it as a starting point for interaction with the participants. The items were brought to life with the stories attached to them and it was apparent that the participants showed an active interest in these items and their stories. Although there was no actual connection between the participants and my own garments of significance, there were occasions when participants were prompted to co-construct their own narratives around these garments. These narratives were unrelated to the original garment but were triggered by them.

The mobile archive represents a snapshot of my lived experience through clothing. By knowing my own relationship to clothing – partly from documenting and reflecting on my Travelling Wardrobe over time (Figure 20) and compiling my mobile archive, I equipped myself to discover elements of importance around garments for others. Within the framework of an empathic design methodology, it sits in the discovery stage (Kouprie and Visser, 2009). Here, I strove to understand the meaning behind my own most worn and most favoured garments. By tracking my own use and love of items of significance, I prepared myself to heighten my sensitivity to others' garments of significance and their experiences. By talking about item(s) that were being passed around to the different participants in the room, each person became an active co-constructor. Moments of extreme sensitivity and care were revealed and interactions were

illuminated by the co-tellership and co-construction through the garments. It was an important exercise for me to be open about my choice of garments and garment types in the mobile archive with my participants. For example, the striped heavy cotton pyjamas and yellow woollen jumper had many responses, as had the crochet wedding dress belonging to my mother (also yellow). The mobile archive was an open entity, flexible and adaptable in its contents. The garments acted as portals, which invited other people's stories about their own garments in. Figures 23, 24 and 25 are some of my garments of significance in the suitcase of stuff. There were many multisensory elements present, which appealed to different people in different ways. I will expand on this in Chapter 5.



Figure 23: Garments of significance from the 'suitcase of stuff': Silk child's dress.



Figure 24: Garments of significance from the 'suitcase of stuff': Woman's silk blouse.



Figure 25: Garments of significance from the 'suitcase of stuff': striped pajamas.

4.3.4 Storytelling: co-constructing moments of lived experience

A study by Lindseth and Norberg (2004), which focuses on lived experience as bearing witness to the essence of the phenomenon of being, shows that the idea of a witness being heard in silence is not possible for research purposes; thus, to extract some of the meaning of the experience of being, humans tell stories. It is often through the narration of stories that meaning in our lives is revealed. In order to interpret the stories, it is best to write them down. In other words, we produce texts from narrated discourse to be able to thoroughly examine and reveal the meaning of lived experience (Lindseth and Norberg, 2004: 145–153). In the introduction to her edited book *Oral History in the Visual Arts*, Linda Sandino (2013: 10) draws the reader's attention to the etymology of the word *communication* and shows that it emanates from the idea of 'sharing talk'. Sandino proposes that narrative is not only an appropriate form for the expression of identity but is also an identity content in which the self is defined and transacted with another in the narrative process (Sandino, 2013: 11). During the course of this research, the participants forged and maintained connections with themselves as well as unearthing shared meaning, while reinforcing and bearing witness to each another.

Ochs and Capps (2001) discuss open-endedness as an inherent property of constructed narrative. Conversation can only be loosely anticipated; the general order of speakers and turn-taking within the conversation cannot at the outset of the discourse even be loosely anticipated (Ochs and Capps, 2001: 6–7).

Participants become speakers and listeners themselves – all shaping the narrative.

In almost all of the case study workshops, the overarching story – the journey – was being assembled through co-construction, of moments of personhood within that overarching story. If, as Mishler (1986) suggests, stories enable the co-construction for self and community of meaning, then stories about and triggered by clothing that has meaning for the participants can only reinforce meaning for all interlocutors. Ochs and Capps (2001) go on to describe the web of narratives as they start to interlock and inform previous experiences, illustrating that the party they were once audience to now becomes audience to them. This was apparent during the workshop sessions, where the role of primary teller shifted around different participants within the group sessions, with the narrative stories often being vividly re-lived as they were being co-constructed.

4.3.5 Virtual wardrobe audit: excavating through narrative

The virtual wardrobe audit was based on a series of informal questions as well as excavating old photograph albums to identify symbolic moments of time where items of significance were worn or discussed. It often required the input of the primary carer/partner in identifying where significant garments from the lived experience of the person with dementia might be in the present time. The wardrobe audit was often carried out in a virtual space prompted by my personal archive or the participants' photographs. I never physically examined any of the participants' wardrobes, but over the time period of the project I was able to

identify important stories and habitual practices around clothing that helped to draw attention to the garments themselves and identify their significance in reinforcing a sense of self and personhood. One such story was Violet's strong sense of social justice, which was tied in to her wearing of the tweed cloaks. These garments were the uniform that accompanied her on those occasions where she attended a protest or partook in the baptism of her adopted children. Iris' keen understanding of the construction of her significant garments was revealed through her handling of them, reminding her of her own ability and skill in her younger years. Finally, Rose's repeated return to the colour red was an indication of her own history within the family of the love of her father and grandmother.

4.3.6 Templates and swatch library: co-creating and co-construction

This section is written in the first person.

For the workshop sessions, in addition to garments, photographs and drawing, I prepared a number of further elements, which I used as a means to enable co-creation between the participants. Before the sessions, I prepared templates, which were developed from silhouettes of generic garments, and shapes of people. During the work with the participants, I resized photographs from the participants' own archives, as discussed in section 4.3.2. I cut out the shapes of the people represented and removed them from the context in which they were situated. I also used a multisensory archive of fabrics, which included different

sensory elements such as touch, sight, smell and sound. Elements of this archive were categorised accordingly, with 'touch' holding fabrics with a particular handle, feel, texture, softness and roughness. The 'sight' collection held differently coloured woven textures, prints, colours, shapes and scales. The olfactory samples held a range of different smells associated with fabric, from the faint residue of lanolin in a hand-knitted woollen jumper to the lingering smell of perfume on a silk scarf, the musty smell of clothing reminiscent of mothballs (indicating that it has not been worn for a long time) and the overwhelming smell of cheaply produced synthetic fabric reminiscent of a new rubber wellington boot. During the workshop, the group discussed words relating to the sound of textiles and co-compiled a short glossary of sound words traditionally associated with textiles and garments and the action of wearing them: These included: the rustle of silk; the sound of the flapping of an outerwear garment in the wind; the slapping of a wet garment on a washing line; the feeling and sound of one's foot moving into a pair of nylon tights; the swish of a skirt; the crackle of static when pulling a synthetic pullover over one's head. Also, in the preliminary sessions, we developed and ran a clothing quiz to instigate thoughts around garments.

Using these multisensory objects as prompts to spark co-creation opened up the possibility of extending beyond the personal archive of garments and photographs. In sections 4.3.2 and 4.3.5 of this chapter I have discussed how these objects came to be created. In section 4.4 I will discuss how they came to be used in the co-creation process. How this worked with participants was interesting, not as an end to itself but more as another method to identify

common responses, continuity of likes and dislikes, descriptive words, personal preferences and emotional resonances. Figures 26, 27, 28 are objects from the suitcase of stuff.



Figure 26: Box of sewing threads in different colours



Figure 27: Sensory library, buttons on a string, felt flowers, shells



Figure 28: Vintage handkerchiefs from Saks and Macy's

4.4 Co-creation and case studies

The MoM was developed individually with each set of participants through a set of four interview and workshop sessions (as discussed in Chapter 3). The sessions had a twofold purpose: to develop a Map for each individual and to refine the set of tools that constitutes the 'basic kit' for the MoM. The workshop sessions evolved from being loosely structured interviews to facilitating deep co-constructions of stories and meaning. In the final workshop sessions, the lived experiences of the participants were excavated and presented in the form of the 'suitcase of stuff' comprising a collection of textile garments, artefacts,

templates, swatches, photographs and illustrative drawings, all of these acting as a means to elicit and reinforce participants' narratives. The 'suitcase of stuff' was the physical starting point for the MoM intervention and this tapped into two readily available resources in most people's lives: firstly, the wardrobe, through people's own clothing; and secondly, the photo album, through photographs of people wearing their own garments. This study is located at an intervention point that occupies the gap between these two sources. The MoM therefore is a type of excavation that unearths that gap through tactile engagement with clothing and photographs. The context for creation of co-constructed narrative with the participants is then activated.

As previously discussed, the participants who took part in the MoM: Caring Through Clothing project were encouraged to visit both their personal wardrobe and their family photographs. They were then invited to explore personhood by reflecting upon their own clothing and garments with meaning for them, such as family heirlooms, quilts, dresses, suit jackets, etc. Narrative and reflection supported drawings, photographs and templates, which then enabled co-creation of a physical manifestation of significant life elements.

This manifestation of the participants' individual MoM was a significant outcome, which comprised a collection of written stories, drawings, textile elements and included photographs pertaining to the lives of the participants and their closest 'others'. The specific format of the Map was unique to the individual participants, reinforcing the idea presented by Rodgers (2014) that co-creation, or co-design, between a number of different participants can often produce more innovative

and responsive results than an individual designer's response to a perceived design challenge or problem. The exercise of documenting my own 'wardrobe of significance' through drawing and observation was only a small part of the overarching co-creation process. It did, however, enrich my research, facilitatory and artistic practice.

4.4.1 The use of narrative and narrative analysis

Ulrich Neisser (1988) stated that narrative was one of the primary bases for self. In the context of this study, storytelling sits alongside lived experience and interactions and is the shared dialogue between past, present and future. As a witness to these multiple storytelling constructs, it became apparent that the stories were only a small percentage of the process. So, too, the elements that were drawn together and held within the process, such as interaction with the photographs and objects, triggering of the senses, recollection of events and co-construction of narrative. On their own, these could only represent a tiny part of the process. Cumulatively, however, the elements assembled, represented a rich overview of lived experience for the participants. Within this assemblage, elements of accuracy and rigidity regarding tasks and memory were abandoned for elements of adaptability and openness. The journey became the important element to focus on, not the most accurate representation of fact. Ricoeur's (1984) work in this area illustrates that narrative enables the tellers/listeners/readers to see and revisit their world in new ways. He illustrated through his work that the telling of a story constitutes a dialogue between the past, the present and the future. He emphasises that we have a pre-

understanding of life, which finds expression in the shape of narrative and stories. If stories give meaning to particular experiences, then objects and relationships, in turn, give meaning back to the overarching story. It is a cyclical – rather than linear – series of juxtapositions (Ricoeur, 1984).

In 'Reaching for Meaning: Human Agency and the narrative imagination', Brockmeier's (2009) observations look at how, within human interaction, it is the process of co-constructing the interaction in time, rather than the particulars or accuracy of the final outcome or story that is most important. It is during this co-constructed process that relationship to the other becomes the focus rather than the individual to themselves. Ricoeur explores this idea in 'one as another' when he suggests that one person cannot be thought of without another, somehow. In his own words, 'one self as another suggests from the outset that the selfhood of oneself implies otherness to such an intimate degree that one cannot be thought of without the other. One passes into the other' (Ricoeur, 1992: 3).

4.4.2 Suitable spaces to flourish

Narrative was one of the key elements, but so too was the creation of a space in which explorations of personhood and the self could be supported. Many elements needed to be in place before co-construction of narrative and co-creation could successfully take place (Neisser, 1988).

For example, to hold the case study workshops 1, 2 and 3, the participants needed to trust that I as the facilitator/researcher was locating a suitable space

in which to 'hold' them. The space needed to be private and enclosed without any interrupting elements.

Participants also needed to be interested enough in the idea behind the project to participate. This meant that the facilitator/researcher needed to spend time observing and interacting with the participants. The participants needed physical triggers to re-live, re-call and re-construct their lives together and lives apart. This required artefacts, both from my personal mobile archive and from the participants' lived experience. As previously discussed, the participants needed flexibility with meeting times. This required planning in advance and adaptivity to changes in the schedule.

The semi-structured interviews, which I had set up before the fieldwork, were initially used as a guide. However, the three case studies moved very quickly away from these semi-structured formats and, eventually, were either mildly modified, heavily modified or completely abandoned. Although the co-creation of a personalised MoM for each participant was a good starting point, it only remained a starting point. Each of the three case studies veered away significantly from the original template of the MoM. The descriptions and results of the workshop sessions are described in Chapters 5 and 6.

4.5 Summary

This chapter has traced the design process for the development of the concept of the MoM. Described is the development of the 'suitcase of stuff' as a curation

process borne of my own personal interrelationship with my own wardrobe. This chapter has discussed the set-up for the case study group workshop sessions and the co-creation activities to develop the MoM with individual participant groups.

Chapter 5: Case Studies

5.1 Introduction: three co-creation case studies

This chapter presents and discusses three case studies of working with PLWD and their caregivers. The case studies were conducted to better understand the lived experience of PLWD and their caregivers with regard to perceptions of self and personhood. They were also part of the MoM empathic process, which was co-designed and used to excavate and reinforce sense of self and personhood.

The fieldwork, including the recruitment, preparation and case study work, took place over 18 months. There were three groups x four empathic co-design workshops, which were held over 11 months between October 2016 and August 2017. During this time, I worked with the three case study groups on exploring their sense of self and personhood while simultaneously introducing, adapting and further developing the MoM in response to the empathic co-design process.

Each of the three groups consisted of a person with dementia and their carer(s). Within this thesis, the case study groups (CSGs) have been named ROSE, IRIS and VIOLET. The case study workshops are named W1, W2, W3, and W4.

CSG1, ROSE, consisted of a woman who lived at home with her husband Larry, who was also showing mild signs of vascular dementia, and their daughter Linda, who cared for both parents. CSG2, IRIS, consisted of a woman who lived in a care home and her two daughters, both of whom cared for her. CSG3, VIOLET, consisted of a woman with dementia who lived at home with her

husband, who is her only carer. I present the workshops in this chapter and follow this with a comparative discussion of the development of the MoM and its evolution during the empathic co-design process (section 5.3) and the impact of the exploration of personhood on the three participant groups.

5.2 Case study group 1: ROSE



Figure 29: ROSE group: At the heart of my own ecosystem: My lived experience through clothing

5.2.1 Introduction to ROSE (CSG1)

Participants for CSG1 included Rose and her husband Larry; they lived at home together. Rose was 80 years of age and had mid-stage dementia. She was diagnosed four years previously. Larry had been caring for Rose until he had suffered from a stroke a year earlier. They were both being cared for by their only daughter, Linda, who gave up her job to be able to do so. The following section is a description of the four case study workshops that were held over 11 months between September 2016 and July 2017. During this period, I used the MoM to interact with the group, including photographing the sessions and drawing some representations of missing elements from the family's collective archive of lived experience.

5.2.2 Description of the four workshop sessions with CSG1

In the following section, the four case study sessions with the ROSE group are described, focusing on key observations and developments both with regard to the participants' experiences and the development of the MoM. The ROSE group were from the Molineux Alzheimer's Café and were invited to partake in the study after the initial pilot sessions with the whole group (described in Chapter 3).

5.2.2.1 Case study workshop session 1: exploring the wardrobe 1

W1 was held after the Molineux Alzheimer's Café in the same room. We sat at a large table and once the Alzheimer's Café attendees had left, it was a private

and comfortable space in which to work. The purpose of the first session was to get to know the ROSE family and to identify and discuss garments of significance from their collective lived experience.

During the initial contact with the ROSE family, I had asked them to bring in garments of significance, photographs of important events and, where possible, the associated items of clothing. Items brought to the session included:

- A tweed cap, well-worn and belonging to Larry
- A christening gown, a hat made by Rose herself, a pair of booties – kept in a box – and a christening shawl made by Linda’s godmother
- A photograph album of Larry and Rose’s wedding day
- Camera
- Drawing tools.

Many of the items were held in high esteem by the family members and had been carefully kept in boxes and in organised photograph albums.

W1 was a relaxed and easy session, with Rose and Linda mainly leading the conversation while Larry contributed less frequently. All of the items presented by the participants had been looked after with care for many years. We discussed the christening gown and shawl, cap and booties, the photograph album and the tweed cap, which was one of three that Larry owns. Larry spoke about his garments sporadically although he did acknowledge that there are

some garments that he prefers to others. The conversation moved between the present with the garments of significance on the table and subsequently moved to the past. The items were very much part of the fabric of the ROSE family's lived experience.

5.2.2.2 Case study workshop session 2: exploring the wardrobe 2

The purpose of this session was to look for loosely manifested themes that might emerge from the co-constructed lived experience of the participants.

Garments and/or artefacts brought to this session by the participant included:

- Photograph albums of Linda's wedding
- Her son's wedding album
- Her parents' wedding album
- Camera, drawing materials.

W2 was held after the Alzheimer's Café in a small area off the hall. It was a little noisy at first but became quieter as the session commenced. This session was held with Rose, her daughter Linda and the facilitator/researcher. There was a lot of conversation around the theme of the colour red. We discussed how red and its related tones had consistently prevailed over the years in Rose's suits and the cakes and flowers for family occasions. Linda also made a connection between her mother's garment choices in the pink and red colour family and her own choices for family occasions. She pointed out that Larry's suits for family

occasions were often grey and had always been chosen by her mother. The two women discussed the grandchildren/children and co-constructed the intimacy between them as a family in their descriptions of their collective lived experience.

5.2.2.3 Case study workshop session 3: co-creation 1

The purpose of this session was to verbally and physically explore the theme of colour that had emerged from the previous two sessions.

Garments and artefacts brought to this session by the researcher/facilitator:

- Notebook
- Drawing pad
- Coloured markers
- Pens
- Camera.

W3 was held after the Molineux Alzheimer's Café. All three participants in the group ROSE were present. Rose started the session by speaking about her love of the colours pink and red. The family co-constructed the meaning of the referrals to the colour red by Rose. They spoke of Rose's father. Rose moved very easily between the past and present, supported by her daughter. Larry did not partake very much during this session. As we discussed the significance of the colour red for Rose, the researcher made notes and did some loose

drawings of some of the significant elements being discussed such as the red roses, red shoes and suits in different hues of red that were worn over the years.

5.2.2.4 Case study workshop session 4: co-creation 2

The purpose of this session was to co-create the MoM for Rose within this family group.

Garments and artefacts brought to this session by the researcher:

- Important family members were represented through photographs, which had been cut out of their borders
- Drawing tools (paper in a scroll and sheets, pencils, pens, markers)
- Scissors, tape
- Swatches
- Drawings of the missing items
- Photographs taken during the previous sessions
- Camera, drawing materials
- Artefacts brought to this session by the participants
- A doll named Suzy owned by Linda in the care of Rose
- The caps belonging to Larry.

W4 was held in Larry and Rose's own home. This session was quite different to the other workshop sessions. The space was a lot smaller and required some reorganisation to be an effective space for the co-creation and co-design to take place. Because the family were 'at home' in their home, it meant that there were revelations about objects and elements that were present in the ecosystem of the family but that had not appeared before.

All three participants were very comfortable and at ease. For example, Larry was much more at ease in this space and wanted to show me his garden. I had 'met' his good cap in the previous workshop sessions but was delighted to meet his work cap at his and Rose's home. The materials that I brought to the home of Rose and Larry were co-created by myself with them and their daughter Linda during the previous sessions. They included, among other things, photographs from previous sessions that had been cut out, photographs from family albums, drawings that represented missing facets of the family's lived experience, and swatches of different textured fabrics in various hues of red. As mentioned above, the space was limited, so we worked together on a large paper scroll that could be unrolled as needed.

The session facilitated a culmination of all the facets from the previous sessions. Important information pertaining to the people, events and hidden elements that had emanated from the sessions for the ROSE group were placed along that scroll. All three participants co-constructed their collective lived experience visually and tangibly using the scroll as a rough timeline. As the co-creation

process was taking place we also discussed how this could be manifested in a manner that would enable Rose and Larry to revisit the experience in the future.

Rose and Larry found it difficult to visualise how this might happen. It was important to Larry as the primary carer that she felt enabled to communicate her ideas within the group. The role of Linda was very interesting. She was deeply understanding of both her parents' situations and was also very much involved in the MoM project as an equal. She enabled her mother in particular to express herself by reminding her of past family experiences. This in turn enabled Rose to encourage Larry to express himself. It was important to ensure that Larry was comfortable and at ease with me – the facilitator. When the idea of an outcome that Larry and Rose could co-create together was discussed, Rose showed a lot of excitement about photographs and drawings that represented some of the elements from their shared lived experience. After much discussion, all participants agreed that the most practical outcome would be something familiar to Rose and Larry.

Within the intimate space of this family's life, the garments and photographs that had been explored existed as points of entry to deeper explorations of selfhood. It was felt by the participants that a visual family archive could be created that would collate all of the disparate elements that they had identified through the sessions. We talked about different format types and considered which would be most appropriate for this family. Although the scroll was a suitable format for the co-construction and co-creation of a visual family archive, the participants felt that a book format would be easier for Rose and Larry to manage and access as

Rose's condition worsened. The participants took it in turns to place different elements along the scroll, often struggling with and abandoning a linear timeline, as non-linear elements were juxtaposed with linear elements. All of the participants (including Larry, who had been less active in the previous sessions) worked actively together to co-create and co-construct the family's shared lived experience.

The final part of W4 was when I was invited to take a walk in the garden with Larry. On the way out of the door into the garden Larry reached up to a shelf and took down his work cap to wear while outside. The garden was a source of pride for Larry and it was during this period of time, without the input from the other participants, that Larry became more expressive and spoke about his interests. It was also the first time he mentioned living with his wife and dementia and how things were changing for them in the home environment.

5.2.3 Development of MoM with ROSE CSG1

I worked with the ROSE family group over a period of 11 months in total. As mentioned in Chapter 3, two pilot sessions were conducted with a group of attendees from the Alzheimer's Café prior to the workshop sessions. Within those initial sessions, some important elements of both family and personal significance came to light, which helped to both develop and respond to the MoM.

Rose was particularly interesting in her narrative recollections. The first, and subsequently repeated, story came from the first time that she held and smelled

a yellow woollen jumper that was part of the 'suitcase of stuff', owned by the researcher. There was something about the qualities inherent to wool that triggered the memory of herself being pushed into the local baths unexpectedly at the age of six. The heaviness and smell of that wool sweater enabled Rose to give a detailed description of the bathing suit that she was wearing 'filling' and extending 'with water' after she entered the pool: 'It filled with water and got all big.' This reinforced a strong emotional connection with her mother, which she expressed, as it was she who had immediately fished Rose out of the pool and comforted her. The recall and reliving of this memory for Rose was vivid and this story further led to a description of her sister's character – 'her' she says. 'Her was always a tomboy, not like me, her is still a tomboy, a police woman' (Transcription ROSE 2). This was the first time that Linda had heard the story of her mother being pushed into the pool. The MoM in a latent manner had unlocked this memory of the experience for Rose and further triggered vivid recollections of her sense of who she was at that time. This set a precedent for a different kind of discussion to take place. Once Rose had started to enter her emotional and physical self in the past through a trigger such as a jumper, she then went on to enter that space regularly during the sessions.

For example, Rose's description of herself as the 'girl with the red shoes' punctuated many of the sessions after that. She makes referrals to herself as not only wearing the red shoes but they also become part of her sense of who she is when she refers to herself as being red in all four workshop sessions: 'I was always red.' 'I'll always go red...' is a statement that appears and reappears

in different manifestations of her past. The response of the researcher/facilitator to this was to encourage Rose to talk about her connection with the colour red. The absence of any physical record or representation of the red shoes opened up an opportunity within the MoM intervention to recreate those shoes. This allowed the shoes to occupy a visual space that through their presence enabled the group to tease out their importance for Rose's sense of herself. As the sessions progressed, the presence of the colour red and related hues became more and more prolific. By excavating the meaning held within the past lived experience, Linda and Rose recognised that red and its related tones had punctuated Rose's whole life – from childhood to the roses on her wedding day and through to the garments that had consistently been chosen for significant family occasions.

During the process, it was noted by the facilitator that the participants moved between time and place quickly and with familiarity. Of particular note was the fluidity with which the family co-constructed their collective lived experience. During the co-creation sessions, the MoM took the form of a scroll to collect the autobiographical moments of personhood in a way that enabled the participants to visually regard an overview of the lived experience. The scroll was physically necessary to enable all participants to partake in the co-creation process in an enclosed space. This also enabled the participants to see the overview of their collective lived experience visually. When we discussed how to manifest the 'archive', the ROSE group decided that a book format would be the most

practical presentation for the family to use in the present and, most importantly, into the future. Figures 30 and 31 depict the co-design of the scroll.



Figure 30: Rose placing the doll onto the scroll



Figure 31: Co-creating the scroll – work in progress

5.2.4 How did the MoM help the participants of ROSE CSG1 to explore their sense of personhood?

In the case of the ROSE group, the MoM worked in a number of different ways, responding to, and evolving from, the sessions. Firstly, it enabled the verbal excavation of autobiographical material and other elements of importance from the lived experience of the family. The MoM subsequently responded to this co-constructed material by visually representing it where it had not existed in a tangible form previously. Finally, it became a repository within which the lived experience could be manifested.

As we excavated the family's lived experience by looking at the garments that were worn on important family occasions, it became apparent to all the participants that Rose had a very strong sense of who she was through varying

hues of the colour red. When probed further to think about the associations held with these various shades of red and pink, Rose was adamant that she still held both the colour and the wearing of the colour as essential to her sense of self. This was verified by and co-constructed with her daughter. Rose and her daughter meandered in co-tellership between the acknowledgement of her colour choice for garments chosen for ongoing significant family occasions and the memory of herself as a child wearing red shoes:

Linda: Even when my son got married earlier in the year, mum's suit was pink.

I: Oh... And did you choose it yourself, the suit?

Linda: You went for the pink...

Rose: Pink...

I: Beautiful.

Linda: And so all through her life it's been reds and pinks...

I: And do you think...

Rose: ...girl with red coat and shoes... was always red shoes...

I: Oh, 'cos you always had red shoes...

Rose: ...as a young, little 'un, you know (Transcription ROSE 1).

While speaking of herself in this manner she called on her daughter to verify her position: 'When you think about it, ain't I, Linda?' (Transcription ROSE 3). Rose often refers to herself in the continuous past as always wearing red shoes. 'I was always red... red shoes, you see ... (Unclear) ... the girl with red shoes' (Transcription ROSE 4).

It seemed that she had lived with red as a dominant colour for herself throughout her life. She openly spoke of the fact that her association with the colour red came from her memory of herself as 'the girl with the red shoes'. 'Up till today, I wore red' (Transcription ROSE 3). This was a theme, which ran through all of the sessions with this group. Similarly, when Rose is talking about her own father, the colour red reveals its significance on another level. Linda reveals the fact that her grandfather actually grew red roses.

Linda: 'But he'd grow them. He'd grow his own roses.'

To which Rose makes the connection between the fact that he always had one for her and she associated with the memory and understanding that it was her father.

Rose: 'And he'd always got a red rose and I always said, "That's my dad"'
(Transcription ROSE 3).

She speaks with the same kind of enthusiasm and emotional connection as she does about the shoes when she refers to her father:

Rose: 'Oh, it was always a red rose. He loved red. He went out, he'd put a red (Unclear) ... rose, drop it in ... Always had a red rose' (Transcription ROSE 4).

During CSG4, I showed Rose a drawing of a bathing suit and asked her to tell us about the experience she had when she was pushed into the water. Rose did not think that the bathing suit looked like the one she had worn but continued nonetheless to relay the story of being pushed into the swimming pool. The two big associations with her in terms of her feelings and the personhood around the event were both fear and comfort. She was fearful of the water and of falling in. She was deeply comforted by her mother being there to help her out of the pool.

I didn't go in the water as much as my sister. My mother used to take me in, you see, and then she'd see as I was alright and then she'd go into the water and I'd stand outside and then that once, somebody pushed me in and ... (Unclear). This was going back years and I was only little. I wasn't like me sister and me brother with it all. I used to go swimming but just one cross there and back. Not to the top. I never went to the top. It was just, get in the water, go to that one side and have a rest (Transcription ROSE2).

Linda was aware of the importance of many different elements of her mother's personhood and actively engaged with this during the sessions. For example, she brought a photograph of Rose's grandmother into the session. Rose subsequently talked about how much time she spent with her nan. She returned

a number of other times during the course of the session to speak about their relationship and how close they were. From here, Rose easily moved into talking about herself as a grandmother, talking about the closeness of her grandson to her when he was a young child. She visibly relives and enjoys this memory of that time and describes the character of her grandson in detail (Transcription ROSE 4).

During the final co-design session, Linda introduced a doll to the session. The doll represented an important element of Rose's lived experience and, as it was revealed, also her sense of self. The doll was in Rose's care and it transpired that Rose washed and dressed the doll's clothing once a week (see Figure 30). She talked about 'not leaving the doll out' (Transcription ROSE 4).

When she spoke about the doll she referred to it as being like a baby: 'I mean, that's a natural thing, int it? How you see a baby' (Transcription ROSE 4). Rose then went on to transport all of the participants back to her childhood when she was 'always with dolls'. The doll was employed as a point of difference, which highlighted the distinction between Rose and her sister and brother 'because I was always out with dolls ... playing with dolls, you see, I didn't bother with me brother or sister, and me sister's the same up till today' (Transcription ROSE 4). The doll represented a link to the Rose of her childhood, her position within the family, and how that position that she held then remained constant up to the present time. The doll could also accompany Rose into the ecosystem of her future self and become a named element of the ensemble that Rose could keep

with her as her cognitive decline deteriorated (see Figure 31: Co-creating the scroll, work in progress).

5.2.5 Interaction

As the material from the workshop sessions was examined and re-presented, the members of the family started to identify patterns of behaviour, which were repeated through the generations between mother and daughter. There was a subconscious transferal of habit and 'doing' that manifested itself in different ways, in the use of red and pink roses for the bridal bouquets of both the mother and daughter.

I: And do you think that you decided on pink – together?

Linda: I think it was just a natural colour to go for...

Rose: Yeah... coz the pink is what I always liked.

Linda: Yeah... we just wouldn't... it was just when we chose clothes for mom it's a natural colour. Isn't it? Look now...

I: You've had, er, something in the red or pink or burgundy line on every time we've met.

Linda: So, it was natural. It was sort of... not looking at the style of the suit, first of all going for the colour, wasn't it? Pink in the...

Linda: Pink in the bouquet as well...

I: ...Yeah, look at that...

Linda: You can see it, erm, following through, can't you?

Linda: It wasn't... it wasn't a thought, was it? It was just natural colour, the, the theme of the... (Transcription ROSE 2)

It became evident for Linda that her mother and herself had subconsciously repeated their individual choices pertaining to how they had both worn their veils on their respective wedding days.

Linda: If you look, there, the way that veil was there and the way you were wearing yours ... can you see? Until it's pin-pointed, you don't realise it. Now, I wasn't copying you on your wedding day, it's just what we have. Style's just there.

I: Yeah, it's innate.

Linda: Look at that, the way my wedding was and Mum's was. How similar. The way you choose things, but you're choosing the same, like the cake. You chose that cake for me, in pink and white, and I chose that cake for you in pink and white. We're doing the same thing without knowing. It's weird (Transcription ROSE 2).

It was present in the use of pink roses on two celebratory cakes – one that was presented to Linda on her 21st birthday, and one that the daughter gave to her mother on her 80th birthday.

Linda: I'm glad I found that picture because I know mum would want her in that. You're making me think, this was my 21st. Look at the cake.

I: Oh my, roses.

Linda: What I'm saying is, the way I chose her cake ... mum would choose that, for me.

Linda: It's making me think how much, unconsciously doing it, but it's there. Obviously, mum would choose that. I wouldn't choose that for myself. And look, that's the key she bought me and look at the backing ... can't see it but it's obviously pink.

I: That colour just features so much in everything ... pink and ... You've gravitated towards blues and maybe lilacs ... That's amazing ... that's your 21st ... Absolutely lovely. Did you have a party?

Linda: We just had people round, didn't we? But I picked that one up because it just jumped out at me, the cake. That was pink and I went and got, mum, the cake with pink on (Transcription ROSE 2).

The mother and daughter co-constructed many moments of lived experience in the sessions, with Larry contributing sparsely. Although quiet, Larry was confident in his sense of himself. When asked about his work garments:

I: And what would you have worn in the mines?

Larry: Just old clothes...

I: Old clothes, and a helmet, so they never, er, they didn't give you a uniform?

Larry: No, it was too hot in places. See, the less you wore, the better.

I: Okay, yeah.

Rose: Sometimes, you said you had to go farther in, don't you? Or...

Larry: Yeah, it's according where you worked.

Linda: The conditions must have been awful.

Larry: Yeah.

Rose: Cos, sometimes, like, when we first got married, you used to have to strip off no sooner as you come in.

Linda: Yeah, cos they like... showers then... they had the showers come... that altered everything, like, you know.

Linda: And, course, 14 when he first went down... Fourteen, weren't you, dad? 14 when you first went down?

Larry: No, 15 (Transcription ROSE 1).

His occasion wear, on the other hand, was always chosen by Rose, who had a strong sense of her own style and habits relating to garments of significance:

Larry: I always have 'em bought for me...

Rose: ...he'll say, "Well, what do you think?"

Linda: Well, you let mum choose it...

Rose: Well, you 'av, int ya?

I: Can I ask you, Larry, do you think that Rose chooses well for you?

Larry: I'm comfortable in 'em (Transcription ROSE 1).

These sessions were characterised by a lot of fun and laughter. The family had lived most of their time and lives together. Nevertheless, to have the space and time to reflect and co-construct that lived experience as well as co-create a visual archive together was a new experience for them (Figures 32–34). The shared lived experience was percolated through the garments of significance. The christening garment had passed through four generations of the ROSE family. Held within the fibres of the christening garment, the stories of four generations of the ROSE family were captured. Through the MoM, the stories pertaining to each of those generations and their specific contribution to the physical garment itself were explored by the participants. Parallels between Linda and her mother in physical gesture, style and habit were evident and enabled another level of reflection within which the themes of their collective lived experience were explored.



Figure 32: The scroll being co-created by all three members of the family



Figure 33: The scroll being co-created by all three members of the family



Figure 34: The scroll being co-created by all three members of the family

5.2.6 Summary

The elements of personhood that were mapped on to Neisser's (1988) five senses of self provided a structure upon which to begin the investigation. In this way, the PLWD (Rose) remained central to the process. The senses of self and elements of her personhood were woven around and through the participant and her family members, Linda and Larry. Referring back to Neisser's conceptualisation of self, the ROSE sessions revealed that the participants' history of their shared selves was built and populated through their interrelationships and interactions. This manifested in their interpersonal selves through multiple references to their grandparents and great grandparents, and in

their extended selves through the shared family celebrations that were deeply resonant with meaning and illustrated continuity of self over generations. This history was also evident in their private selves when we witnessed Rose openly speaking about her fears and facing them with courage, evident in the recognition of each other's worth within the family unit. It surfaced in the individuals' self-worth and informed collective self-worth as a family.

The ecological selves of the ROSE group created a suitable space, which was a holding space for the family to interact both outside and inside their home, in that they were comfortable in each other's presence and secure in the knowledge of shared love and attachment. The grandchildren ran between the different family homes, secure in the knowledge that they knew where they were going and were beloved to their grandparents. Similarly, Rose adored her grandmother and spent many hours in her company. The continuity of that intimacy and attachment was validated in the garments handled and carefully put away for safeguarding – the christening gown, modified for each new generation, the booties, the box wherein the booties were kept, the bonnet. Their shared joy was evident in the marking of important family events such as the baptisms, weddings and birthdays that were given significance through modifying garments for the occasion and shopping for new special garments and then through the acknowledgment of the value of those garments. Their conceptual selves were explored and continued through their shared sense of security, their significance in each other's world, including their acknowledgment of the different uses of different kinds of garments. For example, when Larry

talked about his work clothes he was clear about the type of clothing he needed to wear. Evident here, along with his private sense of self, was his conceptual sense of himself, manifested in the description he gave of the everyday garments that he wore to work. For example, this was present in the two caps that were designated by himself, specifically for good wear and garden wear. Larry loved his garden; the association with practical use around his caps gave him, through the caps, a story to tell, a sense of himself to relay. The cap was either worn on his head or folded up and kept in his pocket when he was inside. In figure 35, Larry is reaching for his garden cap which was kept beside the good cap on a specially designated shelf for both caps on the way out to the garden



Figure 35: Larry reaching for his garden cap

Similarly, in a moment of discussion, all of the participants looked at and reflected upon a very old photograph of one of their ancestors wearing an apron. In Figure 36, Rose's grandmother is sitting with the beloved family dog. She is wearing one of two aprons over the only dress that she owned at that time. Through co-construction, the women considered the difficulties of poverty and the fact that this woman had two aprons only: one for everyday work, and one for Sunday best.



Figure 36: One of two aprons

These few examples illustrate that clothing was tied into their habits as a family and that there was (and is) an ongoing awareness of the significance of clothing held within that family. Hence, using clothing as a starting point to look at habit and relationship brought forth information pertaining to personhood and self that may not have surfaced without a focus on such garments of significance to start with. The MoM was an overarching framework that observed, provoked, and adapted to fit where necessary.

5.3 Case study group 2: IRIS

My lived experience through clothing



Figure 37: IRIS group: At the heart of my own ecosystem: My lived experience through clothing

5.3.1 Introduction to IRIS case study group 2 (CSG2)

The second CSG, IRIS, consisted of a woman, Iris, and her two daughters, Annie and Tina. Iris was 85 years of age and had mid-stage dementia. She was diagnosed four years ago. For the first three years, Iris was living at home with her daughter Tina, but had since moved to live at the ATU care home in Ireland. From the conversations as well as the observations, it became clear that over the last year, Iris was very distressed and appeared to be unhappy with her daughters for moving her to the ATU. Therefore, the two daughters would only visit their mother together because there was less likelihood of her getting upset. Both daughters were tentative and visibly nervous about the potential interaction with their mother.

Figure 37 shows the lived experience through clothing of the IRIS group. Iris is at the heart of her own ecosystem of garments, family and other items of significance.

5.3.2 IRIS CSG2: description of the four workshop sessions

Prior to W1, I had two observation meetings with the IRIS group where the MoM: Caring Through Clothing project was discussed. During this initial contact with Iris' daughters, I had requested that they bring in garments of significance, and photographs of important events. The following section is a description of the four case study workshops with this group, which were held between January and July 2017. Over this period of time, I used the MoM to interact with the

group, to photograph the sessions and to draw some close-up moments of tactile interaction that Iris and her daughters had with the garments.

5.3.2.1 Case study workshop session 1: exploring the wardrobe 1

The purpose of this session was to get to know Iris and her daughters Annie and Tina and to identify and discuss garments of significance from their respective lived experience.

Garments and artefacts brought along to the session included:

- A beige woollen cardigan, hand-knitted by Iris for Tina
- A yellow woollen jumper hand-knitted by my great aunt
- A child's silk dress collected item by the researcher
- The wedding photo album belonging to Iris and Sam held by Tina
- The beige woollen skirt hand-knitted by Annie for Tina to go with the cardigan above
- A fluffy beige lap blanket, which Iris kept with her at all times.

W1 was held in the large dayroom of ATU. We took over a table in the corner of the room and pulled another table close, on which to place the garments. Many of the items, which they identified as having importance or significance, were pieces that Iris had knitted for herself and her daughters as well as one item that Annie had knitted for herself under Iris' supervision.

Iris arrived with her daughter, holding a mid-sized beige polyester fluffy blanket that she arranged around herself as she was sitting down. Although this item was not officially part of the selection, it is mentioned here because it became an important part of the co-design process. We sat in a circle around the table with the garments on the table. During the session, a discussion was started about each garment in turn. Each garment caused Iris to sit up and engage as it was introduced. Iris showed surprise that she had knitted the garments herself although she was quickly able to recall the 'doing' of the garment. Iris could at times get frightened and distressed when asked to look at something directly. This distress was based on her lack of ability to see and therefore she felt that she could not engage. However, when Iris was invited to touch something, she was easily able to engage, visibly relaxed and started to engage on a 'being' level. Iris talks about the world that she grew up in as being a safe place, where objects were made and washed by hand. She notes the difference between the two worlds.

Iris: We had no machine at that time.

I: So, you'd hand wash that as well?

Iris: It's like another world that I grew up in, but 'twas a very safe world
(Transcription IRIS 1).

The following dialogue occurred during the workshop session when the group was introduced to a child's silk dress and slip from the 'suitcase of stuff'. From

the moment that the garment was placed in Iris' hands, she began to relate her thoughts and ideas about the garment.

I: This is actually silk – feel that. It's a handmade baby's dress.

Iris: Oh yeah.

I: From my family again.

Iris: It's a very fine weave.

I: It is, isn't it?

Iris: Very fine... you'd be cold in that.

I: You'd need thick underwear, that's for sure. I think it's probably a slip.
Can you feel the way they do they edge?

Iris: Yeah, that'd be done on a machine I'd say.

I: I don't know.

Iris: Done by hand?

I: Done by hand.

Iris: It's like a kind of backstitch.

I: Almost like a backstitch, or even like a miniature blanket stitch.

Iris: They start on the left and work backwards.

I: Do you feel the organza on the bottom as well?

Iris: Yeah. Is that a kind of lace?

I: It's more like a frill.

Iris: Is that lace on the bottom?

I: A frill...

Iris: An extra.

I: Yeah, an extra little bit.

Iris: Or is it just an extra thread?

I: Yeah, do you want to...?

Annie: It's gorgeous, the stitches are so fine.

I: I know – it's so fine.

Annie: It's incredible; that's phenomenal (Transcription IRIS 1).

Iris and her daughter Annie engaged with the garment and Iris felt it very carefully with her fingers to discover the material and how it might have been made. Iris also related the handle and feel of the material with being cold and this emanated from her experience of garments and making from her implicit memory bank. Iris identified the type of stitch used and then the method used in making the piece, stating 'they start on the left and work backwards'

(Transcription IRIS 1). During the discussion, we explored Iris' early days when she was at primary school. Her daughters prompted her to tell the story of her first sewing work, described by the teacher as 'cat's teeth':

Annie: Mum, tell I when you were in primary school in Kilgeveran and the teacher when she picked up your sewing, what did she call it? Was it Mrs Lynch?

Tina: Yah.

Iris: Eh?

Annie: Mrs Lynch – what she said about your sewing?

Iris: What she said about my sewing?

Annie: I bet you'll remember as soon as I say it. She wasn't happy with it

Iris: Oh, I'm sure she wasn't – she wasn't easy to please.

Annie: She held it up and said, "Cat's teeth". I bet you remember it now!

Iris: Cat's teeth is right, yes – one stitch was longer than the other.

I: Yeah.

Iris: Cat's teeth, haha.

Tina: Little did they know how....

Iris: I was very friendly with her daughter.

I: Were you?

Iris: What was her name... Freda. She'd say, "She drives me, she didn't... she gets on my nerves", she said about her mother.

I: Oh really, about her own mother? (laughs)

Iris: Oh, she was very cross (Transcription IRIS 1).

Here, Iris talks about being scolded by her teacher for her bad sewing. At this stage, the two daughters asked her to tell the story of the cat's teeth. Iris smiled carefully and was not sure of the memory at first but then with the help of her daughter's prompts she was able to relay the story and this led to a second story about the teacher's daughter. Iris then talked about cycling to secondary school, the school uniform, bringing fuel to school, and her experience with the nuns.

Iris: We could walk to school from where we were.

I: The primary?

Iris: For the secondary school we would cycle in; it was tough.

I: What was tough?

Iris: We were tough.

I: You were tough (laugh) – and did you have to take fuel to school?

Iris: We did in the primary school.

I: A bit of turf?

Iris: Bits of turf and sticks.

I: To keep the fire going?

Iris: Sods of turf... My God I, it's like another world.

I: But is it clear?

Iris: Oh, I remember it – what I mean is the living is like another world, everything is switched on.

I: Yes, very different.

Iris: Very, very different – we were worked hard but it didn't do us any harm.

I: No.

Iris: We were fit (Transcription IRIS 1).

The discussion then moved on to Sunday clothes for mass. The use practices around these garments were very specific and related to being presentable for visitors or wearing the best clothing if one was visiting someone in their home. The conversation moves through into a description of going to Tuam to buy good clothes. Iris enters into a kind of living memory when she talks about the thrill of going to Tuam.

I: And would you buy them in Galway?

Iris: No, there were some good shops in Tuam.

I: Oh, in Tuam...

Iris: There were a lot of shops at that time.

I: And was there like a department store in Tuam or was it more like a drapery?

Iris: A drapery. There was Anthony Ryan's, which was the drapery shop. A few more... I forget them now.

Iris: That was when I was living at home in the country. Oh, it was a great thrill to go to Tuam (Transcription IRIS 1).

At this point in the discussion, Iris closed her eyes and took a moment to remember the feeling from her past.

The conversation then moved on to the differences between general sewing and knitting practices at that time and now. When asked if she would wear a scarf, Iris said that she used to. The conversation then moved into the present and Iris said that she would only wear a scarf now if it was cold. One of the final moments of the session was when Iris took the edge of the cardigan that her daughters had brought to the sessions into her hands and questioned its physical construction.

Iris: I don't know – did I knit this one?

Annie: You did.

I: You did, actually, and it's absolutely lovely. Actually, it feels like a tighter knit than the other one, doesn't it?

Iris: You'd have thicker needles to get the loose knit, and then you'd bring it down a shade or two to get the tighter...

I: Oh, would you?

Iris: Is that knitted with it? That wouldn't be knitted on the...?

I: ...the edge?

Iris: There – the binding there...

Annie: You know, I think I sewed that on, I remember.

I: Really?

Annie: The edge was knitted separately; the collar, I think I...

I: And then you stitched it on afterwards? And what was the skirt like?

Iris: Oh, God knows.

Annie: It was long and it was much plainer than that, now; it didn't have the cables. It had a little cuff at the bottom, Tina, didn't it? And it was all plain for ten, maybe 12, stitches and then a little ridge every ten to 12 stitches.

Iris: It was a plain fitter to fit better.

Annie: It was straight.

Iris: It didn't spread as much – you know, the different stitches
(Transcription IRIS 1).

In Figure 38, Iris is shown reading the garment. Iris then proceeded to talk through the co-construction of how the garment was initially made by herself and Annie. By the end of this session, all three participants had gathered around to hold and feel the garment while discussing its construction. Figure 39 is a drawing of the three women holding this garment.



Figure 38: Iris holding and 'reading' the edge of the cardigan



Figure 39: All three member of the IRIS group touching and holding the knitted garment

5.3.2.2 Case study workshop session 2: exploring the wardrobe 2

The purpose of this session was to observe the relationship between Iris and her daughters while identifying, assessing and further discussing garments of significance/cherished garments. It must be noted that this meeting was postponed at least three times due to Iris being unwell and for this reason, her daughters were quite tentative. Before the session, they expressed concern that their mother might not be in a good frame of mind to partake. However, once the session had started, Iris was eager to participate.

Garments and artefacts presented by the participants:

- A knitted purple jumper made by Annie

- Iris' wedding dress, which had tiny silk-covered buttons on the sleeves
- The christening blanket
- More family photographs of the girls wearing dresses that Iris had made, including one of the grandchild being christened in the blanket
- The fluffy beige lap blanket that Iris kept with her at all times.

W2 took place in Iris' room for privacy. She was very comfortable with everyone being there and seemed to be content with the presence of a number of garments around her.

She held the nubbed protrusions of the christening blanket between her thumb and forefinger while gently rubbing them. Figure 40 is a drawing of Iris holding a purple velour knitted jumper. This jumper was loosely knitted with blackberry stitch 'bobbles' and Iris held a bobble between the two same fingers while she spoke. She felt along its edge with her fingers and hands and found the yarn, which was a type of velour, to be cold, commenting that it was 'damp-ish'. Iris engaged with the talk about knitting quite a lot and mentioned the click-clack of the knitting needles.

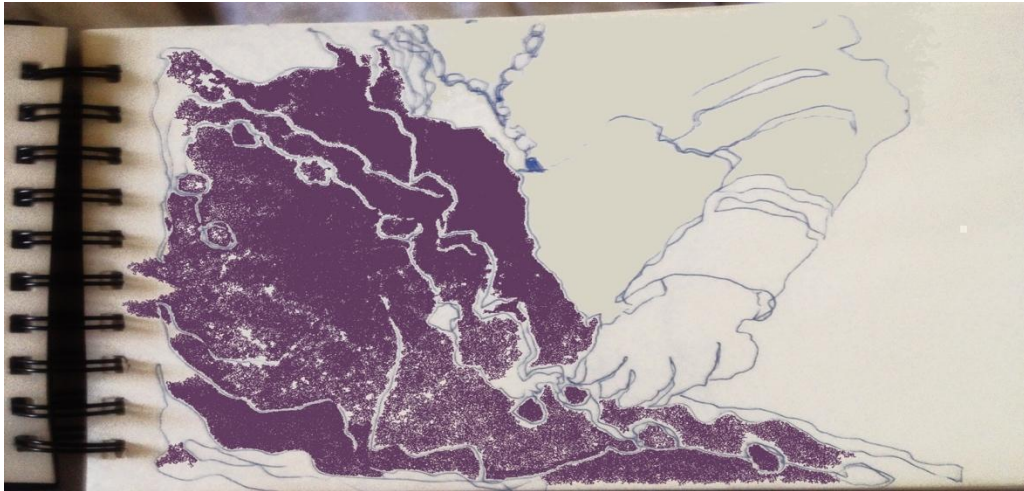


Figure 40: Iris holding the knitted nubbles on the cardigan as she recounts the process of knitting it

Later, when looking at her wedding album together with her daughters, at first, she was resistant to look and only showed interest when all three were looking at a photograph of her in her wedding dress. She found the feel of the wedding dress to be cold also.

I: The girls actually brought in your wedding dress today ...

Iris: Oh ...

I: I'd say it's a while now since it's ...

Iris: I can feel the cold ...

I: Yeah, yeah!

Iris: That was my wedding dress – 'twas a homemade one.

I: Do you remember who made it?

Iris: Oh, I didn't make it; I wouldn't make it, not at that time, anyway.

I: But it was someone you knew, was it?

Iris: Somebody I knew, yeah..

Tina: Do you remember her name, mum?

Iris: No, I don't.

Tina: It was Mrs Webb, wasn't it?

Iris: No, I don't think she'd be able to make it, either. But anyway, it was somebody who knew somebody; do you know what I mean?

I: I'll hold it here, but I want you to feel ...

Iris: I know ...

I: It's cold, isn't it?

Iris: ... hanging in the wardrobe... oh, the little buttons ...

I: Buttons – and they were covered using the same material.

Iris: What material is it?

I: Like a damask?

Iris: Okay ...

I: Silk?

Iris: (Unclear speech) ... in England, of course ...

I: I do ... There are two buttons on this side ...

Iris: And those are the sleeves, aren't they?

I: Those are the sleeves and the cuffs.

Iris: Where's the wedding album?

I: It's here.

Tina: Did you want to have another look at it, and you can feel it, mum?

I: Actually, it's a beautiful album.

Tina: It's gorgeous.

I: It's really beautiful.

Iris: You can take it home with you in case something happens to it.

Annie: Take it home, bring it in whenever you like to look at it.

Iris: I can't see it, really.

Annie: It's nice just to have it in your hand, though, isn't it?

Iris: I know.

Iris: Even just to feel the cover.

I: The cover is lovely.

Iris: ... lovely album ...

Tina: Yeah.

Iris: At that time, they were kind of papery ... you know, dad, God rest his soul ...

I: Did you look at it together, sometimes?

I: Did the two of you look at it together?

Iris: We did, of course. (Transcription IRIS 2)

The theme of colour and the loss of her sight ran throughout the session once more. Iris got quite anxious about not seeing things and the world in the way she used to. She talks about being interested in sewing and knitting – so it was not just a practical way of saving money for Iris. Sometimes when Iris lost the thread of a conversation she would revert to saying something about garments. For example, at one stage she forgot where she was going in the conversation and shifted quickly from silence into old cardigans and jumpers: ‘ ... there was always knitting in our house from the day I could walk’ (Transcription IRIS 2).

Iris went on to talk about remembering and described the physical process of actually knitting something. ‘That’s how I remember’ (Transcription IRIS 2). Iris then described the process of knitting another piece, which was brought in – the christening shawl/blanket. This was a very active session with a lot of

engagement from Iris and both of her daughters. Figure 41 shows a drawing of the items on the table in Iris' room. Figure 42 is a photograph of the same items, the child of Prague, a Brigid's Cross, a crucifix, a wedding photograph of iris with her family, and a statue of the Virgin Mary. Iris took a lot of comfort from having these items close to her and would refer to them in her conversations.

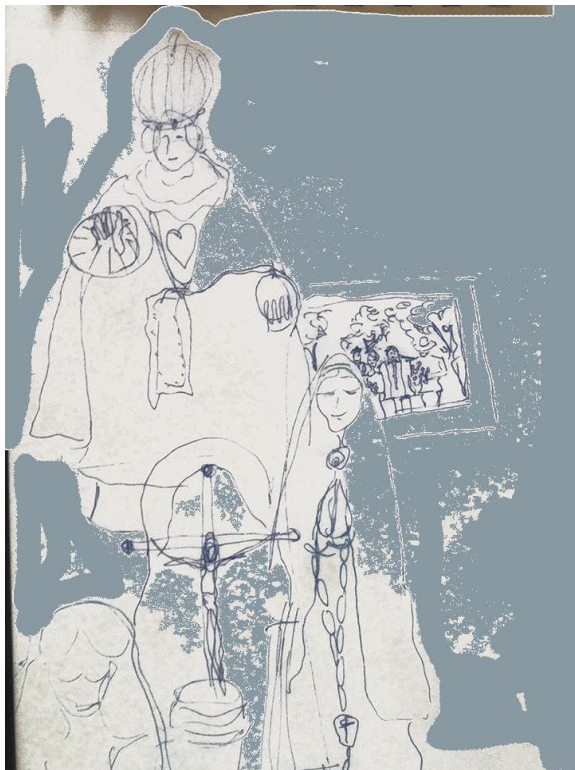


Figure 41: A drawing of the items on Iris' desk in her room



Figure 42: The items on Iris' desk in her room

5.3.2.3 Case study workshop session 3: co-creation

The purpose of this session was to discuss the co-creation of the MoM artefact with Iris' daughters. Tina was unable to attend at the last minute. This meeting took place in the Meyrick Hotel in Galway. The meeting had been due to take place over a number of months but because Iris was unwell it had been cancelled three times, and she was not able to attend. Because the meeting place was in a public place with background noise the session was not audio-recorded, but notes were taken during and after the session.

Garments and artefacts provided by the researcher:

- A leather-bound book containing the following:
 - Photographs and drawings from the previous sessions
 - Phrases and co-constructed narrative from the previous sessions.

During the previous sessions, I had taken many photographs of Iris and her two daughters handling the garments. I also did a series of drawings of all three participants' pairs of hands interacting with the christening blanket together. After the second session, I printed ten of the photographs, copied some drawings and printed the transcripts from the previous sessions with Iris' narrative as spoken text highlighted for her daughters to see easily. I placed there in a leather book as a series of images and words for Iris and her daughters to look at and interact with. The co-design process took the form of a deep reflection on the images, phrases and possibilities for Iris and the family. We discussed the fact that their mother was very unwell. Iris was not eating or interacting with her family much. Her daughter informed me that Iris had been quite sharp in her interactions with them. She had gone into hospital and come out very weakened in body and spirit. We discussed the blanket that Iris insisted on being wrapped around the middle of her body, cocooning her waist and upper legs most of the time.

Annie engaged with the material in the book and together we went through the images and phrases that had been taken and recorded during the previous sessions. The images of her mother holding the garments with such intent and

presence really struck Annie. So too did the snippets of conversation where all three participants had discussed the making process. Annie felt that the collated material from the initial sessions was a good start for the MoM process and asked if she could take it with her to include her sister in the co-design process. Annie reflected on a conversation that the three of them had in one of the sessions where they discussed the making of the knitted suit. Annie got very excited by the prospect of maybe making something together with her sister and mother for her mother to have with her. She identified the lap blanket that her mother kept wrapped around her all the time for warmth and comfort and thought that if they could create something similar together it would be a meaningful intervention. We then went through the images and phrases and extracted those that demonstrated a sensory or tactile connection for Iris. The nubbles, the blackberry stitch, the blanket that Iris kept around her – all of these had particular sensory and tactile qualities that Iris had recognised and to which she was drawn. Figure 43 shows Iris holding the nubbles of the christening blanket. Wrapped around her torso is the beige blanket that Iris kept wrapped around her middle and legs to cocoon her.



Figure 43: Iris enjoying holding and feeling the nubbles on the blanket

5.3.2.4 Case study workshop session 4: co-creation and discussion of the premature completion of the project

The fourth case study workshop session W4 never took place. Two days after the last meeting with Iris' daughter Annie, Iris passed away unexpectedly. This was quite a shock for the family and they were very upset. They requested that the leather book, which we had curated with the design inspiration material from the previous sessions, be used during the wake and funeral. They also asked if

we could meet one last time to debrief and either discuss the return of the book or whether or not they would like to keep the book.

5.3.2.5 Final meeting

The final meeting took place with Annie and we discussed a number of questions concerning the MoM process as it had evolved with herself, her mother and her sister. Annie and Tina felt that they and their mother had been positive and happy during the case study workshop sessions. After her death, they wanted people to experience aspects of her personhood and lived experience, particularly her creativity.

5.3.3 Development of the MoM during workshops with IRIS (CSG2)

The development of the MoM with the IRIS group was both an excavation of the lived experience of the three participants and the co-creation of a 'map' that enabled continuous accessibility of that lived experience both as individuals and within the family. Annie, the younger daughter, felt that the MoM process was a very positive happening in the lives of the three women. It was made known to the facilitator and reinforced by Annie, the younger daughter, that the MoM process was a very positive happening in the lives of the three women. Iris' daughters felt that the interaction between themselves and their mother was both creative and positive. As mentioned previously, all three group members

were tentative at first but became more relaxed as different items were introduced and discussed.

Iris had, through the sessions, entered into an engaged and active interplay with the garments presented. She was very humorous in her discourse, highly perceptive and at times it became evident that between her daughters and herself, a 're-acquainting' was happening. Iris entered into states of mind and body where she was 're-living' lived experience. She reinforced and supported both of her daughters' sense of self through the garment discussions. This will be discussed in more detail in section 5.3.4.

The workshop sessions were extended by further conversations with Annie, where we discussed her mother's creative ability and the parallels with her own creative journey. Annie wanted to engage with the co-creation process as much as, if not even more than, her mother. Working with the women in the IRIS group revealed the complexity of family relationships. It also showed that cherished garments have the capacity to subtly unravel some of those complexities.

The iteration of the MoM that enabled that co-creation process with the IRIS group consisted of three main tangible elements. The first two were the readily available tools that could be used to access and reinforce the collective lived experience of the family. As with the ROSE group, the initial garment that was introduced in session 1 was the yellow woollen jumper from the 'suitcase of stuff'. This enabled a whole series of interactions and discussions that were sometimes constructed by Iris alone in answer to questions from the researcher.

The third part of this was the drawing of hands from the sessions. The two daughters did not participate in the drawing process but did partake in a discussion about knitting Iris a lap blanket. Through the collective excavation, individual moments of personhood were revealed such as the co-created elements that represented the group's lived experience; storytelling that was co-constructed by Iris and her two daughters around the garments of significance; and a series of photographs and drawings of interactions through the artefacts, which were done during and after the sessions.



Figure 44: All three family members co-designing through shared storytelling together

Figure 44 is a drawing of Iris and her daughters discussing the possibility of working with their mother to make something for her while holding a blanket

together. The MoM process instigated the co-creation of something knitted and tactile. Although it was clear from Iris' responses that she felt unable to make something herself because of her sight, her interaction with the garments, her recall of events associated with some of the garments and her physical descriptions of 'doing' the knitting showed an engagement that surpassed limitation of the physical. By entering into the space of holding and sifting through the soils of her memory, Iris was capable of 'doing' mentally when she could no longer 'do' physically. The expected outcome of a co-created lap blanket for Iris never came to pass. The blanket had been intended to hold all of the textures that Iris had recognised in the sessions. It was to be knitted by both Annie and Tina and was to be based on their shared observation that Iris had always held a lap blanket close to her that she wrapped around herself. Instead, an unexpected outcome emerged when Iris' daughter emailed to tell me that the family had chosen to bring the leather book with transcripts, drawings and photographs to Iris' laying out ceremony. The family also used some of the photographs from the sessions in a slideshow at the funeral. This material had all been shared with the family during the discussions to create a co-designed blanket.

5.3.4 Exploration of personhood for IRIS (CSG2)

Neisser's framework (1988) once more defines how different dimensions of self can be manifested in the participants' actions. For example, Iris held a cardigan in her hands, which she had knitted for her daughter 28 years previously. When asked if she would like to keep the garment, Iris decided that she would not

because she would 'roast' (Transcription IRIS 1). The daughter who brought in the cardigan made a point of saying that she did not want to lose it even though the mother was wearing it. From this short interaction, a number of things were revealed: firstly, the garment was a physical symbol of the interrelationship between the mother and her daughters. This falls into Neisser's 'interpersonal self', which is the self that exchanges with another through giving, negotiation and play. There was an interesting moment of interplay and fun where Tina iterated that she would have the cardigan returned to her and their mother would not really be allowed to keep it. Iris was very aware of her sensory surroundings, particularly feeling the surrounding temperature or commenting on how a garment might affect one's ability to be warm or cold. These acknowledgments of her environment were illustrated in her narrative from IRIS W1. For example, when commenting on a child's silk dress: '[It is] very fine... you'd be cold in that' (Transcription IRIS 1). On another occasion, when handling a thick woollen jumper, Iris engages in a very playful way: 'Where are you going... to the North Pole?' (Transcription IRIS 1). This featured in Iris' discourse quite a lot and fell under the 'ecological self'. Iris was reassured by her daughters that the garment would not make her too hot. A light and playful exchange ensued over this, which is indicative of the 'extended self'. There was a sense of purpose and continuity as the garment was then committed to return to its keeper within the family, after doing the rounds within the group.

Iris did not appear to remember much from her early days but when asked if she wore a dress when she was small she answered clearly and made a humorous

comment about being blind: 'our mother would make a dress, she was into sewing and I made dresses as I got older. We learnt to sew at school but... no wonder we're blind' (Transcription IRIS 2). Her ability to seamlessly move in a non-linear fashion, between the past (where she wore a dress made by her mother) and the present (where she acknowledges the effect of making dresses in the past on her present sight), showed a keen sense of her 'conceptual self' in the significance of the continuity of self through the everyday clothing of a dress. Her 'extended self' was represented in her acquisition of her mother's talent of making dresses. Later on in the session, Iris would return to the act of sewing and talked about how much she enjoyed it. This showed the continuity of her 'extended self', along with her 'interpersonal' self through relationships within the family.

Iris easily talked about herself and her experiences of clothing throughout the sessions. When asked whether she preferred to be comfortable or stylish, Iris responded that she liked 'a bit of both'. This would imply an understanding of the purpose of the clothing she was wearing. Again, the 'extended self' comes into play as she acknowledges the existence of significant garments for Sunday wear only. These, she states, were more expensive than the everyday clothes and were 'taken off after mass' unless the family was 'going visiting'. We also discussed Iris' time as a trainee nurse in the UK and Iris acknowledged that she would have a scarf for every outfit at that time. This revealed a series of habits and practices around the wearing of her garments that held significance as social practices as well as interpersonal senses such as belonging and

compromise. Iris talked about the 'great thrill of going into Tuam' (Transcription IRIS 1), and this thrill was evident in the way she recounted the memory.

5.3.5 Moments of interpersonal exchange between the person living with dementia and the carer/family members

Each of the participants in this group was engaged, vocally, quietly. Many moments of sorrow, joy and visible pain were shared and co-constructed by the three members of this group. The participants were eager to listen to one another and prompt one another. Through the lens of 'garments of significance', they spoke of celebrating family events wearing garments of their own and spoke of making and the 'doing' of garments. Many of the elements from the MoM framework collated. One example was when the family started to speak about the wedding dress. Iris immediately took the narrative to another place and started to recite the song that her husband sang on their wedding day. Her daughters were able to engage with this as they also remembered their father singing. In Figure 45, Iris had placed a photograph of herself and her husband on to their photograph album. She had held on to the cut out photograph of her and her husband during the session and eventually, towards the end, placed it on the cover of the wedding album.



Figure 45: Iris places a cut out of herself and her husband on their wedding album

Iris: He sang 'I'll walk beside you' on our wedding day.

I: Did he?

Iris: Did you know that song?

I: No.

Iris: 'I'll walk beside you through the world today, while dreams and songs and flowers bless your way, I'll look into your eyes and hold your hand, I'll walk beside you through the golden land, I'll walk beside you through the

passing years through days of cloud... I'll walk beside you through the passing years through days of cloud and sunshine joy and tears, and when the great call comes the sunset gleams I'll walk beside you through the land of dreams.'

I: Ah, beautiful.

Iris: He was a lovely singer.

I: Beautiful. Did he sing that on your wedding day?

Iris: He did.

I: Ah, that's lovely.

Iris: He sang that on our wedding day. He said that would be our song now.

I: And you still remember it – you'll always have that.

Tina and Annie: Yeah.

Iris: I do, of course (Transcription IRIS 1).

Present throughout the narrative were 'interpersonal' exchange, the 'private self', the 'ecological self', the 'extended self' and the 'conceptual' self (Neisser, 1988), leading to moments of celebration, holding, facilitation (Kitwood, 1997), curiosity, collaboration, consideration (Dewar, 2011), belonging, purpose, achievement, significance (Nolan et al., 2006, 2008). There were co-constructed

narratives such as the story of the making of the skirt, the christening blanket, the velour jumper, and moments where Iris was clearly 'living in memory' and burst into recitations, which, although related, were moments of non-linear exchange.

Although it is beyond the scope of this research to look at exploring personhood and sense of self for the carers, a number of moments did present themselves. Below are two extracts, which indicate that the MoM project with the IRIS group was also useful for them.

'I was really blown away with our sessions with mum, and it's brilliant to have the photos, drawings and transcripts. I used some of your photos in the slideshow at the funeral, finishing it off with the photo of mum sitting alone wearing the cardigan and her dressing table with her statues, photos and St Brigid's cross – it was very poignant.'

Walsh (2017)

'Thanks so much for everything, you really have no idea how much our meetings have helped me and you evoked memories in me as well as mum. It's just such a pity I didn't get the blanket done for mum and that she didn't have a period of comfort and solace in her blanket.'

Walsh (2017)

'Thank you so much for your emails & texts. Your lovely sentiments are a great consolation to us. Mum looks so happy... We brought photos, the

wedding album, one of the girls' Granny projects and your lovely folder for people to look at while they were standing in line yest[erday] evening – it was lovely.'

Walsh (2017)

5.3.6 Summary

The study showed that although the work with the IRIS group ended sooner than expected, the research did have a positive impact on all the participants before and after the death of their mother. During the period of time with the IRIS group, personhood and lived experience were visited and re-visited through the garments. Memory was accessed through narrative and co-construction of lived experience, and the garments and textile artefacts proved to be integral to the lived experience of all three participants – they acted as tangible physical provocations that generated narrative of past and present lived experience. There were moments of sensitivity of self that were explored by all members of the IRIS group. The focus was primarily on the garments as holding connections between the family members. This family's lived experience had been difficult, and their communication had been breaking down since their mother had been moved into the nursing home. Therefore, the introduction of the garments was an entry point for exploration of personhood, which was evident through Iris' descriptions of herself nursing, getting married, cycling to school and shopping in Tuam (Transcriptions IRIS 1 and 2).

The 'ecological self' was present in Iris' descriptions of being cold or affected by the temperature, in her easy recollection of places from her past. The daughters were attentive to their mother's ecological awareness and that led to a number of interpersonal exchanges between the three, which were pleasant and easy. They co-constructed a number of stories around the garments present, which, in many cases, they all had some connection with through making or wearing and or both. The 'private self' was evident in Iris' confidence in her ability to relay the knitting process, the recounting of continuity of herself through the years at different stages of personhood. Iris had a positive feeling of self-worth as both sessions ended at a point at which it was evident that her more tentative self had relaxed as the session had progressed. Both Annie and Tina individually showed moments of recognition at the magnitude of meaning behind those knitted garments. Evidence of the family's creativity was clear and was also manifested through the garments, as the timelines of the garments were woven into the co-constructed narratives. Also present was continuity of self. Both the 'private self' and the 'extended self' were evident through recognition of celebration and achievement. Finally, the conceptual self was evident in Iris' descriptions of garments through the years. Her security was in the descriptions of knitting and her deep physical connection to the making of garments, as a counterpoint to how she felt she was perceived by others as she went blind, and her subsequent reluctance to engage with anything physical because she could not see.

5.4 Case study 3: VIOLET

My lived experience through clothing



Figure 46 VIOLET group: At the heart of my own ecosystem: My lived experience through clothing

5.4.1 Introduction to VIOLET case study group 3 (CSG3)

The third case study group consisted of a woman, Violet, who was 73 years old and living with mid-stage dementia. Violet lived together with her carer – her husband Jim, who was 76 years of age. At the start of the study, they lived at home together in their house in the countryside in Ireland. They moved to Ireland primarily to look after Violet’s brother, who also suffered from dementia. They had five children, three of whom were adopted. Their children lived in the UK. Violet deteriorated very quickly from the time when I first saw her in February 2017. Each time that I met with the couple, her ability to function had deteriorated more. Jim moved from helping Violet to manage their household together to managing everything alone – from cleaning, cooking and paying the bills to helping Violet with the daily tasks of bathing and dressing.

5.4.2 Description of the four workshop sessions with CSG3

The following section is a description of the four case study workshops that were held over 11 months between February 2017 and January 2018. Over this period of time, I used some elements of the MoM to interact with Violet. For example, I photographed the sessions, encouraged Violet to engage with her own garments and drew images of some moments from the sessions of Violet interacting with her garments. Prior to W1, there had been an observation meeting with both Violet and John where the ‘Caring Through Clothing’ project was discussed.

5.4.2.1 Case study workshop session 1: exploring the wardrobe 1

The purpose of this session was to discover whether there were potential garments of significance and/or cherished garments that could be drawn upon for Violet and Jim in the future.

Garments and artefacts presented by the participants were as follows:

- A vinyl record of Violet and her two sisters from 1967
- Their oldest child's holy communion dress
- Photographs from when Violet was a young girl all the way up to the present day
- The lavender tweed cape and scarf that Violet was wearing when I first met her.

W1 took place at their home, where Violet and Jim were living together when I first started to work with them. Prior to the session, I explained that we would be identifying and discussing garments of significance. As there were many photographs and artefacts displayed throughout the house, I did not see any need to bring the 'suitcase of stuff' as a means of eliciting and reinforcing participants' narratives. The 'suitcase of stuff' had been the physical starting point for the other two case studies.

Violet and Jim had their daughter Sue visiting from the UK and she was happy to partake. Violet and Jim brought out a number of photo albums on my arrival.

From the beginning of the session, Violet was open and talked about herself and her sisters while looking at photographs from the 1960s through to the present time. Many of the photographs show her with her two sisters with whom she was singing in a band. Sue was also very engaged and interacted easily and openly with both of her parents. Violet moved very easily between speaking of her sisters and their time on the road to her activism and talked about her children and grandchildren. Violet was very specific when she talked about herself in photographs, referring to herself and the different places where she had visited frequently. At that point in the conversation, Sue brought in an album that had a lot of old photographs from the days that Violet was on the road with her sisters. In a number of these photographs, the three sisters were wearing capes. Sue talked about some of the holidays that they had back in the 70s when the children were young and broached the subject of the racism that they experienced. They spent a lot of their holidays on campsites where other children called their brothers 'niggers'.

Sue brought in her mother's tweed cape along with a tiny communion dress that had been kept in a drawer upstairs. We discussed the communion dress, worn by their first child. Jim said that it would be good for himself and Violet 'to get talking about things' (Transcription VIOLET 1). Toward the end of the first session, Violet highlighted her sense of justice as she told a story about having to go into the school where her kids were because she did not want her kids calling other kids in school names. Jim talked again about the racism that was prevalent at that time. The session ended as we started to put the photographs

away. Violet still had her cape on as I was leaving and she wore it like a queen. Figures 47-49 depict Violet and her capes over the years. Figure 50 shows Violet and Sue looking at photographs together.



Figure 47: Violet singing and wearing one of her capes



Figure 48: Violet and her sisters wearing capes while touring with their group



Figure 49: Violet wearing the purple tweed cape, with her mother and daughter celebrating outside the courthouse



Figure 50: Violet wearing the purple tweed cape with her daughter looking at photographs from their lived experience as a family

5.4.2.2 Notes from between case study sessions 1 and 2

Prior to the meeting, Jim had informed me that because of Violet's condition, having so many clothes in multiple wardrobes in their house was getting very difficult for both of them. Jim called the researcher to discuss this on two occasions and the researcher recommended some small interventions that could take place around the home, which would make dressing less of a challenge in the short term, such as removing from the wardrobe very old items

that have not been worn for a long time, items that bore little significance and placing Violet's most favoured garments into a near-empty wardrobe. That way, she could see them all, decide quickly what to wear and not get confused or overwhelmed by an overly full wardrobe.

5.4.2.3 Case study workshop session 2: exploring the wardrobe 2

The purpose of this session was firstly to discuss the capes in more detail and to identify what their significance was for the lived experience of Violet and Jim. A secondary purpose was to observe whether there might be an opportunity to assist Violet and Jim with some of the problems associated with the clothing problem mentioned above.

Garments and artefacts provided by the researcher:

- Photographs of Violet and Jim taken by the researcher on the last visit.

Garments and artefacts presented by the participants:

- Photographs of Violet wearing different capes from when she was a young girl to the present day.

This second meeting W2, also took place at their home. The session started off with a discussion on having too many clothes. I talked about my collections of garments and spoke about the difficulty of housing them in a way where they would not simply become obsolete at the bottom or back of the wardrobe. Violet directed her annoyance at Jim, who talked about putting a curtain rail up and left the session for about 45 minutes. Violet talked a little about her clothing and

during the next 45 minutes, Violet and I walked through the downstairs area of her house looking at the photographs on the walls. We went through the downstairs closet together and Violet told me about each garment. However, Violet could not locate the lavender-coloured cape during this session, so we focused on the photographs in which she is wearing it. We discussed her other cape, a dark green Avoca wool cape, which she had owned for as long as the lavender cape. Violet put on this cape and wore it for the duration of the session. We went through photographs and some showed Violet wearing both capes on many occasions, including her husband's graduation, her daughter's graduation, and activist marches. When I asked Violet if she wanted me to help her with going through her clothing she told me that by the time I came again she would have gone through and sorted them. Jim returned and the session ended very soon after that.



Figure 51: Violet with her husband wearing the green cape with small badge



Figure 52: Violet at her home, touching and examining the purple tweed cape

5.4.2.4 Notes from between case study sessions 2 and 3

Over the period of the study, Violet's ability to communicate and engage lessened and she began to get short tempered with her husband Jim, particularly in regard to anything related to her clothing and dress practices. Jim had to cancel some of the scheduled meetings due to Violet's sudden illness. Between the second and third meeting, Violet had to go into hospital for six

weeks. It was difficult for them when Violet returned home because her ability to communicate had worsened considerably.

5.4.2.5 Case study workshop session 3: exploring the wardrobe 3

The purpose of this session was to physically interact with the two capes that had proven to be significant garments in the previous sessions and to discuss how together we might be able to find a solution for organising the clothing in Violet's three wardrobes.

Garments and artefacts presented by the participants:

- The lavender cape and the green cape
- Photographs from Violet and Jim's own albums showing Violet wearing the two capes over the years.

Garments and artefacts brought to the session:

- A navy wool cape.

Some photographs had been taken during sessions 1 and 2. The photographs had been enlarged and had most of the background cut off. They showed Violet at home and interacting with her husband Jim. She is seen handling and putting on capes in these photographs: the lavender tweed cape and scarf and the green tweed cape.

I had brought these photographs and a few drawings from the first two sessions for Violet and Jim to look at. I directed many of the questions specifically around

the capes. I brought one of my own capes to show Violet. Most of the session was spent looking at the two capes, discussing their significance for both Violet and Jim and looking at photographs to support conversations about events where the cape had been worn. Figure 53 shows Violet wearing the purple cape in a photograph and figure 54 shows Violet wearing the same cape during a workshop session.



Figure 53: Graduation day: Violet's mother, Jim and Violet wearing the purple tweed cape



Figure 54: Violet wearing her purple cape at home

5.4.2.6 Notes from between case study sessions 3 and 4

During the time between sessions 3 and 4, Violet's husband had a heart attack and had to go to hospital for some time. This resulted in Violet having to go into a nursing home. This was completely unexpected. During this time, the sessions were suspended but I had two significant telephone conversations with Jim, who

told me that although they had been managing quite well up to this stage, the stress of helping Violet to get dressed and ready to go out was causing Jim some anxiety. When Violet went into the nursing home she brought her lavender coloured tweed cape, along with another green cape. These capes were very much part of her identity – she was very proud of them and had a strong attachment to them. Within only a short time of her moving into the nursing home, one cape went missing. Both Jim and Violet created a fuss over the missing cape, and it was subsequently found after two weeks. Difficulty arose then because Violet became fearful about having this garment in the nursing home and she worried that it would disappear again. Her husband was adamant that the two capes stay at home with him. This very significantly resulted in Violet being denied a fundamental symbol of her personhood and sense of self while in the nursing home. We discussed the problem on the telephone before scheduling the workshop session and Jim suggested jokingly: ‘if the cape could talk it would be safe with Violet in the nursing home’ (Transcription VIOLET 3).

Unrelated to this study, the issue of laundry had arisen when my own father had a stroke and needed to be cared for in a care home. Two of his most treasured items of clothing had disappeared within two months of his arrival at the care home. The garments were eventually found in another resident’s room. The garments had been tagged with numbers, not names. The numbers usually coincided with the person’s room number, which struck me at the time as notable. There is a broad spectrum of identifying garments in institutions. For example, adding name tags to children’s coats at school is common practice.

Within the school system, the name of the child is present and is not reduced to a number. Within the care home system, when people are at their most vulnerable (particularly PLWD), it is common for clothing to be tagged with the number of the person's room. This removes a layer of important information for the staff who are distributing the laundry. The garment is automatically associated with a room and not with the occupant of the room. See figure 55 which depicts this problem. Therefore, garments often get misplaced and or lost – and without a name tag or label that shows the name of the person, they often remain lost.



Figure 55: 'These are not my clothes' is an illustration that depicts this problem

5.4.2.7 Case study workshop session 4: co-creation

The purpose of this session W4, was to take elements from the previous sessions and represent them visually so that Violet and Jim could co-design something that would guarantee a safeguard for her capes.



Figure 56: Violet and Jim at home during the co-design workshop session



Figure 57: Violet wearing the purple cape during the co-design session



Figure 58: The green cape with the badge that Violet had made to raise funds for the release of the 'Birmingham Six' prisoners



Figure 59: Violet and Jim co-designing a label for her garments



Figure 60: Empathic co-design process with Violet and Jim



Figure 61: Violet and Jim deciding on the final label

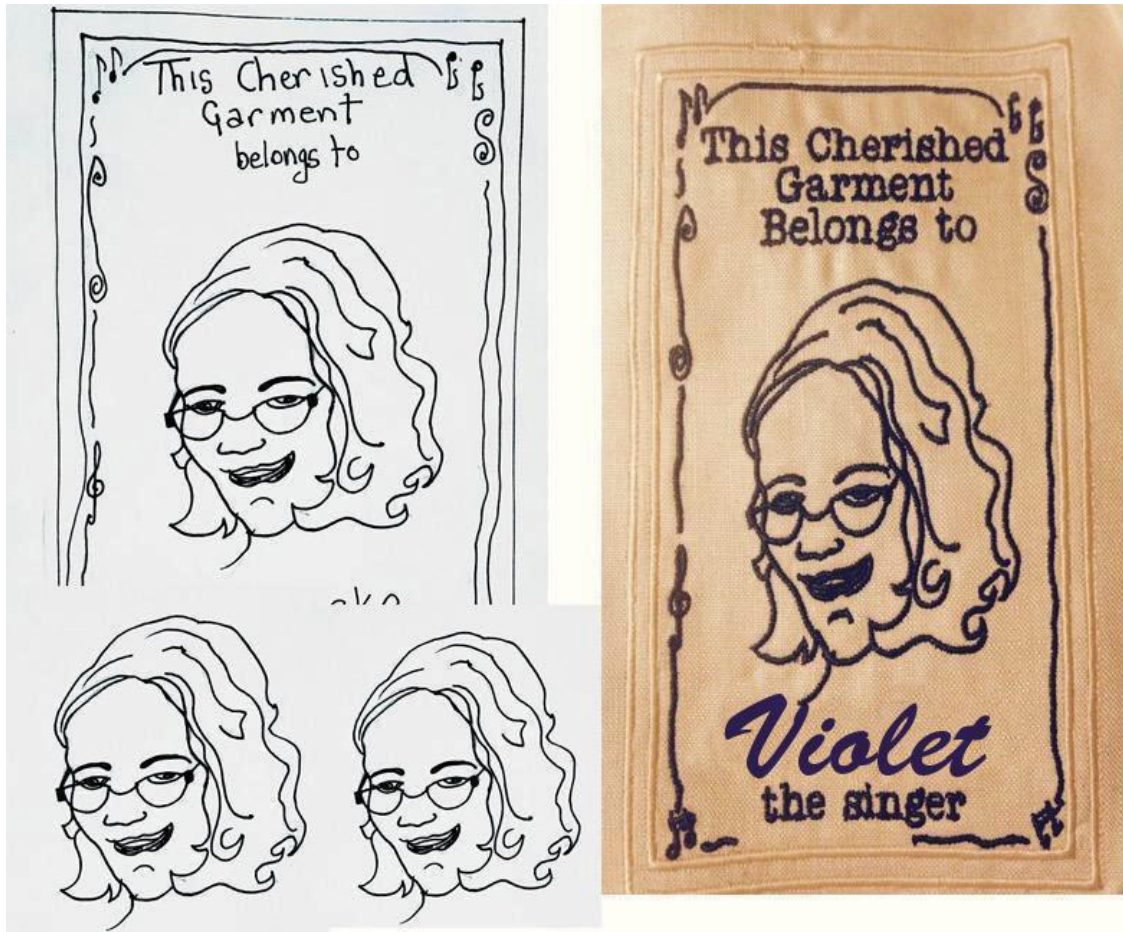


Figure 62: Mock-up of the co-designed label on the left and the final label on the right



Figure 63: Violet admires the new label which she co-designed with Jim for her green cape in the nursing home



Figure 64: The co-designed label on the purple tweed cape



Figure 65: Collating things from the box of ribbons and threads and newspaper clippings

Garments and artefacts provided by the participants:

- Photographs from Violet and Jim's own albums showing Violet wearing the two capes through the years.

Garments and artefacts brought to the session:

- Photographs from sessions 1, 2 and 3, which were enlarged and showed Violet and Jim interacting. In the photographs, Violet is also wearing her two capes: the lavender tweed cape and scarf and the green tweed cape

- Sketches of Violet's face and other elements that were drawn from photographs taken in the previous sessions.

For this session, I gathered many of the co-created elements from the previous sessions including sketches of Violet, her face, her hands interacting with her capes, photographs taken in the earlier sessions, and words and phrases triggered by the capes that had emerged from the previous sessions, which I had written down on pieces of paper. Violet had revealed that she had had many different phases of personhood over the course of her life. She was a mother, a singer and an activist. Jim was very content to join in the session and gave a lot of input, which Violet seemed to agree with and accepted freely. This session focused solely on the creation of a label that would transform Violet's significant garments from being generic garments to being unmistakably *her* cherished garments.

5.4.3 Development of MoM with Violet CSG3

The start of the co-design process had the participants identifying photographs of significance from their collective lived experience. In VIOLET session 1, we looked at some of their old photographs and focused on photographs of Violet when she was a singer in a group that toured around the UK and Ireland. These photographs represented a particular moment of personhood with which Violet identified and that reinforced her overarching sense of self as she recalled the related events and their significance for her. The researcher photographed the participants handling the photographs laid out before them and photographed

Violet handling and wearing her capes. The researcher had then gone away to print photographs taken during the sessions, and to draw elements that were memorable or could reveal something. Photographs from the family archive were copied. These artefacts became the elements that the design process needed to evolve. From these artefacts, it became apparent that Violet had been wearing capes throughout her life.

In photographs from her time touring as a singer, Violet wore a short cape or a long white cape. Then, as time progressed, Violet was seen in various photographs representing different periods of personhood wearing either a lavender coloured cape or a green one. These visual and narrative clues revealed Violet's connection with capes from an earlier time in her life. This added to the design process as we were able to focus on them in subsequent sessions. When their significance became increasingly apparent as Violet moved to the nursing home, the MoM process had co-excavated the relevant agents to co-create an intervention such as a label based on the following elements:

- Co-constructed narrative throughout the workshop sessions that revealed Violet as an activist, singer, and mother
- Co-created visual material including cutting out old photographs, cutting out new photographs taken during the sessions, and sketches that were drawn after the sessions from photographs taken during the sessions

- Two wool capes: lavender tweed and green wool.

It was apparent to any of Violet's family and network that Violet needed to have her capes with her, but there was an overriding fear that they might get stolen and so they needed to be safe and recognisable as belonging to herself. Therefore, we returned to Jim's comment about the capes being able to talk, looking at it in terms of the capes being able to speak and 'having agency'. The co-design cohort looked at the idea of labelling Violet's cherished garments appropriately. The label would need to encompass Violet's sense of herself, both in the past and present. It would need to communicate the importance of that specific garment to that specific owner. A label that showed a visual representation of the person could immediately create a visual reference point between the garment and its owner. We set about co-designing a label together. Violet spoke about how she would best like to be portrayed on this label. The session started with a discussion of Violet's name. Violet made it clear that her married name was the name she identified with more rather than the maiden name (which was the name she had gone by during her career). We looked at colours of significance that Violet had been drawn to throughout her life. Violet spoke of the colour purple because it had emerged as a colour of significance during the previous sessions. Violet said that she was often drawn to it. We then looked at some of the photographs and sketches that represent Violet as she is in the present. She chose a sketch that had been drawn from one of the photographs taken at the first session. With all of these co-created elements in place, it was possible to start to co-create a label based on how she wanted to

be represented, which Violet could then sew or have sewn into her most cherished garments. Having co-designed the label, a local embroiderer then chose vintage linen as the substrate, and with the name embroidered so that it had a raised texture, the colours chosen were contrasting so that Violet could read them easily. Her name was embroidered in purple. The label was a tiny piece of art co-created by Jim and Violet together based on her lived experience.

5.4.4 How did the MoM help the persons of CSG3 to explore their sense self and personhood?

Moments of self and personhood for Violet:

If personhood relates to a synchronic or specific point in time, then one's sense of self relates to a diachronic running sense of self through time. For example, personhood for Violet was present in her days as a young woman on tour in the UK, which was represented by a photograph of herself with her two sisters, all wearing capes. Other aspects are represented in the moments when Violet refers to herself as an activist marching for the release of the Birmingham Six (Figure 58), and the moment when she was standing outside the courthouse with her newly adopted daughter (Figure 49). As the overarching diachronic sense of Violet's life becomes evident, it is noticeable that there are many synchronic moments of personhood where Violet is wearing a cape. The moment that Violet picked up her purple cape after the label had been placed by Violet and sewn into the garment was beautiful to behold. She stood up and

commanded space in the care home and started to sing. This is depicted in Figure 66.

Moments of sense of self and personhood for Jim and his role as the primary and only carer:

Although it is beyond the scope of this research to look in-depth at an exploration of personhood and sense of self for the carer, a number of moments did present themselves where it was apparent that the carer was also exploring his/her changing sense of self as the dementia journey progressed. Within the husband and wife relationship, Jim was the primary carer. His relationship with his wife, who has dementia, was changing rapidly and he admitted that he felt incapable of doing anything for himself as his wife's needs were increasing. But as soon as Jim put on his fine tweed overcoat his words were 'it fits me lovely, I think' (Transcription VIOLET 3). He visibly and verbally recognised his own sense of self as he went on to recall his dress through the years as an academic. He said that he quite liked the way he looked when he wore it. He then specifically looked over at Violet and thanked her for getting it for him. This represented a moment where Jim wanted Violet to see him the way she used to see him – before her illness. Jim talked about going to the second-hand shops with Violet and always looking out for tweed. He referred to his own clothing with disregard when he said he wished he only had one set of clothes to put on and take off every day. But this appeared to be a direct reference to the problem of Violet's multiple wardrobes and confusion around dress which Jim, as her carer and husband, was facing every day and night.



Figure 66: Violet puts on her newly identifiable cape and starts to sing

5.4.5 How did it affect interaction between the participants with dementia and their family members/carers?

Observations on Violet and Jim and their interrelationship:

Jim actively engages with Violet when he talks about the many times and scenarios in which Violet wore her capes over the years. At times, Violet would get caught up in minor detail and might move the conversation elsewhere, but mostly Violet would return back to the initial story and enter into the co-construction with Jim. Jim was very proud of Violet from this time in their shared

past and recalls the impact of Violet's passion and sense of justice very fondly and with strong admiration. She describes events and populates them with information from other past events. As she meanders her way through the conversation, the presence of her husband Jim is constant. He accompanies her, supporting her version of events, or sometimes veering slightly away from Violet's path and correcting the information en route; more often than not, Jim stays on the path with Violet and agrees with her. He says that he still holds all of the respect for Violet that he had for her throughout their married life and does not want any conflict. It seems that Jim is still deeply in love with his wife and is trying to support her in every way that he can but it has been getting increasingly difficult for Jim to manage Violet's dress, and the organisation of her clothing.

Moments of difficult interaction between Jim and Violet:

For the second case study workshop, Jim had requested that I broach the subject of Violet's clothing. When he did enter the room and add to the conversation, Violet was quite irritated and provocative with him. Jim became more silent during this second workshop session. As Violet experienced more cognitive decline she became more controlling of her husband's narrative output, particularly in relation to Jim's thoughts on her garments and how she was going to manage dress and her wardrobe in the future. However, during the other three sessions, which were based specifically on photographs and garments, Jim and Violet were both reliving and co-constructing their shared lived experience. Violet would often look to Jim for the final part of the story, or for the answer to something; Jim would immediately interject and deliver his part

of the story, delighted to be invited and happy to be asked for his contribution. Thus, co-construction or co-tellership can both inhibit and encourage narrative. Figures 67, 68 and 69 show Violet and Jim together during the workshop sessions.



Figure 67: Violet and Jim enjoying one another during workshop session 2



Figure 68: Violet and Jim showing affection during the final workshop



Figure 69: Violet and Jim working together to place the label on the green cape

5.4.6 Summary of CSG3 VIOLET

The study has shown up to this point that Violet's capes enabled her to define synchronic moments of personhood, her references to the Báinín (the traditional Irish knitted white wool jumper) clad bombshells in the 60s and 70s, her activist self on the marches, the campaign for the release of the Birmingham Six, the graduation of her husband and daughters, right up to the present day where she took part in marches against water charges and the memorial walk that commemorated the heroes of the 1916 Easter Rising.

Through their habitual use, the capes therefore also represented her diachronic overarching sense of herself within the context of relationships, place and shifting ideologies. The garments were used for specific occasions but were also used as everyday wear if necessary. They were taken care of and cherished. The presence of the capes and interaction with them over the course of the project allowed Violet to revisit her lived experience and explore her many personhoods. She explored her 'extended self' with a huge sense of purpose and justice. She was validated as both a mother and an activist in her decisions to both adopt and have her own children. Violet and Jim's 'interpersonal selves' were seen through their collaboration and compromise when co-constructing their stories. The MoM highlighted their obvious strong emotional connection to one another and to their shared experience while also giving space for Jim to demonstrate a high level of consideration of Violet's increasing needs. Violet and Jim also explored their 'private selves' through the medium of handling the garments and through photographs and drawings. For example, when Jim brought out his own coat and enthusiastically tried it on during the session he exclaimed that he thought he looked well. He felt good. The label was a combined and distilled version of the previous co-creation workshop sessions. The addition of a co-designed label immediately stamped the cloaks with their owner's mark. They reinforced the ownership and made the autobiography of both the cloaks and their owner visible. The label gave the owner of the cloaks an added layer of embedded security in her retainership of the pieces. Similarly, it imbued the cloaks with information about Violet's personhood that disrupted

the existing system to safeguard against the cloaks going missing. This will be explored in more detail in Chapter 6.

5.5 Reflection on the setting up of the case study

workshops

In this section, I will discuss the overall elements of place, suitable space, time and physical triggers, all of which needed to be present for the workshops to take place successfully. I will also discuss the limitations and logistical challenges that arose.

Place:

The place where the workshops were being held needed to be suitable for that purpose. However, when the place afforded for the session was not suitable, we needed to improvise quickly. In the case of the ROSE group, the family home was small and did not facilitate a workshop session around a table. Therefore, the researcher/facilitator used the floor of the living room area to develop the MoM 'remaking memory' scroll. The previous sessions (which all took place after the Alzheimer's Cafés) were limited by the fact that the group did not have a completely private place in which to hold the workshop sessions.

In the case of the IRIS group, the first session took place in the day room of the nursing home where Iris was living. After the first session, we decided to hold the forthcoming and subsequent sessions in Iris' private room. The second

session in Iris' room enabled complete immersion into the session without interruption.

In the case of the VIOLET group, the first session took place in the Alzheimer's day care centre. This presented similar problems to the above as the space used was not fully private. Two subsequent sessions took place in the home of the VIOLET group and the last sessions took place in a private room in the care home.

Suitable spaces:

Neisser (1988) argues that narrative was 'a' basis not 'the' basis for self. Narrative is one of the key elements of self as is the creation of a space where the self can be supported and explored. Many elements needed to be in place before exploration of self, co-construction of narrative and co-creation could successfully occur. For example, to hold the three case study workshops, the participants needed to know that there was a suitable space where they would be held. When the potential participants revealed that they would need to be interested enough in the ideas behind the project to participate, this meant that the researcher needed to spend time observing and interacting with the participants before the project was fully introduced. The creation of a suitable space was as much about the potential participants being comfortable in the company of a new person (the researcher) as it was about feeling secure within the space. It was my responsibility as the researcher/designer/facilitator to co-create that space with the participants and this required consideration and time.

Time:

The participants needed flexibility with meeting times. This required planning in advance and remaining adaptive to changes in the schedule. Where I had initially thought that one observation session with potential participants would suffice, it became apparent that there was a need to spend many observation and interactive sessions in the form of a pilot project with the groups. These have been discussed in Chapter 4. It was also very difficult to schedule appointments for sessions due to illness, doctor's appointments and the difficulty of caring for a PLWD. The data collection and design process sections of this research project took a lot longer than anticipated. This is an element that any researcher working with older people with dementia and their carers should factor in as it is part of the process.

Physical triggers:

The participants needed physical triggers to re-live, re-call and re-construct their lives together and lives apart. This required the artefacts from my personal archive and from the participant's lived experience described in Chapter 4.

Physical triggers included:

- Garments of significance
- Artefacts from the 'suitcase of stuff'
- Photographs

- Drawings
- Other objects.

5.6 The changing nature of the MoM

This section discusses the changing nature of the MoM on one hand, but also acknowledges the similarities between all human relationships and the most exploratory way to excavate lived experience. The MoM is an all-embracing intervention that provides a means for the participants to explore their sense of personhood and sense of self in a safe, active and creative environment. The MoM began as a process developed specifically for the study (Kitwood, 1995; Neisser, 1998; Nolan et al., 2006; Dewar, 2011). Informal questions around garments pertaining to the sense of self and personhood were asked. The questions were provocations, initially used as a foundation around which the participants could begin to build the structure of their own MoM. A secondary element of the MoM encompassed the physical elements held within the 'suitcase of stuff', the drawings, created as a response to observations from the participants' lived experiences. Again, these acted as instigators to provoke a response from the participants. A third element of the MoM was the identification and subsequent excavation of garments of significance, through the wardrobe, through photograph albums and through any other means available. In the

instance of the three case study workshops, the MoM as a process was iterative and responded differently in each case.

However, the three case studies moved very quickly away from these semi-structured formats and eventually were either mildly modified (W1), heavily modified (W2) or abandoned (W3) as I observed how people interacted with each other around lived experience through clothing. Further, as the sessions began, the data revealed that a linear timeline was an impossible idea within which to work. Therefore, the focus of the sessions was not so much on the time or days when certain big events happened but on more emotional elements, such as who was present, what the bride wore, what stories were woven into those moments, which of these stories could be easily revisited and reconstructed through collaborative narration. In general, for all three groups, the whole story was being constructed through the co-construction, by the participants, of the isolated moments within that overarching story.

All three participants co-created a large version of their cumulative lived experience with elements of storytelling represented by drawings, photographs, cut-outs and templates; these were then placed by the family members along a loose timeline. The data revealed that the IRIS family made a transition from experiencing sadness and anxiety around their mothers situation in the nursing home, to experiencing collaborative creativity. The ROSE family wanted to manifest their cumulative lived experience somehow. The workshops helped to assemble the elements necessary for creating a large scroll. The space was too small to use the table but by clearing the area in the middle of the room and

using the floor space, which was given a boundary by all three participants, the space opened up to enable the co-created 3D scroll, which would represent their collective lived experience.

When we were discussing the format for the final intervention, they asked that the final MoM be in a book format so that Rose could access it easily on her lap as the dementia progressed.

As is customary in most care homes, most of Violet's clothing had a number attached. This number was specifically for her garments and was printed on a small plastic disc attached to her clothing. This is an ongoing attempt by the nursing home to separate residents' clothing and ensure that it returns to the correct person after being laundered. However, over the duration of this study, this researcher has witnessed that there is a problem in the area of laundry. Laundry staff constantly lose residents' clothing, often delivering the wrong garments to the wrong owner despite the numbering.

The underlying problem, which was identified through observation and emanated from the data over the course of this study, illustrates that clothing is not recognised as a signifier of people's agency within the care home environment.

Jim: Violet has lost her cape. It was mistakenly taken to the laundry and has disappeared.

Violet's daughter: I keep buying her favourite cardigan from M&S and it

disappears – it's a good thing it is a staple so I can keep replacing it (Transcription 5 VIOLET group).

The numeric labels do not give any indication of the identity of the person who owns the garment. It might appear to be a way of safeguarding specific clothing for specific people to identify garments with a number, but it does not guarantee that the garments are assigned to the correct owner. Clothing is cared for but in isolation. Within the two care home environments that I witnessed and observed, there was little continuity between the collection, washing, drying and redistribution of garments to the correct owner.

The people doing the laundry do make an effort to keep the numbers together as much as possible but the numbers can neither conceal nor reveal information about the owner of the garments. The clothing is the active symbol of the residents' sense of self and personhood, yet this information is not transferrable. The data from the sessions with Violet revealed that when the garments were tagged with numbers and not the name of the person that owned them, they were divorced from their human owner and hence ran the risk of not belonging anywhere. They subsequently often got lost. A number is merely a number even if and when it is assigned to the room in which a person is living until the end of life. It does not transfer the dignity of a name, which is attached to sense of self. It presents as a symbolic association only. It denies the owner of the garments the actuation of their legacy of self. When a person is reduced to a number, personhood cannot thrive.

5.7 Impact of MoM on the participants (people with dementia and their carers/family members)

For all three families, the MoM provided starting point, which acted as a repository for the co-constructed lived experience centred around personhood. Although the focus of the sessions appeared to be around linear storytelling, the actual sessions contained juxtaposed and often enigmatic or complex elements, like the interrelationships between who was there then and who is not there now, when children were born, walked and talked, who they especially loved and who loved them. Stories were woven into those moments of personhood, which, by being revisited, were being co-constructed and tended for the future family running sense of themselves over time. Or, as Ochs and Capps) state:

... personal narrative oscillates between a yearning for coherence of life's experience, and a yearning for authenticity. Narrative and storytelling both provide an interpretive frame and do justice to life's complexities, while also acknowledging the enigmatic aspects of experience.

Ochs and Capps (2001: 241)

In the IRIS group, when holding a knitted garment made by herself, Iris' ability to relive the making process verbally was without fault. Iris did not always remember making the specific garment or wearing it, but she could read and replay the 'code' of her own making in her sensory engagement with the item. On the realisation that there was no pressure for Iris to knit something herself,

she relaxed into describing the process of knitting, which was then assigned specific emotional and family-related 'tags' with the input of her two daughters. The focus and energy were never on the accuracy of the narrated outcome but were on the actual process of touching, smelling and feeling the garment – with her daughters listening in awe as she recounted the instructions for knitting the different stitches.

Iris held and interacted with each of the garments presented to her and unlocked their making technique within seconds of holding them. Tactile engagement with the garments enabled all three family members to recount stories relating to the garment's significance within the family. This eventually led to the creation of a book that showed the last months of Violet's life for people coming to pay their respects to Iris and her family. It was used during the funeral service and embodied some of the person Iris was through the eyes of her daughters, herself and the researcher in the months leading up to her death. The book contained quotes, photographs and drawings of Iris with her two daughters at different stages of the research process. The projected outcome was a blanket for Iris knitted by her two daughters based on the co-construction of Iris' narrative on knitting, which took place during the sessions.

The ROSE family were highly reminiscent and highly engaged. The activity of exploring the story of Rose's personhood was done through a number of co-constructed narrative workshops where small discoveries were excavated and placed in a 'holding zone' until they were contextualised within her lived experience. The exercise of excavation took a slightly different direction to the

other two case study groups. As photographs were examined and handled, conversations were also taking place in which Rose was recollecting stories from her youth and all three of the participants would co-construct lived experience together. As noted, similarities between Linda and her mother began to become apparent in particular traditions around colours and flowers, which the two women had subconsciously been following for years without ever having discussed or recognised it hitherto. Linda and Rose took great delight in this shared non-verbal and meaningful legacy. The final outcome was created from an initial working design that was adapted to suit the small working environment.

The VIOLET family were also engaged with each other. The shared recollection of Violet and Jim's lived experience was based on an extensive family archive of photographs, artefacts and the two capes that belonged to Violet. The intervention grew out of the MoM process that identified important elements and garments from both Jim and Violet's lived experience. This was particularly so in the case of Violet, where the intervention – a personalised label – enabled the participant Violet to hold on to garments of significance without the worry of them going missing. The information on the label tells the person reading it who the owner is and something about the kind of person the owner is. The label identifies the garment as cherished and 'owned'.

5.8 Summary

This chapter has discussed lived experience as a continually growing ecology of interactions and happenings where time ceases to be linear, memory is not

dependent on fact, and stories are evolving in their content as they are constructed, and deconstructed, and reconstructed by multiple participants. In this chapter, examples are given where the story was a co-construct of various times, dates and people. This was argued out between two or three participants until the story was agreed upon, not agreed upon, or sometimes completely forgotten. The chapter highlights that that the story was often not the primary outcome or aim of the exercise. During the course of the research, it also became apparent that it was the interaction between the participants, their individual sense of themselves and their shared lived experience that were the important elements. Within the space of the MoM: Caring Through Clothing project, garments were excavated to reveal stories, family members were able to explore and acknowledge their shared experience and individuals were enabled to be themselves.

During the course of the design research, it became apparent that although cognition seemed to be decreasing on some level for many of the participants with dementia, competency in other areas was changing rather than diminishing. It was revealed that other memory systems were falling into place. Because the MoM was creating a space for the exploration of lived experience, many of the PLWD were actively reinforcing their sense of self and personhood in new ways, activated through interaction with the garments. For example, some of the PLWD showed signs of being creative with language when describing implicit memories such as being scolded by the sewing teacher in primary school for stitches like 'cat's teeth' (Transcription IRIS 2).

The participants also partook in humorous expressions of narrative and co-tellership. One example of this was when the VIOLET group were describing their camping trip in Ireland in the 1970s with their two adopted children, who were shouted at by a bully to go home and wash but who ended up becoming close friends with the bully. The laughter and interaction that these stories provoked were instigated by holding garments that had been used in the past for the children, garments that had been co-created by the mother and daughter and garments that had completely disappeared from the life of the PLWD but were still very much present in the implicit memory through storytelling (Transcription VIOLET 3).

Much of the research carried out at CARIAD (Centre for Applied Research in Inclusive Arts and Design) at Cardiff Metropolitan University has shown that haptic and physical stimulation is more appropriate for PLWD than direct cognitive stimulation (Treadaway et al., 2016, 2018). While some of the participants had lost the ability to do certain tasks, they were able to do other activities related to but not the same as the old tasks. The garments were triggering deeply embedded activities from different memory banks such as opening and closing buttons, putting a cape on, and taking it off with a swirl of the garment around the shoulders. One of the participants even gave the instructions for knitting the very garment she held in her hands, which had been co-created with her daughter 25 years previously. Creating and encouraging co-creation that is person-centred, achievable and appropriate fosters and feeds into motivation and reward as well as deepening the existing relationships with

carers. This is an important part of ensuring that the psychological well-being of the PLWD is upheld (Treadaway et al., 2016). Treadaway (2016, 2018b) and Zeisel (2010, 2016) maintain that more activities that are achievable need to become available. As the ability to complete tasks decreases with the onset of dementia, there is a need to strive at becoming good at something else. As the participants were re-introduced to materials within their own personal and family archives, their creative and imaginative responses were a powerful testament to their own present and past lives. This further enabled them to co-create an intervention for their future lives. Many of the participants re-lived their stories in the moment as they were telling them: Iris with her 'living knitting'; Rose with her experience in the swimming pool as a child, wearing a woollen bathing suit; Violet when she was reliving the experience of marching for the release of the Birmingham Six wearing her cloak.

As each of the participants' lives was constructed around and through their lived experiences, they were further constructed and reinforced by the stories and sense of self-attached to their life's journey. When Iris became agitated at the idea that she might have to perform a task that she felt unable to do, the focus naturally shifted to her ability to relive the knitting process itself by the other participants. This is, according to Zeisel (2020) one of the most important ways of ensuring that apathy does not take the place of activity. It is, he says, 'encourages a focus on maximising abilities, know-how, and aptitudes for skill development, rather than on compensating for disabilities.' (Zeisel, et al., 2020:17).

Because the co-construction of narrative often started with a loose description of the artefact being handled in the participant's own words, the integration of a sensory and tactile artefact with the sharing of stories pertaining to that artefact helped to support and enhance existing relationships between the person with dementia and their partner/carer, as well as disclosing some of the lived experience around the garments. The garment was a trigger for the narrative but it was also the repository of many sensory lived experiences that were assembled during the narrative process by all participants in a co-construction of meaning and communication. In the case of the VIOLET group, the cape triggered many responses related to activism and the extraordinary sense of injustice that Violet fought to change throughout her whole life – the cape triggered deep elements around the personhood of the wearer and owner. In the ROSE group, the continued reference to the colour red, by Rose and her excavation of stories relating to why red was so important, triggered responses around the close bond between mother and daughter. In the IRIS group, the interaction of Iris, the mother, with any hand-knitted garment brought the process of her own knitting back to her. These moments led to Iris describing in great detail the methods that may have been used, with her daughters joining her in these moments of co-constructed narrative in co-tellership.

It is important to note that the MoM process frequently focused on the 'journey' and not on the most 'accurate representation' of the situation. The mutual transactions through narrative between the participants displayed moments of multiple tellers, multiple beginnings and even, at times, multiple outcomes. The

outcomes of the stories were secondary to the process of weaving the stories. Lindseth and Norberg (2004:150) note that as humans are familiar with their life practices, 'this familiarity has to be expressed through the way of living, through actions, through narratives and through reflection'. The elements of accuracy and rigidity regarding tasks, perceptions of truth and memory, quietly abandoned for adaptability and openness.

Chapter 6: Findings and outcomes

6.1 Introduction

This chapter presents and reflects on the themes and findings that have emerged during the analysis. This section reviews the thematic elements that emerged from the process. Discussed is the development of the MoM: Caring Through Clothing research project as an agile and adaptable co-design intervention and presented are the findings revealing how the MoM facilitates exploration of personhood and sense of self. The chapter further reflects on the MoM as a means in which to explore the interrelationship between the person with dementia and their carer/family member. The second part of the chapter, from 6.5 to 6.9, discusses the tangible and intangible design outcomes and posits guidelines for future researchers in the field of co-design for dementia. The impact of the MoM on the three case studies is discussed. The penultimate section is a reflective summary of the journey of the facilitator/designer and researcher through the entire process from the initial observations all the way through the co-design process to the final stages of the project.

6.2: Important themes emerging from the narrative analysis

The MoM provided a receptacle where specific markers of lived experience from the different participants could be held and explored for future recollection.

Although some of the areas of personhood and sense of self that were developed as a basic foundation were predetermined by the MoM intervention, the MoM was developed in such a way that it remained open and responsive to the life stories that emanated from the participants. There were multiple and varied expressions manifested in the data. These became, according to Ryan and Bernard (2003: 88), 'abstract themes', which were enabled by gestures and manifested in the significant garments, images from the photographic albums and human expressions/gestures in the form of co-constructed narratives.

Previous to the data collection and co-design phase, certain themes were identified that were relevant to an understanding of personhood and sense of self from best practice nursing as explored by Kitwood (1997), Nolan et al. (2006, 2008) and Dewar (2011). These elements were mapped on to Ulrich Neisser's (1988) five senses of self and deeply informed the MoM framework. This provided a structure upon which the overall thematic associations were built.

The following five themes emerged as part of the process and the process, in turn, informed the emergence of the themes:

Space, others, garments, storytelling and memory

If one places Neisser's 'senses of self' within the context of various neurocognitive views where consciousness and cognition are defined in relation to the body as discussed by Morin (2006) and Neisser (1998), we see that the ecological self corresponds with basic consciousness, perceptual self-

awareness, the sensory and non-verbal self. From here, the interpersonal self is presented and basic social collaboration and awareness of others takes place. The extended self sits in an extended view of self-awareness where reflection over time from past through to present and future can emerge. This supports the private self where thoughts and feelings in relation to self and the environment take place. With the meeting of self-awareness and meta self-awareness, we enter the fifth of Neisser's senses of self, the conceptual self, which explores self-concept and extended consciousness (Neisser, 1998; Morin, 2006). In this way, the person with dementia becomes the focal point around whom the senses of self and elements of personhood are woven in a way that reflects the five major themes that emerged from the data.

Although all of these elements were necessary for the MoM to enable co-creation, they could interact with and co-relate to each other in different ways at different times over the course of the process. For example, in the IRIS case study, the first case study workshop was held in a quiet corner of the nursing home (ecological) and the second case study workshop was held in the participant's own room. Iris relayed a 'story' that then triggered in her the desire to talk to the other participants about the woman who made her wedding dress (garment and other). It was supported and enhanced by her recollection of that particular day (memory). Similarly, many scenarios could be constructed and reconstructed using the parameters of these themes (Transcription IRIS 1 and 2).

When combined with other elements, drawing enabled placement of time and space outside of linear representation. The material that the MoM helped to excavate held the possibility of being used in the future world of the PLWD and their primary carer. This could potentially extend the ecological self through consciousness into core consciousness, sensory awareness, as well as the minimal consciousness level, and potentially to the non-verbal stage (Brown, 1977; Farthing, 1992; Neisser, 1998; Schooler, 2004; Morin 2006).

One of the most important and most basic elements that needed to be in place before the MoM process could unfold was the environmental need for a 'suitable space'. This enabled interaction to take place with an 'other or others'. Being in the presence of 'another' raises the need for the presentation of self to 'other' and this is where 'garments' are often a representation of self, bridging the gap between self and other. Garments can give rise to 'stories' that further give rise to 'memories'. The themes have been ordered to comply with Neisser's senses of self.

A number of sub-themes emerged, which are discussed later in the chapter. Figure 70 shows the person with dementia at the centre of the star surrounded by the senses of self. The star represents the elements of the empathic co-design process and design tangibles, which, when taken as a whole entity, represent the MoM.

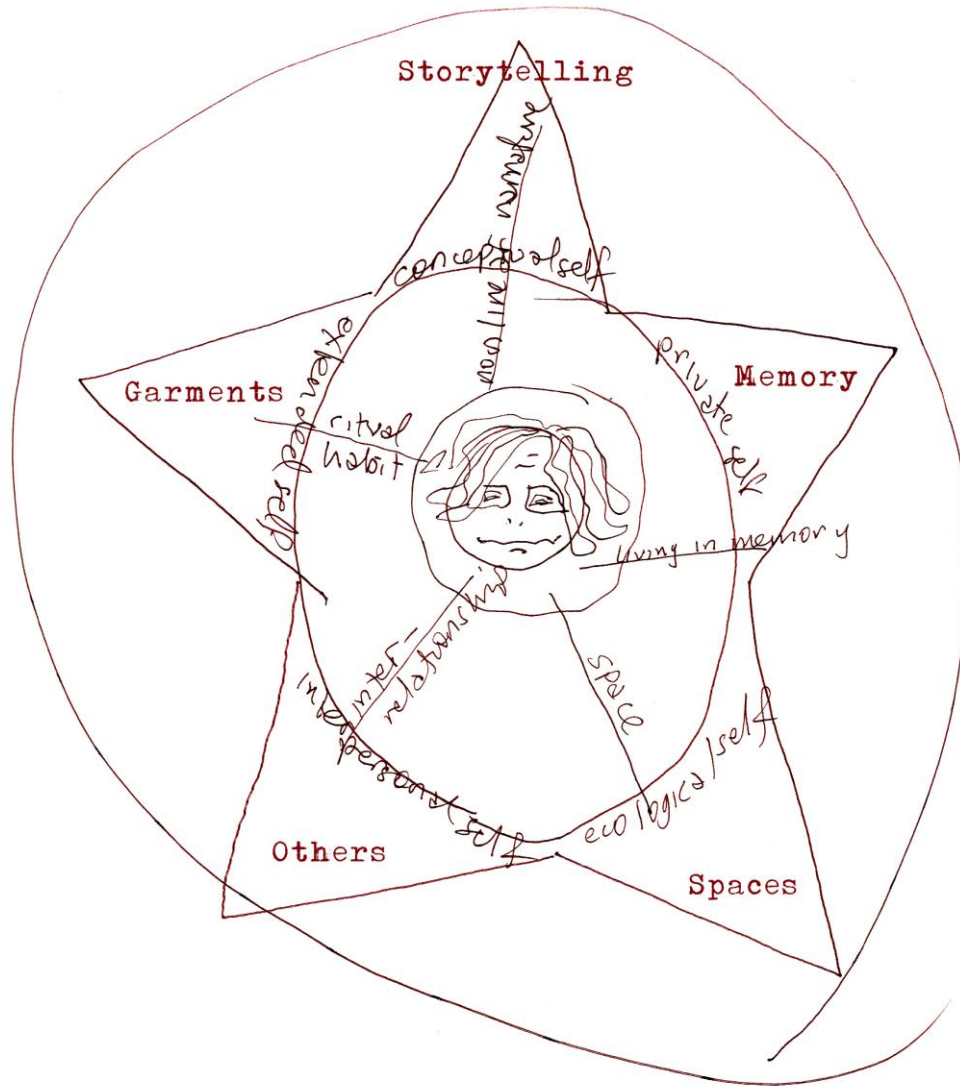


Figure 70: The five major thematic areas that emerged over the course of the study

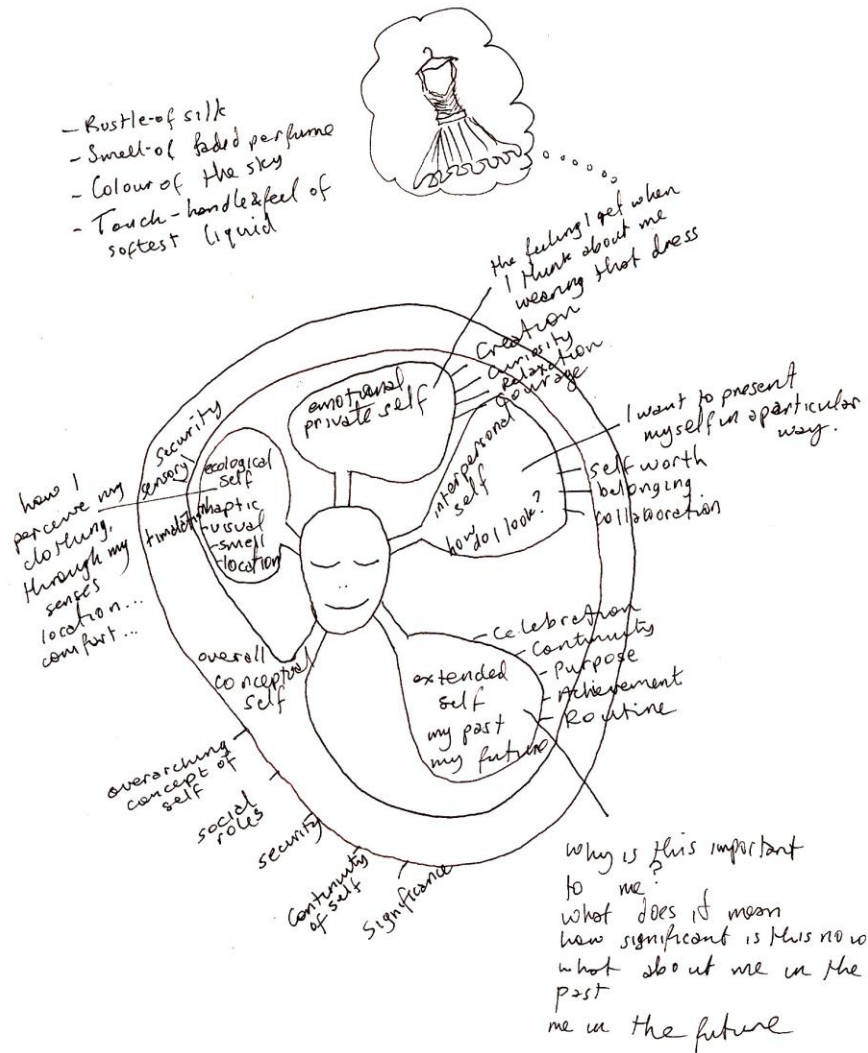


Figure 71: The 'senses of self' according to Neisser (1998) and other elements

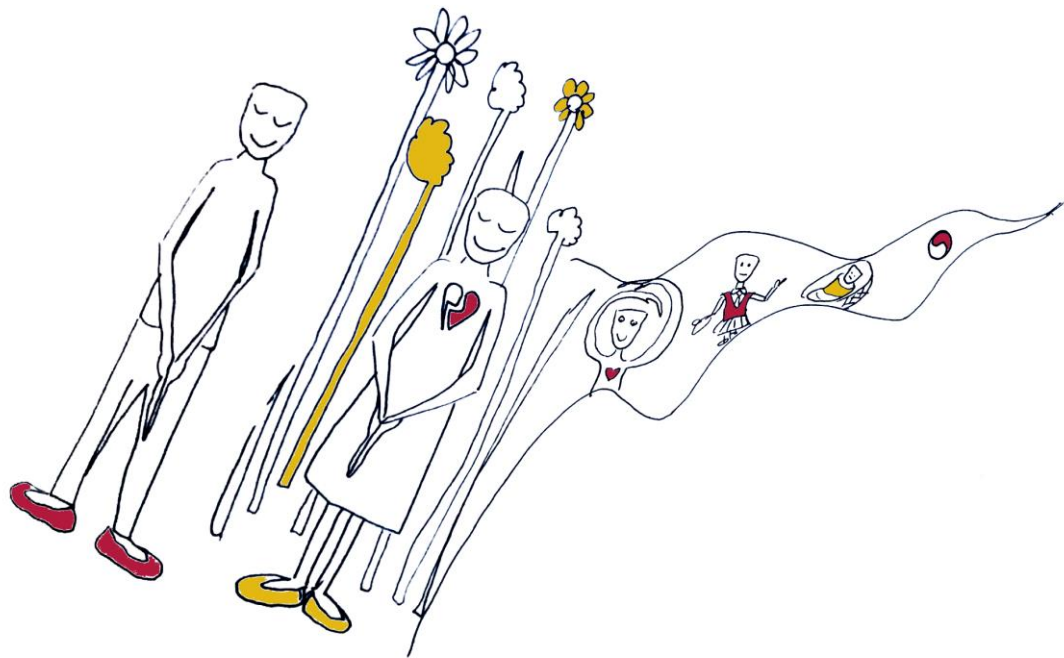


Figure 72: Journey through personhood

6.3 Design process

6.3.1 The use of the MoM as an agile and adaptable design intervention

The MoM was designed in such a way that it was fully responsive to the multiple needs of the participants while also enabling the participants to flourish within the co-design sessions. Each case study was a completely unique ecosystem in itself, an ecology of interactions with people and artefacts within their surroundings. Each individual participant within the three case study groups

responded differently, in a manner unique to them. So, too, I responded accordingly, adapting in a specific way to the particular needs of each of the situations presented. For the MoM to work to the maximum of its potential capacity it needed to be partnered with a researcher. The agility of the MoM framework meant that it could be adapted to suit the specific situation presented. The framework could not reach its potential without the animating element of the participants, who had the capacity to be intuitive, to evoke interrelationship and exploration of self and personhood, to encourage excavation of significant garments and related moments thereof. Therefore, the presence of an 'other' who was unrelated to the family in the form of the researcher enabled certain elements that were inherently necessary for the MoM.

Below is an overview of the co-design process elements that were necessary for the MoM framework to function at its full potential. The creation of a 'suitable space' was necessary for all participants to feel at ease and comfortable. The PLWD and their partner/carer was at the heart of the MoM process. It was the intention of all participants to co-create a repository for autobiographical and family experiences. The significant garments, drawings and related photographs were essential to the potentiation, in that they enabled the excavation of lived experience. This was explored through senses of self, personhood and co-constructed storytelling, which all fed back into the garments, reinforcing the physical and emotional connections between the participants and their cherished garments. The co-design process also fed into the interrelationships between the PLWD and their primary carers.

6.3.2 The MoM: working with fixed and variable elements of the process

The outcomes, both tangible and intangible, that did emerge from the MoM co-design process were variable. While many of the procedural elements of the MoM framework were constant within the process there were also significant variables to allow for customisation for each participant group. What at first appeared to be fixed elements started to evolve into variable elements early in the process. Each of the three case study groups came from very different locations and backgrounds. While the 'suitcase of stuff' and the creation of a suitable space were fixed, initial responses to the elements from the 'suitcase of stuff' presented in the first workshop sessions were completely different for all three of the PLWD participating. For example, each case study started with the fixed element of a PLWD and either one or two primary carers, a researcher and a location familiar to the participants, that was private. The 'suitcase of stuff' was the starting point of the MoM process, as it comprised the physical elements of my own cherished garments and provided me with the opportunity to tell a story about them, which then triggered storytelling between the other participants. From here, the garments of significance were identified and introduced to partake in the MoM framework.

Photographs from the past lives of the participants were excavated. Photographs and drawings of the process that pertained to all three case studies were created. The photographs and drawings were working elements that were

used in a practical way, they were not finished or fixed outcomes in themselves, but were working active elements used for further exploration of personhood and sense of self.

When presented with the yellow woollen jumper, Iris, from the IRIS group, with her fingers, read what gauge the needles and the thickness of the wool were by handling the garment. For Iris, this was a procedural memory activated by an embodied experience, felt and consequently remembered through her sense of touch. In the ROSE group, when Rose felt and smelled the yellow jumper she was reminded of the time when she was six years old and fell into the swimming pool wearing a woollen bathing suit. Her sense of smell and implicit memory recognised the scent of lanolin in the wool, which activated her memory of the smell of the woollen bathing suit. The memory of the traumatic experience was triggered by the distinctive smell of the wool. Violet from the VIOLET group did not engage very much with any of the elements in the 'suitcase of stuff' and ignored the woollen jumper when presented with it. Nonetheless, for two of the PLWD, it was a trigger for something significant from their past. With Violet, the workshops revealed that she responded mostly to elements from her own archive of lived experience – the photograph albums, the capes, the conversations about her children, activism, and being a well-respected singer in the 50s and 60s.

The moment in the study at which the three case study groups were introduced to the 'suitcase of stuff' revealed that each case study moved in its own creative co-design journey. All three took different routes through the respective lived

experience of the participants. The garments of significance for each family were identified through the family's own tangible archives (the wardrobe, the photograph albums and co-constructed stories based around these two archives). It was at this stage that Violet from the VIOLET group began to engage fully with the process. The constant element across all three of the sessions of taking photographs from within the sessions to document the present lived experience of the participants was another step in the evolution of the MoM. However, another variable entered when the visual representation of certain garments/elements was not present. I, as the design facilitator and researcher, drew images of those missing elements from the family's shared past. These were my personal observations as well as representational drawings that captured moments of the sensory interactions and interrelationships. It was through the act of drawing and taking photographs of the participants as they interacted with each other and the garments that my empathic responses to the participants became more specific.

6.3.3 Ecologies of interaction and habit

The three case studies were very different to each other as each comprised individuals with certain elements pertaining only to them. However, one of my aims over the course of the study was to look at those elements of personhood and sense of self as sitting within an ecosystem. Therefore, lived experience sits within a live system. By observing the interactions between the smaller ecosystem of the PLWD occurring within the larger ecosystem of the surrounding elements, it has been possible to draw certain similarities and

differences between the three case study groups as a whole. Figure 73 shows the three case study participants within their own ecology of context, ritual and habit.

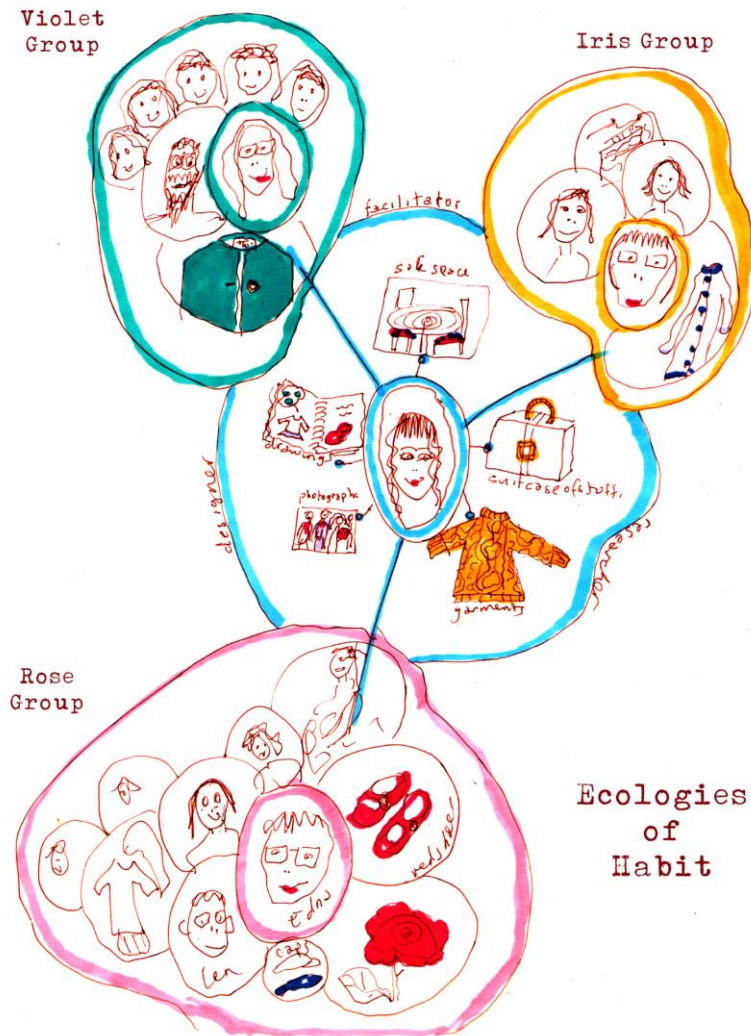


Figure 73: Extended ecologies of habit. Each participant shown at the centre of their own ecosystem

I am building on the work of Kate Fletcher (2018) in *Fashion Ecologies*, and also Alexandra Georgakopoulou (2006, 2008), who looks at narrative from a co-construction model. According to Georgakopoulou (2006, 2008), the co-construction model of looking at narrative moves narrative away from the 'active teller and passive listener' or 'canonical' model and towards a more inclusive and non-canonical discourse where multiple co-tellers exist in an ecology of interactions. By mapping the multiple and often complex elements within the overarching ecosystem of the PLWD it was possible to identify an environment that was comprised of multiple ecosystems.

The MoM process facilitated an ecology of interactions between people. It also (on a more tangible level) facilitated the excavation of ongoing interrelationships between people and their garments the complex web of associations that emerge from these interactions. With the active participation of all members of the case study group, including the facilitator/designer/researcher, the MoM process further enabled the co-creation of multiple stories and interactions that meandered in a non-prescribed direction. As the co-design workshop sessions were focusing on garments and related elements that were significant to the person with dementia and their primary carer, the garments triggered different forms of narrative. For example, the narrative was rarely presented in a linear canon, it was often interrupted or disrupted by others with the resulting narratives co-constructed and relayed by multiple tellers. The participants referred to upcoming and past events fluidly and they often moved in a non-linear journey between different story threads and different time periods. The

stories flowed easily between interlocutors. For the most part, there were few direct questions and no fixed answers to the questions.

From the initial idea that Georgakopoulou (2006, 2008) presents, of narratives being co-constructed with multiple tellers in an ecology of interactions, during the course of this study it became apparent that there were many layers of interaction taking place each with their own ecology and sharing some elements. In Figure 73 I have illustrated the extended ecology of interactions that presented themselves as the study progressed.

At the centre of the ecosystem is the PLWD surrounded by garment(s) of significance and the 'others' (the carers and family members) who are also inhabiting their own individual ecosystems. These then overlap to become a larger ecosystem comprising many interactions, many objects, many garments of significance and many interrelationships.

One could almost make an argument for the wardrobe (and specifically, the garments within the wardrobe) as having an 'extended ecology of interactions', which enters and exits the orbit of the wearer's 'ecological system' on a regular basis, animated by its participation in the broader context of the wearer's life and system while also retreating back to the inanimate realm of the wardrobe. This places garments in a unique position where they both bear witness to and contribute to autobiography as they travel through multiple systems or ecologies.

Within the overall ecosystem of the PLWD and their surrounding elements, the garments of significance have their own life cycle that touches the ecosystems

of the people with whom they interact. The garment, therefore, becomes a silent witness to the life of the PLWD through those life journeys. By highlighting the importance of the garments for the wearer, one bestows upon it a renewed value that places it in a cycle of 'use' and thus a place of importance and aliveness rather than dormancy until the garment is eventually forgotten.

Figure 74 shows the garment in its own life cycle. It is a satellite entity that supports our sense of ourselves as it fluidly meanders through a number of different ecosystems. It enters different states of 'being' such as wearing, waiting, washing, drying. The garment is essentially inanimate until interaction with its 'guardian', the person who owns it. Then, it is animated by the lived experience of the person wearing it, handling it or narrating the story attached to it. Each of these interactions bestows value and embosses the garment's significance within the ecosystem of the wearer.

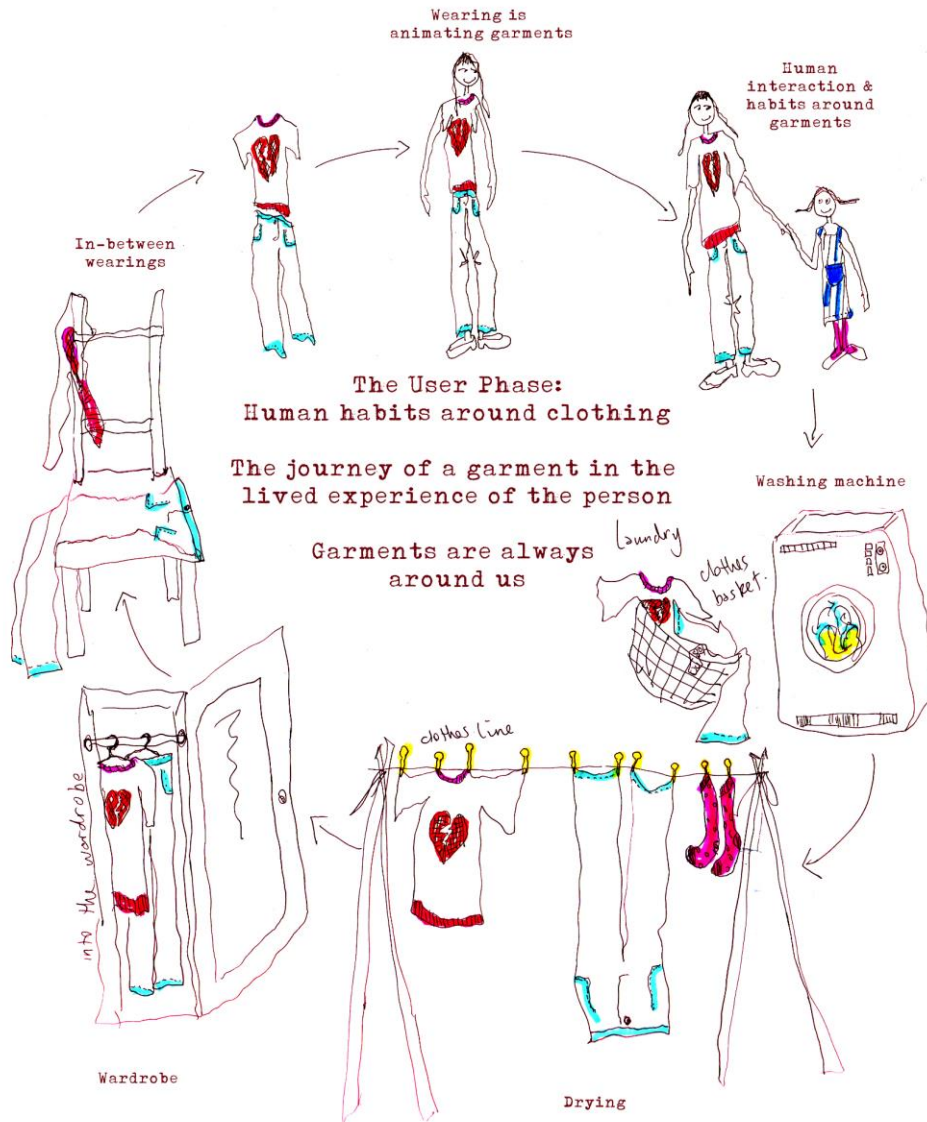


Figure 74: Journey of a garment in the lived experience of the owner

These ecologies of interaction and habit were evident in all three case study groups in different ways. The VIOLET group referred repeatedly to activist marches and protests that they had been attending throughout their lives. They had just attended a march the previous year and were preparing to attend

another one in the coming year. The garments of significance – the two capes – were the garments that Violet always wore to these events. They became part of that ecology of interactions. In the ROSE group, Rose and her daughter Linda were actively creating habits over generations within their family ecosystem. This was evident in the shared love of the colour red. In the IRIS group, Iris and her daughters were embedded together in the practice of ‘making’ together. Georgakopoulou (2007) identifies that the events contained in these types of ‘non-canonical’ narrative constructs refer to links between the participant’s recent previous and future interactions, including their shared stories in various local settings. Thus, the stories are heavily embedded in their immediate discourse surroundings as well as the ‘larger history of interactions where they are intertextually linked and available for recontextualization’ (Georgakopoulou, 2007: 148).

6.4 Design tangibles

6.4.1 Use of the MoM to explore personhood and sense of self for the participants

The section looks at how the MoM enabled the exploration of personhood and sense of self for the participants. Specifically, the MoM framework enabled the co-design process starting with and stemming from the significant garments, which then enabled narrative, both individual stories of personhood and the overarching stories relating to the sense of self, which were co-constructed by the participants. This fed back into the significant garments and reinforced the

existing emotional and physical bonds between garment and participants and participants with each other, while also creating new moments of insight enabled by the exploration of personhood and sense of self. The MoM framework allowed for the outcomes to take different forms and the outputs for these three case studies could never take the exact same form although the process itself enabled the formation of these different outputs. It is significant that although the outcomes were different the impact of the outcomes was similar.

The following section highlights the tangible outcomes as well as the intangible outcomes from this empathic co-design process with the participants. The MoM template for mapping sense of self and personhood through clothing was a fixed tangible outcome, in that for each of the three case studies it was a receptacle for the shared lived experience of the participants to be archived. Variable tangible outcomes were also physically represented through individual creations dependent on the individual stories.

The exploration of personhood and the overarching sense of self that emerged from the data took the form of the ecological sense of self and personhood, the interpersonal, the garments, non-linear and linear storytelling, and co-constructed memories.

6.4.2 Use of the MoM to explore the ecological self

The garments of significance acted as visual and kinaesthetic stimuli that evoked different responses from the participants. The responses to the garments existed on the conscious level of perceptual self-awareness (Neisser,

1988). The yellow woollen jumper from the 'suitcase of stuff' was the most evocative garment for Rose and Iris. Although the garment was new to both participants, it triggered a memory for Rose and a sensation for Iris. Their own garments evoked even greater responses; these were directly triggered by emotion and memory attached to an event or a specific time in their lives.

In the IRIS W1 session, Iris visibly gets great pleasure from feeling the blackberry nubbles on the jumper.

Iris: It's lovely (Transcription IRIS 1 W1).

In the IRIS W2. Iris feels the jumper and holds on to it while keeping it slightly at a distance. She puts her hands into the jumper without looking at it and says it is 'Very cold and dampish' (IRIS 2). Later on, a similar moment occurred when Iris' daughters brought her wedding dress to the session. Iris tentatively feels and starts to 'read' the fabric of the dress:

Iris: Eh?

I: ...

Iris: Oh ...

I: ...

Iris: I'd say it's a while now since it's ...

Iris: I can feel the cold ... (Transcription IRIS W2)

This gently implies a heightened awareness to, and of, the garment, her wedding dress, her sense of body awareness within the space and also consideration of the significance of time when she recognises that it has been a while since she has seen or touched her wedding dress.

In ROSE W1 we see a slightly different manifestation of the ecological self. The discussion in ROSE W1 turns to Larry's two caps. They are both traditional tweed men's caps and Larry has one for work and one for going out. Larry calls them his hats. The hat comes out when Larry is working in the garden, particularly if it is a cold day. There are a number of associations present here: The extended self is present in that Larry recognises that the hat has a specific purpose: he associates it with gardening and keeping his head warm when it's cold, which implies an inherent awareness of his environment and the garment, his hat.

Linda: If he's in the garden and it's a cold day, he'll probably wear the other one, but when he goes out, he wears that one.

I: Okay.

Larry: One for the garden and ... (Transcription ROSE W1)

In the following exchange from the ROSE W4 session, the father, Larry, shows us his two caps and his wife interjects with a few comments about his hats and keeping his head warm. She associates Larry wearing a cap with him being a miner in the past, implying a continuity of self. Earlier in this session, while

looking at a photograph of Larry with his hat rolled up and sticking out of his pocket, we had observed that he always rolled up his hat and put it in his pocket. This was how he kept it when not on his head, signifying a long history of habitual practice around the two hats. Larry also had a special shelf made for his two hats above the door of the garage.

I: That's Larry.

Rose: With his hat on.

I: I love that hat. And do you have another one?

Larry: Yeah. Do you want to see it?

Rose: I'll say, "Take that hat off".

I: Why, do you not think it's... ? Is it not good enough for her?

Rose: ... old fashioned ... keep your head warm ...

I: I know!

Larry: It could be the same hat.

I: It's different.

I: Is that the one you wear when you're gardening?

Larry: Yeah.

Rose: But he used to be a miner, hadn't he, as well?

Larry: ... shove it on.

Rose: See how he folded it up?

I: I love that. Does that fit in your pocket?

Larry: Yeah ... pocket ... (Unclear).

I: They're handy to roll, aren't they? They roll up really small. That's really nice.

Rose: I'll say, "Take that off!" (laughs)

I: Now, roll it again. Let me see if I can ... That's perfect. It's very similar to the other one.

Larry: Yeah.

In ROSE W4, Larry showed me around his garden. He talked about the plants and pointed out a bar that he had installed to help him with balance after he had a stroke. Larry had a heightened awareness of his physical self through the limitations on his mobility after having a stroke. Here, he talks about the physical strain on walking long distances and his need for a stick. He also speaks about his environment as being a support for him. The wall became a support for him to lean on.

Larry: Yeah. I put that little bar on when I first had my stroke, you know.

I: Oh, the bar, yeah.

Larry: (laughs) ... to get over the fence ...

I: Yeah, but your mobility is very good.

Larry: Yeah, it's a lot better now, yeah, it is, to be quite honest. But if I've got to go a distance, I have to have my stick.

I: You have your stick. You need it.

Larry: I mean, like, standing here now, I'm alright if I just hold on to something ...

I: Yeah, yeah.

Larry: But if I was to walk down the street, I've got to have me stick, or the wall and then I'm alright until I've got to cross the road ... (Transcription ROSE W4)

During another session, ROSE W3, the memory of Rose's mother and father are linked to a specific sensory element – the colours pink and red in the form of roses. This memory is embedded in Rose with the consistency of her father's habit of always carrying a red rose. So too there is a link to his continuity of self and hence their continuity of the memory of him in the way that he always took great care of his appearance before going out. The consistent association of Rose with the colour red and the related hues of pink and burgundy imply a continuity from her father's and to a lesser extent her mother's sense of self through the colour red.

I: What do you mean, your mother was pink?

Rose: Pink? Er, used to like pink things. Like, I like... but my dad... it, when he went out, like the flowers then as they used to have, he'd always got a red rose.

(Background noise / talking)

Linda: But he'd grow them. He'd grow his own roses. Mum...

Rose: And he'd always got a red rose and I always said, "That's my dad".

I: Aw...

Rose: I could tell my dad, wherever he was, cos he'd always got a red rose.

I: Aww... that's lovely...

Rose: He loved a red rose.

Linda: My grandad would not go to the shops without putting a tri... his suit and a trilby on. He had to be immaculate when he went out. But in the house... (laughter)

(Transcription ROSE W3)

As the garments were being passed between the participants, they took their time, smelling and handling each garment with considered care. Elements of positive interaction such as timalation (stimulation of the senses) (Kitwood,

1997) and continuity (moving between former and present manifestations of self) (Nolan, 2006) were present in the way that each garment was carefully handled, examined, and this sensory interaction frequently evoked a response, before being passed on to the next person. By absorbing information through the senses, the person as 'ecological self' becomes, and is, aware of their position, their posture and gestures with respect to the environment within which they sit (Cadell and Clare, 2011).

During the sessions, most of the participants were relaxed in a space that was familiar to them. This meant that on a 'body awareness' level the participants were at ease; their ecological selves were present and aware on the level of body consciousness, which opened up the potential for advanced consciousness, self-awareness and meta self-awareness to take place.

6.4.3 Use of the MoM to explore the interrelationship between the person with dementia and their carer/family member

While this research is looking at the relationship between a PLWD and their clothing, it is also looking at the potential for a renewed interaction between the PLWD and their partner/carer. Chapter 2 explored the relevance of different ways of being in the world and interacting with others; for example, Martin Buber (2013), who explored the 'I and it' and the 'I and thou' ways of being in the world. This idea of two ways of being in the world seems to hold particular resonance for people living with dementia and their partner/carers. It is necessary to have different ways of being in the world when everything that you know is changing

so rapidly that you cannot predict, recall or hold things as before. Different ways of being allows for space between those moments of change. Working within the MoM co-design framework allowed for different ways of being between the person with dementia and their partner/carers. By focusing on the garments and using them as a tangible trigger, many conversations that took place allowed a different type of interrelationship to occur. In the IRIS case, it enabled Iris to reconnect on a different level with her daughters. Iris was immersed in the significance of the garments and this became the subject of conversation. Once the garment was produced, the daily routines were abandoned for a discussion on the garment; in this instance, it was the habit of tension arising from when Iris asked for a tissue, between all the participants of the IRIS group:

Annie: Have you tissue there...

I: I have tissues here, I think.

(inaudible – two or three talking at the same time)

I: Now, I have brought... yeah, I have in my bag...

Iris: Oh great, thank you.

(laughter)

I: So this is...

Annie: Oh, beautiful.

(Interviewer hands the participants a yellow woollen jumper and a child's cotton dress)

I: Cotton – maybe cotton and wool, something like that. So you're a knitter?

Iris: I was, years ago.

I: You used to knit... yeah, coz I brought this in from my great aunt – she made that for me.

Iris: Ooh, it's a heavy one that is.

I: It is, isn't it?

Iris: I used to love knitting on the big thread. It would grow very fast
(Transcription IRIS W1).

The individual is not so much the area of interest in this study. The nature of the onset of dementia is such that the person living with the disease becomes more reliant and dependent on the 'other' or, as Buber states, the 'thou'. 'I and thou', moves ideas of consciousness from being in the realm of the individual and towards the realm of interpersonal relationship – towards an 'other' person, disclosing vulnerability and maintaining spontaneity. Buber (2013) calls this the path to fulfilment and joy, even if the introduction of the other can be peppered with fear and anxiety. The introduction of another means being engaged in a dialogue that implies that there is potential for both telling and listening.

This study found that the focus on interrelationship had potential to bring joy, shared meaning and meaning making. Throughout the MoM process, at certain times, the PWLD and their partner/carers drew together to co-create their own meaning. In the case of the ROSE group, it was the recognition of family gestural traits over the years; for the IRIS group, it was the ability of all three members of the group to communicate in a relaxed and easy way together while co-constructing their past lived experience; for the VIOLET group, it was the shared storytelling of their lives together around Violet's capes. At times, some of the participants needed to disengage from the intensity of the situation by withdrawing for a short while. The uncertainty of the daily interactions with the PLWD placed a lot of strain on the partner/carers, who needed to withdraw at times to reflect and gather themselves. The MoM framework provided a clear space in which all participants had the capability to reset the parameters of their interrelationships. In the case of Violet and Jim, Jim often remained silent when he and Violet were discussing events. With the focus being brought away from them and on to the garments, it provided an opportunity for a different kind of exchange to take place between them (VIOLET W2).

With the IRIS group, both of Iris' daughters were usually tentative when arriving to visit their mother. They needed to feel secure within the interaction and consequently they mostly approached her with caution. Iris herself chose to withdraw at times into her own 'suitable space', which was often located in her own past experience. The MoM created the space for Iris to reminisce about her husband and her past life with him. It also enabled Iris to 'live in memory' as she

retreated into her own space to relive and recount that particular experience (IRIS W1 and W2).

The MoM framework enabled the uncovering of a knitted suit, linked to all three members of the family. The recounting of the shared experience of knitting the suit relaxed all of the participants and created an opportunity for the two daughters to enter into a shared and easy space with their mother. In the following exchange, the three family members were looking at a photograph in which Tina was wearing the knitted suit. Iris' two daughters co-constructed the lived experience behind the knitting and wearing of the suit. The cardigan and skirt were made from the same wool and co-created within the family unit by her mother and younger sister for the older daughter (Tina) who wore it during her pregnancy with the family's first grandchild. The physical and verbal interaction between the three family members was very animated as was evidenced through the storytelling, facial expression and bodily movement. For Tina, the cardigan represented a time from before her son was born. She talked about telling her son that the cardigan was older than him. When she referred to her mother having knitted it she talked about it as having complex knitted stitches. This was information that she learned from an understanding of her mother's extraordinary ability with knitting; this ability was manifested verbally by Iris herself at many times throughout the study, as has been discussed:

Tina: I was pregnant now, there ...

I: This is the cardigan ...

Tina: Yeah, and I was probably almost fully ready to have the child ...

I: Were you? So do you associate this cardigan with that period?

Tina: Yeah, and I was probably almost fully ready to have the child ...

I: Were you? So do you associate this cardigan with that period?

Tina: Yeah and I'd say to Darren now that I was 27, so it was knitted the year before, the winter before. Well, he'll be 27 in two months, and I'd say, "This is older than you".

I: That's the cardigan, which you must know, because you knitted ...

Tina: You knitted, mum, and there's cables and twists and things in that and that's the skirt that Annie knitted. It's very heavy, isn't it, mum? It's very heavy.

I: It's absolutely beautiful ...

Tina: We have a photo of me and I was pregnant with Darren, probably seven or eight months pregnant and wearing that cardigan and wearing the skirt that Annie knitted to go with it, so it was like a knitted suit (Transcription IRIS W2).

Within the ROSE family, the MoM played a slightly different role. This family did not have some of the issues from the other case studies that were revealed within the co-design process, but instead tapped into the MoM framework to discover hidden synchronicities within the relationship between mother and

daughter. During the later co-design sessions, these patterns emerged and became recognised more easily by the participants, who rejoiced with each new revelation:

I: Linda's nails are always perfect, too.

Linda: I mean, the way ...

I: Absolutely ...

Linda: You hold your fingers ...

Rose: I hold my fingers but I ain't got the same ...

Linda: Different hands, but same gestures mum (Transcription ROSE W3).

The study revealed that it was the interaction between the participants, their individual sense of themselves and their shared lived experience that were the important elements. Within the space of the MoM process, family experiences were excavated to reveal garments and their relevant stories, family members were able to explore and acknowledge their shared experience and individuals were enabled to be themselves within those caring interrelationships.

The use of a participatory co-design model extended the process of design beyond the creation of an object. The design process began to take place during the preliminary sessions while the participants were excavating material. This was evident from the beginning of the data collection period. For example, it was

evidenced in the co-constructed narratives of mother and daughter in ROSE W1 where they discussed the red shoes that would prove to become the basis for many of the defining garments of significance for Rose throughout her life:

Linda: What colour was that dress, mum? Would that have been black, or was it red? Your picture, mum, your picture – would that have been black, or did you have red shoes with it?

Rose: Probably had red shoes...

I: Red shoes? Would you always have worn shoes to match as much as possible?

Rose: Well, I'd liked it, but sometimes you couldn't get the...

Linda: Your favourite colour was red shoes, though?

Rose: No, me other red shoes...

I: Yeah...

Rose: Girls... red shoes... I was all red... (Transcription ROSE W1)

This was further manifested in the daughter's creative response to the material as it was revealed. She started to make connections between traits in her mother's and her own sense of self by observing moments of personhood. Objects, colours and garments that had before stood in isolation became indicators for intergenerational migrations of personhood. In ROSE W4, Linda,

the daughter, had pieced together her own sense of self as it was connected to her mother's:

Linda: What I'm saying is, the way I chose your cake ... mum would choose that, for me.

Linda: It's making me think how much, unconsciously doing it, but it's there. Obviously, mum would choose that. I wouldn't choose that for myself. And look, that's the key she bought me and look at the backing ... can't see it but it's obviously pink....

Linda: Look at that, the way my wedding was and mum's was. How similar. The way you choose things, but you're choosing the same. Like the cake. You chose that cake for me, in pink and white, and I chose that cake for you in pink and white. We're doing the same thing without knowing. It's weird.

I: It's lovely, though.

Linda: Yeah, but it just shows, doesn't it? You're not doing it intentionally, but it's ... (Transcription ROSE W4)

In the final sentence, Linda trails off after she identified the phenomenon as a subconscious repetition of moments of personhood. These have been manifested in colours that punctuated the co-constructed narrative of the family over time in objects, clothing and food associated with family ritual and celebration. In her responses to garments, and the handling and observing of

them, Linda starts to discover connections between her mother's and her own style synchronicities:

Linda: My veil on my wedding dress and your veil ... making us think about because I never even noticed it until you ... it's just something that's there. You're not physically thinking about it, but we were very much alike.

I: Yeah, and obviously, your nan as well.

Linda: If you look, there, the way that veil was there and the way you were wearing yours ... can you see? Until it's pinpointed, you don't realise it. Now, I wasn't copying you on your wedding day, it's just what we have. Style's just there (Transcription ROSE W4).

As another example, in the VIOLET case study, while having a conversation with Violet and Jim about garments generally, Jim turned the conversation to garments that Violet was wearing on that day. Jim said that Violet was wearing a skirt that 'fits her very nicely'. She replied by saying that she liked it because it was advertised in a photograph somewhere. Violet then made the point that seeing someone wearing something can make one like it more. This was a moment of easy interaction between them. Jim was admiring Violet wearing the skirt and she responded by making a connection between seeing a photograph of someone wearing the skirt in an advert and herself wearing it. For both Jim and Violet, who were experiencing a huge amount of stress as the parameters

of their relationship was changing, this interaction was gentle and easy, without any stress or expectation.

In this section, I have looked at the interrelationship between a PLWD and their clothing. I have also looked at the potential for a renewed interaction between the PLWD and their partner/carer through interaction with the garments.

6.5 Moments of linear and non-linear narrative

Moments of both non-linear and linear narrative were demonstrated throughout the workshop co-creation sessions. Narrative is somewhat suspended between these two ideas of the juxtaposition of time and place. The ROSE family were quite determined to map the history of their lived experience chronologically although Rose rarely stayed within the boundaries of a linear timeline. Hence, there were often parallel discussions where canon was split between tellers as previously mentioned but also where different time frames and moments were placed together. The incidences of non-linear narrative were particularly interesting within the context of this research because the journey of dementia is often described as a non-linear journey, which superimposes many instances of personhood and moments in time over the course of the lived experience of the PLWD.

To further embrace and encourage the idea of a non-linear journey, as far as possible, the co-design sessions did not follow timelines of lived experience in chronological order, but rather focused on the moments of personhood and

sense of self – held within the timeline but not directed by its boundaries. In the following section, from IRIS W1, Iris acknowledges that the cold is okay if you dress for it. She moves to her extended self and talks about the need to dress for the cold as something she has dealt with for years. She then very quickly and easily jumps back into a time years ago – almost as an observer when the children from the countryside would push each other out of the way to get at the hob by the fire:

Iris: It is if you dress for it but I'm anyway always cold for years.

I: Yeah.

Iris: ... and the kids growing up in the country – always fighting for the hob (Transcription IRIS W1).

One continued observation is that it is often the person with dementia who takes the other participants on these non-linear journeys. In the following conversation between Linda and her mother, Rose has just been asked about what she feels when she looks at the family christening gown. Rose says that it reminds her of her mother – she speaks about her mother (this is the inter-personal self – almost as if she were still a child waiting to be reprimanded). She then moves into a more extended sense of herself when she jumps from that thought to how her mother and father idolised Linda when *she* was a small child. She mentions indirectly that Linda would have been tied to a chair. Linda picks this moment of the story up and continues it along another trajectory clarifying that this was due to the fact that there would not have been enough money around at that time to

purchase a high chair. Here, there are two parallel narratives taking place: Linda is talking about her family within the context of the social climate of that time, while Rose is on another track remembering her father referring to his own working hands. The narrative is winding through different subject matters, time frames and foci:

I: What feeling do you get when you see it – when you look at it?

Rose: Well, first of all, I look at it, and I think straight of me mother, because it was she what bought it.

I: Oh, she bought it, of course, yeah ...

Rose: And I always think I'll never get rid of it because of me mother is watching me ... (laughter) ... and I can't help it ... (laughter) Do you know what I mean? Because me mother just idolised her, and me dad, 'er couldn't do no wrong with, and 'er knows it!

I: Her knows it! (laughs)

Rose: Cos 'e can't shouted at 'er, even at (unclear) dad or (unclear) grandad, take no notice on 'er. You know? And he'd say, he's look at her and he'd say, "Look at them hands, they're me working hands", and we'd have her tied on the chair, when we went to me mum's, they'd have her tied on the chair, you see ...

Linda: That was because they didn't have high chairs ...

Rose: ... and we'd have to sit on 'em ...

Linda: Save me falling off ...

Rose: ... and he'd say, "Look at them for working hands, they're me working hands them are".

Linda: Because they didn't buy those sort of things, did they? And (possibly money) wasn't around ... (Transcription ROSE W1)

Rose is very much living in that moment of memory but still wishes to impart the information from her own world while Linda on the other hand is connecting with me on another level. The two narrative trajectories are occurring simultaneously. There is a freedom in the way that the narratives are winding around each other but they do not quite meet. This is a very good example of the kind of exchange that occurs between the PLWD and the 'other'. It is also typical of this kind of narrative journey.

In this section, I have discussed moments of non-linear and linear narrative as they were demonstrated throughout the workshop co-creation sessions. I have also discussed the juxtaposition of different time frames and moments where they are placed together.

6.5.1 Memory: living in memory

An important inductive theme that emerged from the data has been named 'Living in memory'. This is an extension of self, related to the extended self

(Neisser, 1988), and it bridges the gap from the present into the past through the themes of continuity and emotional connection with something around the time of the narrated event(s). Perhaps, as in the case of Rose, the manifestation of an emotional connection with someone who has passed away. In the case of Iris, revisiting a particular moment of her personhood manifested through the recitation of a song sung by her husband. Or in the case of Violet, when she is asked if she remembers her mother's clothing, she enters the world when her mother was still alive and talks about her wardrobe being intact at the home house. She is showing living memory and private continuity of self as well as security in the emotional connection with her mother and the home place.

Within the theme of living memory, it was found that role-play often took place, where the PLWD assumes a personhood from their past lived experience. This was identified during the sessions when observing participants' interpretation of certain memories. In the ROSE study, when the PLWD, Rose, is talking about her past personhood and associating herself with the colour red, she slowly 'becomes' the 'little girl in the red shoes' or the girl who was 'pushed into the swimming pool' and acts out the role of that six-year-old girl, referring to it in the present while embodying the past personhood. It is a transferral of the sense of self that straddles the roles of personhood in the present and personhood in the past through actively engaging in the sense of self as if one were still in the past. The responses of the PLWD are those of the past personhood all the while continuing to inhabit the present personhood. In the VIOLET study, when asked about her mother's clothing, Violet responds by saying that

she 'should have brought some of her mother's clothes' and that 'they were probably quite nice'. When asked if she remembers them she speaks in the present, saying, 'I do remember them and they are in her wardrobe all the time and have been there ever since'. Violet speaks about her mother in the present tense and clearly identifies her mother's home and wardrobe as continuing to exist in the present. According to Violet, 'she lives in Bellahy ... in the pub' with Violet's sister. The person who is 'living in memory' often looks to their closest family member or carer to validate what they are experiencing or bring them back to the present. In the case of Violet, at the end of this conversation she invited her husband to connect her to the present using 'Bellahy' as a transition point.

I: No, well she, your mum has passed away now hasn't she?

Violet: No, she's not gone today [unclear]

I: She hasn't?

Violet: No.

I: Okay, okay – and where is she living now?

Violet: She lives in Bellahy.

I: Aah.

Violet: In the pub.

I: Okay, with your sister?

Violet: Yeah.

I: Aah, okay, okay.

Violet: And us when we arrive there too, we stay in Bellahy as well, don't we? (*Violet looks to her husband as she asks this*)

Jim: We do (Transcription VIOLET W4).

In the IRIS study, Iris moves between her present sense of personhood and her past personhood on a number of different occasions, often referring to her dead husband. In the following conversation, the participants are discussing how knitting was part of the family habit with Annie and her mother sitting knitting together in the evenings. Iris enters the conversation here:

Iris: Click, click of the knitting needles.

I: Yeah – Do you remember the sound of them, of the knitting needles?

Iris: Oh ... I'll walk beside you ... (Transcription IRIS W1)

Here, Iris looks up but is not actually looking at anyone directly. She starts to recite the song that her husband sang for her on their wedding day.

At another moment in that workshop session, Iris tells the group that her husband said that would always be their song. She visibly moves into a different emotional mental state where she is living in memory.

This is a transferral of the sense of self that straddles the person(hood) of the present and the person(hood) of the past through actively engaging in the sense of self as if one were still in the past. As Iris talks about her husband she is transferring her sense of self in this way.

Iris: He sang that on our wedding day. He said that would be our song now.

I: And you still remember it – you'll always have that.

Tina and Annie: Yeah.

6.5.2 Garments: significant garments linked to occasions and family rituals

Drawing the attention of the owner of garments in to explore the meaning and habits that lie embedded within these garments of significance reinforces the owner with the memories associated with the garments. As a starting point, the MoM had a rich pool of resources from which to draw. Because many of the garments were associated with occasions, handling them or looking at photographs of them brought the emotional associations that were attached to the garments, along with the family occasion itself, to the fore. The garments renewed their position of significance and presence within the family archive and through the co-constructed narratives became re-animated in the present as vessels to carry the lived experience of the family forward into the future. This was evident across all three case studies. For example, in the ROSE group,

Rose and her daughter Linda explored their shared sense of self as well as their individual lived experience through the family christening gown, which spanned four generations. It was the first time that the garments' place within the family archive had been delivered as a complete story (co-constructed over a number of sessions) for someone outside the family. The garments' story revealed the various births that had taken place within the family over time. Focusing on the christening gown itself revealed the modular nature of the gown and its accessories as it had been creatively altered by the owners to suit the gender of the babies who had worn it. The revelations that came from the family were linked to those members of the past generations who were honoured and 'summoned' during the sessions. The future of the christening gown was discussed in relation to the possibility of the gown being used again. The overall lived experience of the family was mapped, documented and co-created into a book format.

In the IRIS group, Iris was quite reticent about answering questions around the cherished knitted suit until she actually handled the cardigan and immediately started to verbally speak of the embodied habit of knitting from her past. Her sense of herself at that period of her life when she was an avid and talented knitter rose easily to the surface and enabled a host of further interactions and synergies between her daughters and herself such as shared knitting stories, the story of that particular skirt and cardigan suit knitted by Iris, finished off by her daughter and worn by her other daughter. The tactile interaction between Iris and her daughters led to her daughters wanting to co-create a knitted garment

for their mother with sensory elements derived from the cherished garments explored during the sessions.

In the VIOLET group, the capes worn by Violet through her life were excavated along with the related stories and contexts within which the capes were worn. Violet made constant references to the capes as being the garment that one would wear because they were 'practical and looked well'. As Violet's condition worsened, she left her home and went to the care home with her cape, which went missing. The prior focus on the capes and Violet's life in relation to them was used as the raw material for co-creating the autobiographical label that would become part of the cape(s) identity. By highlighting part of the autobiographical story of the wearer and somehow attaching it to the garment or affiliating it with the garment you expose this garment–person interrelationship. Through the autobiographical information presented on a label, the garment gets afforded something of the status of the owner.

6.6 Development of the MoM framework: an ensemble of elements

The MoM was developed as a loosely structured framework for the exploration of personhood and sense of self through the excavation of lived experience, using garments as triggers for storytelling and memory. It is an interactive ensemble of elements that convene to highlight the existing ecosystems within which the lives of the participants are lived. The MoM is a space to observe, an enabler of evocation, narration and co-creation. It was adaptable to the elements

of each particular case study. The MoM held, within its process, provocations around the clothing and related elements to explore different aspects of self. The MoM framework harvested moments of personhood by focusing on the garments and constructed stories of the participants. These stories revealed the interrelationship between the PLWD and their carer(s) in the present during the workshop sessions, and also over time as their lived experience meandered from the present into the past and on to discussions about their future (Ricoeur, 1992; Cohen and Marsh, 2002). Below I give some of the reasons and conditions that were essential for the successful co-creation process held within the MoM framework. As mentioned previously, an objective researcher with a particular responsive skillset (Manzini and Rizzo, 2011; Koskinen et al., 2013) was essential, along with the other elements for the potentiation of the co-creation process held within the MoM framework:

- The creation of a suitable 'space' that would enable the PLWD and their partner/carer(s) to explore their individual and shared sense of self and personhood.
- The holding of that space for the participants to reach potential for creativity and co-design.
- The workshop sessions needed to fit into the participant's schedules, therefore the researcher also need to be adaptable to their schedules.
- The identification of important garments of significance owned by the participants, to enrich the co-design process.

- Focusing on these same cherished garments and discovering their connection to the lived experience and associated meaning within each specific case study group.
- The excavation of related photographs and family heirlooms to reinforce these meanings and associations.
- The drawing of narrated artefacts that were made present through the co-constructed stories but were missing from the visual manifestation of the shared lived experience.
- Taking photographs of interaction with the garments, family photographs and drawings during the case study workshop sessions to continue documenting the present lived experience in a tangible way.
- The drawing of specific moments captured either from observation or photography to highlight certain moments of intimacy with interaction.
- The enabling of a different kind of communication between participants – one that existed outside the usual interrelationship of the person being cared for by their carer.

6.7 Impact, and tangible and intangible outcomes

6.7.1 The impact of the MoM on the participants during and after the study

Impact on the interrelationships during the study:

For the IRIS family group, The two daughters spoke about the interrelationship between their mother and themselves as being strained and difficult. During and after the MoM process the two women felt that this changed considerably as the participants interacted with renewed ease. This was apparent during the sessions

For the ROSE family group, the daughter and mother talked about seeing each other in an enlightened way while reinforcing their own sense of themselves in the light of their 'other'. The positive revisiting was relayed by both the daughter and mother during and after the study. They found that visiting habitual gestures together allowed them to mirror one another over the years. This reinforced their connection to one another which was evidenced in the daughter's 'discoveries' during the process as well as her verbal responses afterwards.

For the VIOLET family group, the impact of the MoM on the interrelationship between Violet and Jim helped them to identify small, specific issues to work on together to alleviate stress. For Jim, he realised that Violet needed her capes and her favourite clothing with her in the home. He also realised that Violet needed to have the opportunity to dress up and go out to concerts with him. This kept both of their sense of themselves vital and present.

Impact on the interrelationships after the study:

ROSE Case Study 1: This family have expressed that they will continue to carry the work of the co-creation sessions with them into the next phase of their journey. They talked about a deepening of their knowledge of each other over the period of the study.

IRIS Case Study 2: The study was incomplete when Iris passed away quite suddenly. However, Iris' two daughters wanted to continue to use the material from the co-design sessions. The younger daughter returned to knitting and started an art class because of her experience with the MoM study.

VIOLET Case Study 3: Violet is living in the nursing home and has one of her capes with her there. The cape with its label now symbolises Violet's sense of herself even more than it did before. It has become a much larger part of her world now that her world has grown smaller. For Jim, his sense of Violet is also fortified by the presence of the cape, and his sense of them as a couple is similarly reinforced. The cape is worn at times when Violet and her husband go to a concert or visit the park – Jim said that for him the cape now represented another level of security because he is separated from Violet and it means that he feels she has something with her which is related to their world as a couple together. The cape is safe in Jim's eyes, for were the cape to be mislaid again it would be easy to identify its owner from the autobiographical label.

6.7.2 Tangible outcomes for all case study groups: the MoM template

The MoM templates were drawn as the information from the respective groups was unearthed. Figure 75 shows an early version of Violet's MoM from the reflective sketchbook.

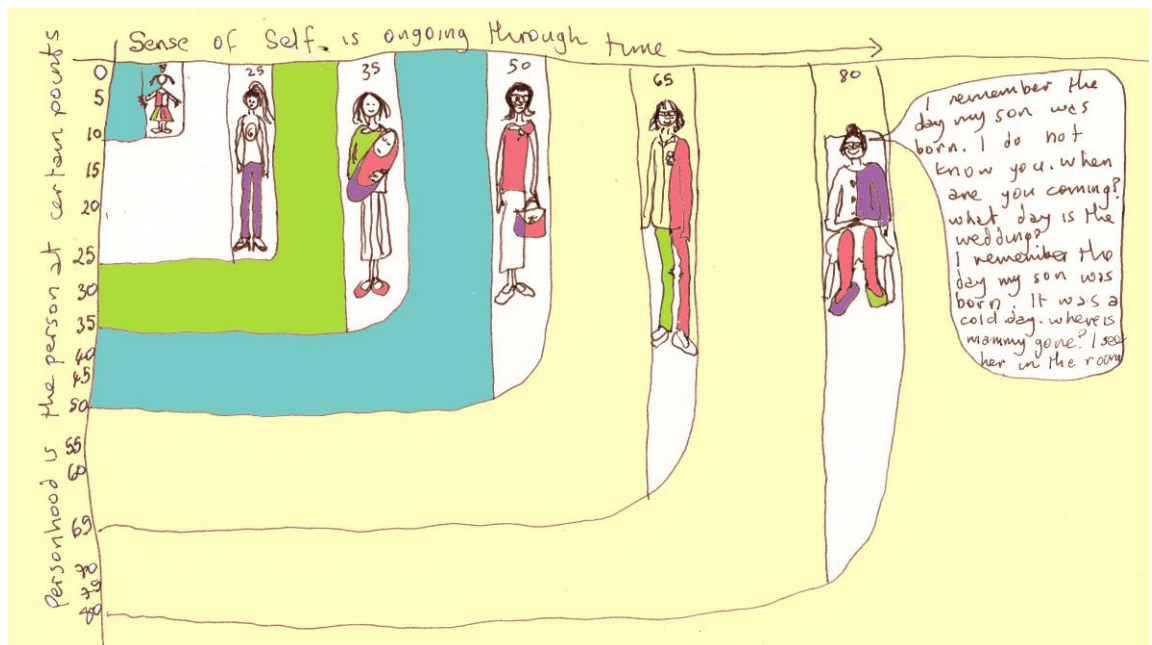


Figure 75: An early drawing of the Violet MoM template: My journey with garments through personhood and sense of self

In this section, I introduce outcomes for each of the case studies. The outcomes were a mix of tangible and intangible elements. Both of these outcome categories are important. The intangible elements supported the tangible and vice versa. Together, both included artefacts, drawings, photographs, assemblages of words, moments of personhood, sense of self, lived experience,

renewed connection with garments of significance and ways of being in relationship.

Tangible outcomes included:

- Observational drawings that included drawings of elements from narrative missing from the visual materials
- Photographs of the sessions
- Phrases and stories from the transcripts.

ROSE Case Study 1: A book that represented the family timeline through garments, photographs, drawings and stories from the sessions.

IRIS Case Study 2: A large display book containing drawings and photographs from the sessions that also included quotes from the participants. This was requested by the family and was displayed at her funeral for all of her friends and family to share.

This took the place of another planned outcome, which was a lap blanket knitted by daughters using sensory elements that the mother identified during the sessions.

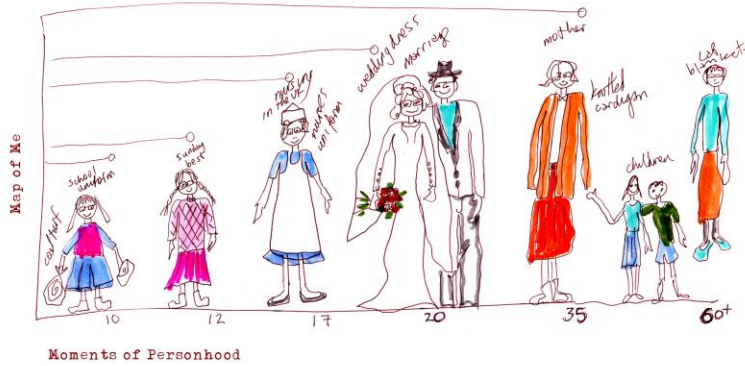
VIOLET Case Study 3: An embroidered label, sewn into Violet's two capes and winter coat, containing autobiographical information about the owner, enabling Violet to have the capes with her in the nursing home.

Another outcome derived from the research is the definition of a set of conditions, necessary to enable the MoM's potency and adaptability. Figure 76 shows the MoM for all three groups.

Rose - Lived experience through garments of experience



Iris - Lived experience through garments of experience



Violet - Lived experience through garments of experience

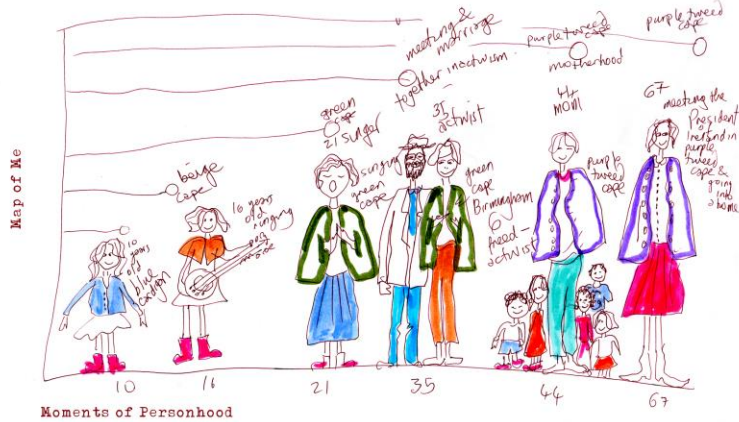


Figure 76: The MoM for all three case study groups. Top: ROSE Group, Middle: IRIS Group, Bottom: VIOLET Group

6.7.3 Intangible outcomes for all case study groups

- A renewed relationship with the cherished garments
- A renewed way of relating to each other
- Shared storytelling around garments and lived experience
- Moments and examples of exploration of sense of self and personhood
- Focused attention on family traits and habits that spanned generations.

6.8 ‘Notes for future researchers’: handing over the MoM creative baton

This is a loose map for the next generation of researchers. I see it as an open and practical protocol for MoM framework and also for the next researchers to take over.

As shown in the previous section, the input of the researcher was linked to a number of fixed and variable conditions that needed to be present for the MoM process to take place in a productive, creative environment. The framework is comparable to the garments of significance; they lie dormant until animated by the wearer or the storyteller. So, too, the researcher can use the MoM ensemble in their own way, with the other participants in collaboration to animate the co-design process further. From my direct experience during the process the following ‘notes for fellow researchers’ have emerged as an outcome.

(1) ECOLOGICAL self: create and hold a 'suitable space' for the participants

The physical environment in which the co-design sessions took place were 'suitable spaces'. The participants dictated their preferred spaces and the researcher accommodated that to maximise a feeling of security, holding and stimulation within the workshop sessions. Each participant's body awareness was present and relaxed. This was achieved by creating a suitable and private space for the participants in an environment familiar to them. (In the case of the IRIS group, it was the residential care home; for the ROSE group, it was the Alzheimer's Café and the participants' own home; and for the VIOLET group, it was the participants' home and later the residential care home.)

(2) The EXTENDED self: identify the garments that hold most emotional attachment

These then act as triggers for co-construction of the narratives for the whole group, family ritual outing, etc.

The three case study groups often referred to past and upcoming family events fluidly in their narratives, which unveiled their importance and relevance for the family as a whole. Within the MoM framework, garments of significance took many forms. The garments were often linked to lived experiences encompassing family occasions, rituals, everyday garments, work garments, garments with emotional attachment and more. The garments that showed most emotional

attachment for the participants in this specific project were often garments linked to occasions and family rituals.

(3) The PRIVATE self: focusing on the garments to alleviate any pressure on the PLWD

By placing the focus on the cherished garments and their related stories, the pressure or concern on the individual participants to 'perform' canonical stories or relate past memories was not present in these workshops. Instead, the focus was aimed directly on the garments and this was a rich source of storytelling and co-constructed narrative that was often non-canonical in nature but still revealed important autobiographies of both the garments themselves and the participants. The co-constructed narratives of shared lived experience around garments flowed very easily and did not appear to bear heavily or cause any stress for the participant members within all three case study groups. There are two things to note here. The first is that the presence of cherished garments brought another familiar and sentient 'collaborator' to the space. The second relates to the phenomenological experience of interacting with the garments. The co-design sessions were encouraging a sensorial and experiential set of personal phenomena, which were underpinning the verbal story.

(4) The INTERPERSONAL self: focusing on the creative gifts that the participants are imparting to the researcher

The interrelationship that was ongoing over the course of the study highlighted profound moments of 'gifting' in the form of sharing creative responses and

stories. One of the ways that the facilitator encouraged this was to re-gift their own stories and personal anecdotal stories around clothing. This consistency was an important part of the co-design process, which was enhanced through the interrelationship.

Some of this relates to how the participants with dementia were consistent in their creative and engagement levels during the duration of the MoM process. It also became apparent that although competency was decreasing on a physical level for many of the participants with dementia, their ability to be creative with language, expression and co-constructing narrative around their own lived experience was constant. Witness Rose's light and happy telling and retelling of herself wearing the red shoes and claiming to be 'all red' throughout the co-design workshops; likewise, the poetic recitations from Iris that ran consistently throughout her sessions. In the case of Violet, her references to being a mother, singer and activist were intertwined and that sense of social justice percolated through her three 'personhoods' in her telling and retelling of her lived experience. The family and caring members who were present during the sessions helped to sustain these creative and expressive moments.

6.9 Reflections on the co-design journey for the researcher

In this section, I reflect on the journey through the research, the co-design process, my personal design journey and the overall experience of doing this work. Paul Rodgers (2017) and Manzini and Rizzo (2011) discuss some of the

complexities within participatory design, particularly when it is extended to encompass areas outside design but within social change and innovation. The role of the designer in a traditional sense can be restrictive and bound by the perimeters of design processes alone. Designers working in a 'co' or 'participatory' design situation, on the other hand, assume many roles that bleed into one another and become more relevant depending on the need at that time (Manzini and Rizzo, 2011; Rodgers, 2017). Over the course of this study, I realised that I needed to be adaptable as a co-designer, in that as the designer my role was multifaceted. I needed to participate in the co-design process; I needed to be an objective facilitator; I needed to hold a space for the co-design process to take place and to be attuned to different roles, to be adaptive and responsive to the process as a participant as well as the researcher.

Manzini and Rizzo (2011) talk about designers acting as facilitators; they can also be the triggers for new initiatives or ideas. The designer can be an activist wherein the outcome is not solely for the 'end user' but has a meaningful social aspect that could affect many others in a beneficial way (Manzini and Rizzo, 2011). The study required my full input as a person with the roles of researcher, facilitator and designer, all three of these being interchangeable and essential. Susan Kozel (2008), in *Closer: Performance, Technologies, Phenomenology*, speaks about the first and third persons as presenting very different and particular ways of communicating content. Overall, there were a number of elements that I needed to cultivate for all three ways of participating in this study. As a researcher, I was searching for unfolding elements that would enrich

my inquiry into the feasibility of using old garments and textiles as triggers for storytelling and co-construction of self. As a facilitator, I was ensuring that all participants were at ease, comfortable with the materials they were handling, and facilitating the co-construction of narrative in a protected environment. As a co-designer, I was straddling the roles of researcher and facilitator with design intuition, personal observation and subsequent integration.

The empathic co-creation process gave me a deeper insight into the understanding of how drawing can be used in many ways. Within the context of this study, it was used as a revelatory framework to illuminate and represent the journey of others. Within my own experience, it awarded a deeper comprehension of the subject matter – in this case, the participants and some of the significant garments. I drew upon Petherbridge (2010) and Lyons (2012) – both leading practitioners in the world of drawing – to support my use of drawing as an observational framework as much as a way of understanding my subject matter. McNiff and Prior support this idea where the art is both the outcome and the process and it reveals as it manifests. Drawing became for me, personally, a revelatory process that enabled the unfolding of my theoretical understanding of the research process. (McNiff, 1998; Prior, 2018)

During the course of the study, I noticed that, where no physical representation of an important artefact existed, I found myself in a reflective space after the sessions where I wanted to somehow give form to some of the missing items. For example, the red shoes that Rose had received as a little girl in the in ROSE group existed in Rose's narrative from her childhood. There was no physical

representation of this artefact. As I was reflecting on the symbolic significance of the shoes, I found myself drawing what I might imagine them to be. When presented with the drawing of the red shoes and asked if they reminded her of the shoes she had worn as a child, she flatly said no, but held on to the drawing and placed it on the timeline of her life, nonetheless. I, on the other hand, drew the red shoes as a means for me to physically enter into the woman's story. Such artefacts – the red shoes, the woollen bathing suit, the red roses – were all elements that were not evidenced by a physical artefact or photograph. Drawing them enabled me to see the missing elements and to see overall patterns in this family's lived history. Drawing also expanded its own boundaries to enable the participants to 'draw' with photographs, illustrated representations of objects from their lives and even storytelling. There was an element of embodiment in the way that the participants interacted through the workshops. Ida Appelboorg, in her drawings and paintings, moves outside the traditional boundaries of paper in her drawing. She often sets out, as Petherbridge (2010: 420) notes, to 'reassemble the scrambled relationships of mismatched items of de-sequenced narrative into new meanings'. The participants were already familiar with the images, and therefore when the images were taken out of context, they naturally re-animated them, spoke about them and deliberated over the details of them. Their co-construction then acted as a mark maker on the timeline of that families shared lived experience. This gave the participants full authorship over the marks made by themselves on the timeline of their own lives.

Over the course of this research process, the participants illustrated that the 'running sense of self over time', or the idem identity, is not bound by a linear structure. It is a composite of many synchronic moments of personhood represented by the 'ipse' identity (Ricoeur, 1992; Cohen and Marsh, 2002), which, through narration, are exposed and often contextualised through discussion of a timeline but can also be left de-contextualised by time. They exist as isolated moments that can be placed on that timeline, yet they do not depend on the timeline to exist in themselves. Similarly, the overarching sense of self does not rely on the recall of moments of personhood to continue its existence. Therefore, with the onset of cognitive decline as the overarching sense of self becomes less clear, it stands to reason that having a map that visually and sensorially represents moments of personhood could fill the gaps within the overarching sense of self.

During this design process, we (the participants and the facilitator researcher) co-created biographical maps of personal sartorial history through narrative, drawing and tactile engagement with clothing and photographs, which cumulatively became the MoM. Hence, throughout the co-design process, much of the lived experience of the participants was revisited and re-introduced somewhat in line with Benjamin's 'meticulous examination' (Bullock et al., 2005: 576) and this yielded important co-design implications for all three case studies. In the ROSE case, a reference to red shoes worn in the past led to multiple memory markers within the strata of the lived experience. These were often revealed through co-constructed narrative between the participants. In the IRIS

case, the accidental triggering of a long unused skill led to an intervention that visibly enhanced the relationship between Iris and her daughters. For the VIOLET case, the excavation of their cumulative lived experience yielded the necessary elements to safeguard a garment that has been and still is significant for Violet.

6.10 Conclusion

6.10.1 Excavating lived experience as a projected plan to support the challenges of the unknown future for people living with dementia and their carers

It is well documented that multisensory approaches are proven to be beneficial and can improve the lived experience of people with dementia and their carer/family members (Heyn, 2003; Ellis et al., 2008; Cheryl and Riley-Doucet, 2009). The garments and photographs acted as physical markers that represented a means by which to access the treasures of lived experience of the participants. They provided the entry point to the sedimentary layers of lived experience through sensory means while sifting through the layered soil of memory. They were part of a multisensory approach that combined physical and cognitive provocations with co- design sessions. Lived experience is a continually growing web of interconnections and happenings, as seen in the three case studies over the course of this project. Time ceases to be linear,

memory is not dependent on fact, stories are evolving in their content as they are constructed, deconstructed and reconstructed by multiple participants. In many examples during the period of time in which this research took place, when working with the participants, the story was a 'co-construct' of various times, dates and people, which was often argued out between two or three participants until the story was cemented, let go or sometimes completely forgotten. It became apparent that the story was often not the primary outcome or aim – but was one of the assemblages used to relate, listen and co-relate in co-presence.

6.10.2 Summary

In this chapter, I have presented the findings from the study. I have discussed the design process, the tangible outcomes and moments of linear and non-linear narrative. I have discussed the development of the MoM framework as an ensemble of elements. I have presented the outcomes for all case study groups and I have given a set of notes for future researchers. In section 6.9, I presented a reflective passage on the co-design journey from my perspective. The chapter concludes with a short discussion on lived experience and its role in supporting the challenges of the unknown.



... just begin... to
to know someone... you need
to... Be with them, and...

... Observe... and...

... Listen... and...

be kind, generous of
spirit, and.....

... over a good long time...

... Understanding....

... sometimes that means...

... being Patient....

... just sitting with
someone...

..Quietly.

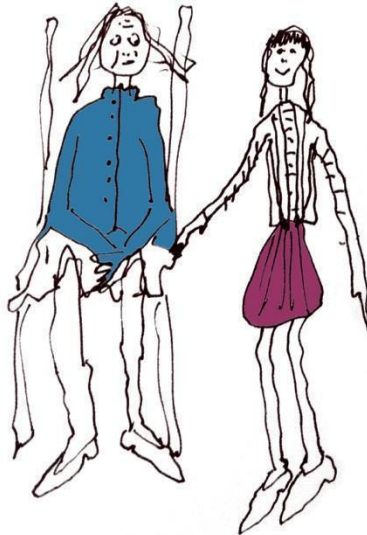


Figure 77: Conclusion: Listen while I speak

Chapter 7: Conclusions and recommendations

7.1 Introduction

'The self is dependent upon its surroundings for its wholeness ... the epidermis is only a superficial indication of where an organisation ends and its environment begins' (Bennett, 2010: 102).

This concluding chapter reflects upon and discusses the findings arising from the case study workshops set out in Chapters 5 and 6, informed by and in association with the theoretical part of the research outlined in Chapter 2 and built upon the methodology and methods discussed in Chapter 3.

Chapter 1 presented an overview of the Map of Me: Caring Through Clothing study, outlining the context and motivation along with the research questions framing this thesis and its methods. Key terms were discussed, along with new terms that evolved over the course of the research. Chapter 2 presented a contextual review situating the research within the related fields, particularly co-design for dementia. Existing ecopsychosocial interventions for PLWD were presented and discussed. This chapter also included a critical review of published literature relating to the domains of dress, personhood and empathic co-design, and provided a theoretical framework for the investigation. Chapter 3 presented the research methodology. It also discussed the methods used to gather and analyse subsequent data from the case studies presented.

Chapter 4 presented the MoM: Caring Through Clothing ensemble and provided a discussion on empathic co-design, the development of the 'suitcase of stuff' and the use of drawing as a means to represent and investigate complex elements. The case studies were described in Chapter 5, with reference to detailed observations and interactions. Initial observations and outcomes from the investigations were also conveyed. Chapter 6 presented a detailed discussion of the findings and outcomes related to the theoretical framework described in Chapters 2 and 3. Finally, in Chapter 7, an overview of the thesis outcomes was outlined including recommendations for further research in the area.

The PhD study posed the question as to how garments might be used to co-create an ecopsychosocial intervention to excavate the lived experience of PLWD. It studied the relationships and associations of three PLWD and their primary carers. It further examined the efficacy of exploring sense of self and personhood by co-designing with the participants an empathic ensemble of elements around the aforementioned 'garments of significance'. This co-designed ensemble of elements is the MoM. The elements include but are not limited to the following:

- (i) Objects and stories relating to objects
- (ii) Relationships and the interrelationship between people and objects
- (iii) Memory and placement of time and space within the lived experience of the participants

- (iv) Moments of personhood and sense of self within the placement of time, space and objects
- (v) Place, suitable spaces.

The MoM framework was developed specifically in order to explore personhood by focusing on garments of significance. The basic framework was modelled on Neisser's senses of self. Best care practice evolved from Kitwood's writings on personhood, and the inspiring work of Dewar and Nolan were used as navigation tools that were mapped on to the base model of Neisser's senses of self. The empathic co-design methods emerged from this theoretical framework.

7.2 Research objectives

The purpose of the PhD study was to explore the efficacy of the sensory and intangible nature of 'garments of significance' for co-creating an eco-psychosocial intervention that enables excavation of lived experience for PLWD with their primary carers. The secondary aim of this study was to investigate whether interaction with such garments of significance could then be used to trigger memory and inter-personal storytelling, with the overall aim of exploring sense of self and personhood.

This thesis – encompassing the written thesis argument, the appendices providing additional data and evidence, and the practice-led elements including drawing –provides a full account of this qualitative study. The original

contributions of this study are situated within the main and relevant cognate fields of the inquiry.

Anonymised but indirectly very present through a continual focus on them are three remarkable people living with dementia and their primary carers. The thesis has captured the process of the co-creation of the MoM framework using an ethical empathic co-design framework. The impact of the MoM and its responsiveness to each of the participants has been recorded through the course of the journey.

7.3 Summary of original contributions to knowledge

The MoM is situated in the context of a rich body of research that has contributed to its inception. The empathic co-design framework that has been developed over the course of this research study has drawn from progressive research in the field of dementia care from such pioneers as Tom Kitwood and John Zeisel. The work around clothing from Twigg and Buse, including the research at Bristol University headed by Rebecka Fleetwood Smith. Progressive and reminiscent work such as the ‘Suitcase of memories’ project (Mullins et al., 2022). The LAUGH and Sensor E Textiles projects at Cardiff Metropolitan University and the importance of object–human relations in the ‘Material Citizenship’ project at Southampton.

Within the context of existing research, this thesis makes an original set of contributions to knowledge, which emanate from the overarching ensemble of the MoM: Caring Through Clothing, detailed as follows:

- The MoM ensemble of elements for use and further evolution by future researchers, carers and co-designers
- An interdisciplinary horizon scan and literature review that situates this developing field of study
- Original data gathered in anonymised form for future researchers
- A full thesis argument that positions the PLWD at the centre of their own ecosystem and owner of her or his own agency and sense of self
- An approach to the application of art-based and qualitative methodologies to the lived experience of valued and vulnerable members of our society: an intervention with potential to reach into the wardrobe and beyond scholarship to enable small and meaningful change in care practices for elders and their families.

The research has:

1. Developed the concept of the MoM: Caring Through Clothing, an adaptive empathic co-design methodology that utilises a practice-led ensemble of elements and engagement with PLWD and their primary carers.
2. Developed the MoM ensemble as a set of co-designed elements that explored and enriched:

- The collation and physical presence of garments of significance, drawings and related photographs
- The relationship and interrelationship between people and objects
- The placement of memory, time and space within the lived experience of the participants
- The excavation of lived experience through storytelling related to garments of significance
- The exploration of sense of self and personhood for the participants
- The identification of a 'suitable space' that enables the participants to partake in the workshops comfortably.

3. Developed and identified the following outcomes from the process

- Excavating lived experience

The MoM provided a receptacle where specific markers of lived experience from the different participants could be explored and held in a repository archive as a future intervention for the care of the PLWD.

- Animating the present with the past through garments of significance

Certain garments renewed their presence and significance within the family archive and through the co-constructed narratives became re-animated in the present as vessels to carry the lived experience of the family forward into the future.

- Harvesting the unseen

With the onset of cognitive decline as the overarching sense of self becomes less clear, the presence of the MoM ensemble of elements that visually and sensorially represents moments of personhood can fill gaps within the overarching sense of self.

- The garment labelling as a mutual tagging identifier

By highlighting part of the autobiographical story of the wearer and attaching it to the garment or affiliating it with the garment the interrelationship between the person and the garment is revealed. The label is a mutual tagging system. It is through the autobiographical information presented on the label that the garment gets afforded some sense or trace of the status of the owner. Similarly, the owner's relationship to the garment is reinforced by the presence of the label, which indicates ownership and thus some sense of active agency.

- Supporting a symbiotic system

As the garment of significance moves through its own life cycle it also has the opportunity to bear witness to and accompany the lived ecosystem of the wearer or person safeguarding it. Thus, the MoM can develop with the PLWD and their primary carer to grow into a functional resource that can support personhood as cognitive function deteriorates.

- Handing over the creative baton of the MoM

The designer/researcher/facilitator has the capacity to use the MoM ensemble in their own way, with other participants in collaboration to activate and animate the empathic co-design process. This study has a set of loose recommendations outlined in Chapter 6 as 'Notes for fellow researchers'.

The following four key terms that have evolved over the course of the research were developed as part of the process of naming elements and situations as they arose and/or appeared a number of times. The terms are 'Caring Through Clothing', 'garments of significance', 'living in memory', 'MoM'. I have discussed these terms in more depth in the glossary of key terms.

7.3.1 Limitations of the study

The data presented here were collected from three people and their partner/carers. Bearing the limited size of the sample in mind, this research could be read as a proposal or exploration for a more extensive research study. Because of the nature of the vulnerable people involved in the study it cannot be a fixed process. The MoM is a proposal for a deeper level of interactional encounter and is contingent on the conditions presented being met with both structure and spontaneity (McNiff, 2018:81). I have given recommendations for future scholars, but this study should not be taken as a readymade template.

Each participant was chosen based on the criteria that they were living with early to mid-stage dementia. For people living with more advanced dementia, the MoM intervention as presented in this study would not be feasible.

Another criteria was that the PLWD had access to a carer/family member who could bring them to the workshop sessions and who would commit to engaging with their loved one to work through the MoM intervention and partake in the journey together. The study would not have been possible if each of the PLWD had not had the support of their primary carer. The researcher was mostly working alone with the families after the initial period of observation within the community had taken place. The workshop sessions could have benefitted by having a second facilitator. Within the care home setting, nurses and care staff do not have time to work on an individual level with the residents; therefore, again, this type of intervention relies on the investment of family members, which could exclude potential participants in residential care homes without a strong family support network.

A significant limitation of this study includes the fact that illness is a real possibility when dealing with vulnerable adults. Over the course of this study, all three of the participants became ill and one of them passed away before the study was complete.

Gender could also be a limiting factor. It was beyond the scope of the research to recruit an equal number of men and women. The three women who did partake each happened to have a rich history of lived experience with their garments. Of the three female participants, two were being cared for by their daughters and only one of them had a male primary carer. This raises questions around traditionally gender-oriented roles within care, which may shift with

generations to come. Unfortunately, this rich research area was beyond the scope of the study.

Facilitating the design workshop sessions required both time and skill. Both of these elements were needed to build relationships between the participants and the researcher. Skill was required to provide the opportunity for all present to participate, which was also time consuming and challenging at times. The amount of time that is required for this level of engagement uses a lot of resources. This is worth noting for future studies of this kind.

Outside of the workshop sessions it was not possible to observe how these garments of significance were used in the participants' own respective ecosystems.

7.3.2 Key findings related to empathic co-design

This study revealed five elements that enabled the MoM intervention to reach its full potential within the empathic co-design process in the context of this study. While the study is limited by sample size and other constraints, within the context of the MoM process the following elements were necessary for empathic exchange and co-creative collaboration to occur.

- The finding of a 'suitable space'
- The collation and physical presence of significant garments, drawings and related photographs

- The use of the MoM to excavate lived experience through storytelling
- The use of the MoM to enable sense of self and personhood for the participants
- The use of the MoM to enrich the interrelationships between the PLWD and their primary carers.

The empathic co-design process was the basis for the creation of the MoM. It also reinforced the physical and emotional connections between the participants and their cherished garments.

7.3.3 Key findings related to garments of significance

The person-centred research of this PhD sheds new light on the important role that garments of significance play within everyday habits and rituals, and on the liberating and empowering impact this can have on individuals and their families, through the following:

- The elevation of garments of significance within the personal ecosystem of the PLWD
- The process through which garments of significance were reanimated as vessels of lived experience for exploring sense of self and personhood through shared co-tellership

- The attention paid to garments of significance, which itself elevates their status within the ecosystem of the PLWD and therefore increases their value.

Taken together, these elements of the study's unique focus on garments within the ecosystem of the PLWD proves useful in expanding our understanding of the very concept of care. Most importantly, it illuminates the role of the PLWD, the carer, and the family, through garments that can be seen to have renewed their position of significance and presence within the family archive. This then allows the co-constructed narratives to be reanimated in the present as vessels to carry the lived experience of the family forward into the future.

While this study was conducted before the Covid-19 pandemic, the impact of the study on and for PLWD, their carers and family network is particularly poignant. The pandemic saw so many of our elders endangered and 'cocooning' without access to their families and the people they love. The absence of physical touch, which is ordinarily part of everyday interactions in the form of hugs and physical affection, has been felt even more keenly by all of us during lockdowns, but would be a key component for those PLWD and their families. This study has brought renewed ways of interacting and being together through garments of significance to the three families in particular before this period of time. It is hoped that the findings, though limited in sample size, may encourage more research in this area and in doing so, help to shape a more connected and supported experience for other elders and families in months and years to come.

The presence of a favourite sensory object such as a garment of significance from the PLWD's own wardrobe and ecosystem holds even more significance during times of extended isolation. Perhaps this project can contribute in a small way to future research around clothing and the wardrobe as an intervention for PLWD and their carers and families.

7.3.4 Key findings related to exploration of self and personhood for people living with dementia

The study demonstrates the following key areas of impact in relation to exploration of sense of self and personhood:

- The importance of garments of significance for reinforcing and exploring sense of self and personhood for people living with dementia
- The MoM held a repository where the shared lived experience of the participants was mapped, archived and revisited, reinforcing personhood and sense of self
- Utilising narrative as a basis for co-tellership, co-presence and interaction with the garments of significance.

The MoM ensemble of elements adapted to different circumstances and participants and became a repository where the shared lived experience of the participants was archived and revisited. Exploration of the overarching sense of self that emerged from the data was evident in the storytelling and shared

tellership and interaction around personhood. Mapping the lived experience of the participants was just one of the tangible outcomes – for all three case studies.

The exploration of personhood was also evident in the responses of the participants to the study through their individual creations. While the primary carers were fully involved in the empathic co-design process and displayed many moments of exploration of their own lived experience, introduced in Chapter 5, it was beyond the scope of this PhD study to also explore the sense of self and personhood of the primary carers in depth. This, however, stands as a rich area for the MoM ensemble to be explored in future research.

7.3.5 Findings related to the application of narrative storytelling practice for this intervention

The research illustrated the following key points in relation to the importance of narrative storytelling for the MoM:

- Narrative about and pertaining to significant objects where the garments are the focus and act as a fulcrum/central point around which meaningful interaction and intimacy can take place
- The storytelling is both elicited from the MoM ensemble and also iteratively feeds back the MoM in a virtuous circle.

The journey of dementia is often described as a non-linear journey that superimposes instances of personhood and moments in time over the course of

the lived experience of the PLWD. Narrative is somewhat suspended between time and place where different time frames/moments and places are easily juxtaposed together. In the context of this research the narrative was triggered by collating the curated elements of the MoM ensemble of elements. One of the more subjective outputs of this PhD research is the confirmation, backed up by evidence that humans do indeed need to share stories in order to build hope and to share moments of intimacy and love with one another. Small stories, individual stories, may seem less important on the surface, but these are the richest sources of material capturing the essence of vital everyday rituals and habits. These are, therefore, the most important narratives to which we must pay attention in our efforts to enhance and support all communities and our experiences of being included, heard and respected within those communities.

7.4 Future implications of the MoM and areas for future research

Other possible areas for future research arose during the final year of the process of writing up of this PhD thesis. These findings provide the following insights for future research.

The results of this study will be made available for future researchers. This qualitative art-based approach, which was supported by the collaborative stakeholder – the Alzheimer Society of Ireland (ASI) will be further extended and made available to the (ASI) research library as a resource with a specialised focus on the UK and Ireland. In discussing these outcomes, it has been

acknowledged that garments of significance play an important and lasting role. A copy of the research will be therein deposited. Dissemination of this research will take the form of journal articles and peer-reviewed papers.

The content of the thesis provides a practical protocol for future researchers to take over and utilise the MoM intervention. Implementation of this process would fit with the ethos of the Alzheimer's Cafés where the observation and initial preparations for the study were initiated. The research offers an opportunity to further develop and refine the MoM intervention if undertaken at the postdoctoral stage, with a view to facilitating training and workshops aimed at making the MoM available for educational purposes, nursing programmes, families, designers and artist practitioners. The type of research advocated by this thesis must, to be faithful and consistent with the MoM process, maintain a certain intimacy and closeness as is required by the empathic co-design method. To this end, it is advised that any future research building on the MoM should scale up in a series of sub-pods of PLWD and their primary carer, rather than in the context of a larger cohort. Ideally, future research would progress in a context wherein one or two research facilitators would work on a pod basis with a small number of families per researcher.

7.4.1 Scope and transferability of the MoM in future research

The scope and time frame of this PhD thesis did not allow for some of the ideas generated by the research to be fully explored. For example, it was beyond the scope of the study to engage in an in-depth exploration of sense of self and

personhood of the primary carers, as noted above. However, the study does document some of the carers' responses to the garments of significance and their interrelationship with the PLWD. This stands as a rich area for the MoM ensemble, which could be expanded for future studies. For example, future research could focus on documenting and exploring sense of self in more detail and from the perspectives of the primary carers. Through the journey of the thesis the participants and the researcher together discovered important new knowledge that could be applied in future, either at postdoctoral level or in future research by others.

In terms of potential transferability, moving beyond the study group presented in this research, the MoM intervention holds the potential to enable the exploration of self and personhood for other vulnerable groups such as individuals and communities who have been displaced due to conflict or political upheaval. Communities of minority groups, people with disabilities, people struggling with addictions people who have suffered from brain trauma, people on the Autism spectrum, and people struggling with mental health issues. These and many other groups could find empowerment and a sense of agency through a customised application of the MoM.

In short, the MoM is a transferrable ensemble of elements that is responsive and fully adaptable to the circumstances of other vulnerable participants.

Future plans to expand the interdisciplinary nature of this work even further could include working with health professionals, charities for social improvement

and primary carers as well as with technologists, artists, designers, ecologists and researchers. The inclusion of ecology in this list is intended to open up the possibility for PLWD to be their own landscape artists co-designing their own ecosystems. As the knowledge and understanding of the type of cognitive decline experienced during the dementia journey is expanded, so too must the interventions and advocacies expand within the dementia community; they must be self-designed, self-organised and self-actuated.

7.4.2 Digital design application

One area of future research is the translation of this framework into a digital design application. The MoM process and ensemble of elements could be utilised as is, in 'real-world' care settings for PLWD and their families. It could also be personalised and modified to suit the needs of specific people and settings. Each personal story iterates differently, as seen from the three case studies. The framework derived from the examples given provides future researchers with a map to follow and to customise for their own purposes when working with PLWD and their carers. The evolution of the MoM from inhabiting a fully analogue space in terms of care to a hybrid of an analogue and digital application would enable an efficient and consistent transfer of important autobiographical information between care teams and stakeholders pertaining to the PLWD. This process would require significant attention to detail, and the digital application would merely be a support for the analogue process.

Additionally, it should be noted that a new trend emerged towards the end of the thesis project: this was a rise in the use of augmented reality (AR) tools, which have become ubiquitous and thus much less expensive and more instinctive to use. Future research could thus, realistically and without great expense or technological challenge, explore the creation and testing of a digital AR MoM, which would consider phenomenological qualities of 'real' versus 'digital' agency in this context. The researcher is in discussion with an AR research group at SMARTlab, University College Dublin, with expertise in this area, and an (Goodman et al., 2020).

7.5 Conclusion

This study has identified that excavation of the wardrobe for garments of significance is a rich starting point for an ecopsychosocial intervention that explores lived experience for PLWD.

The MoM intervention was co-designed, tested and analysed during the years of registration for this PhD study. The 'suitcase of stuff' was curated over that time. Recommendations for future scholars are based around a common starting point that evolved to reach three different outcomes that were dependant on the unique interactions of the specific individuals and their personal ecosystems. The study focused primarily on revealing and gathering the lived experience shared by the PLWD and their primary carers.

Important aspects of self can become inaccessible with the onset of dementia. A study such as the MoM draws attention to the small stories of everyday rituals and habits that, although buried, can be made accessible by tapping into the sensory and autobiographical repository of garments of significance. These are the narratives to which we must attach our most focused attention as scholars and qualitative researchers, as families and carers for PLWD. Together we must pay attention to the journey through dementia and work collaboratively to support the evolution of communities to meet and address the challenges of that journey.

Personal narratives are never constructed in isolation; rather, they are gestated and birthed within the context of community and environment. The loss of a sense of self for one person within a family unit can destabilise the wider family's response to loss and ways of being. The moving of a PLWD from the centre of their own ecosystem and home into a nursing home without consideration for the objects of importance in that person's life only serves to diminish their overall sense of self and personhood. As this study has demonstrated, the elements of accuracy regarding tasks and memory are often abandoned for elements of adaptability and openness. The journey is the important element to focus on here, not the most accurate representation of events or occurrences. The garments held within the personal ecosystems of PLWD, particularly in the early stages, need to be identified, recognised and incorporated into the ongoing journey of the family. It stands to reason, then, that sharing the process of excavating lived experience through these garments of significance is a

necessary condition of the reinforcement of the meaningful interaction that enables personhood.

As has been shown through this research and reiterated through other research in this area, working with and advocating for better lives for PLWD and their primary carers needs to be both inclusive and collaborative to be effective as a real-world intervention. The development of the MoM is one of many first steps being actively taken toward a more inclusive methodology for co-designing with PLWD. Thus returning to the analogy of the care and well-being of PLWD as being an ecology of care and elements. The MoM ensemble draws on an interdisciplinary wellspring of ideas and methods that have been constructed and examined over the course of the project, showing that garments held within those personal ecosystems need to be identified and recognised for their importance.

Epilogue

It is imperative that we provide vulnerable older adults with the resources they need to live well. This body of work has revealed the need for familiar and sensory objects of significance to be identified and re-introduced into the daily lived experience of PLWD. To function within the care system, the MoM intervention would need to be embedded within the every day systems of care, as part of habit and best practice forward planning. In the event of small everyday situations around care such as anxiety, or more extreme situations such as the Covid-19 pandemic arising in the future, the MoM ensemble could be 'activated' or 'implemented'. When PLWD are moved from their homes into care homes, it is our collective responsibility to relocate them with garments, objects and other significant elements from their own ecosystems.

Humans create rituals around their daily lives and engage in habits and practices that enable them, in their journeying, to enter and exit the world with dignity and meaning. The Map of Me: Caring Through Clothing is an ensemble of these practices and habits that has been co-designed with and held by the participants. It is a collection of garments of significance, important objects, people and habitual rituals of lived experience. The onset of dementia is a journey taken by the PLWD and they are accompanied by their nearest family and primary carers. On my own life journey, I have been privileged to witness many difficult and equally rewarding journeys – always made memorable as shared experiences.

Where I grew up in the Burren in Co. Clare, Ireland is a karst region clad with limestone and caves fed by underground water springs. There is a specific cave in the Burren called Glencurran Cave, which has undergone excavation over the last 20 years. The discovery of a child's remains within the cave is a deeply provocative reminder of the inevitable or sometimes unexpected journey that we all, ultimately, undertake when we die. The evidence suggests that this child was buried with great care in the cave over 3,500 years ago. Laid on a bed of rushes the child was accompanied by a pouch or garment adorned with 50 periwinkle and cowrie shells, which had been sewn on to the substrate, now long disintegrated (Dowd, 2009). The shells live on, and through them, the lost substrate remains and, with it, the community of care that held the child. Within the experience of being human, this is not new. Historically, around the world, humans have taken great care when sending our dead on their journeys to the otherworld often with precious objects from life.

Here, the intention is not to make a laboured comparison between the journey of dementia and the journey to the otherworld after death. Rather, it is to highlight the fact that the practice of journeying, with precious artefacts from lived experience in life or in death, is and always has been innately important to the experience of being, and knowing yourself to be, human.



Figure 78: Epilogue: The journey continues

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Appendix 1: Consent form templates

1a. Caring Through Clothing consent form for

Participant 1

To be signed by the person living with dementia

I understand that I have been asked to participate in the project **Caring Through Clothing** and that I will be asked to take part in interviews and discussions about my experiences related to clothing.

I confirm that I have read and understood the information sheet for the above study and have had an opportunity to ask questions and any questions that I may have asked have been answered to my satisfaction.

I understand that my participation is voluntary, and that I am free to withdraw from the above project at any time / up until commencement of data analysis.

I understand that my data will be stored securely and confidentially and that I will not be identifiable in any report or publication.

I understand that the researcher may wish to publish the study and any results found for which I give my permission.

I hereby consent to the video and photographing of myself and the recording of my voice. I understand that all information will be anonymous, peoples own names will not be used and that images will be blurred.

To opt out of being videoed and photographed please tick the box.

I understand that should I lose capacity to consent before the end of the study I would like to continue participating in the study.

To opt out of continuing in the study in the case of loss of capacity please tick the box.

I agree to take part in the above study.

Signed.....

Date.....

1b. Caring Through Clothing consent form for

Participant 2

To be signed by the carer or partner of the person living with dementia

I understand that I have been asked to participate in the project **Caring Through Clothing** and that I will be asked to take part in interviews and discussions about my experiences related to clothing.

I confirm that I have read and understood the information sheet for the above study and have had an opportunity to ask questions and any questions that I may have asked have been answered to my satisfaction.

I understand that my participation is voluntary, and that I am free to withdraw from the above project at any time / up until commencement of data analysis.

I understand that my data will be stored securely and confidentially and that I will not be identifiable in any report or publication.

I understand that the researcher may wish to publish the study and any results found for which I give my permission.

I hereby consent to the video and photographing of myself and the recording of my voice. I understand that all information will be anonymous, peoples own names will not be used and that all images will be blurred.

To opt out of being videoed and photographed please tick the box.

I understand that, should I lose capacity to consent before the end of the study, I would like to continue participating in the study.

To opt out of continuing in the study in the case of loss of capacity please tick the box.

I agree to take part in the above study.

Signed.....

Date.....

1c. Caring Through Clothing assent form for the carer/partner

To be signed by the Participant who is caring for, or partner of, the person living with dementia if necessary for ongoing consent.

I understand that I am signing for who has been asked to participate in the project **Caring Through Clothing** and that I am giving consent for to take part in interviews about their perceptions and experiences related to this project.

I confirm that has understood the information sheet for the above study and has had an opportunity to ask questions and any questions that they may have asked have been answered to their satisfaction.

I understand that’s participation is voluntary, and that they are free to withdraw from the above project at any time / up until commencement of data analysis.

I understand that’s data will be stored securely and confidentially and that they will not be identifiable in any report or publication.

I understand that the researcher may wish to publish the study and any results found for which I give’s permission

I hereby consent to the video, photographing and the recording of I understand that all information will be anonymous, people's own names will not be used and that all images will be blurred.

To opt out of being videoed and photographed please tick the box.

I give 's permission to continue participating in the study should lose capacity to consent before the end of the study

To opt out of continuing in the study in the case of loss of capacity please tick the box.

I give consent for to take part in the above study.

<p>Signed on behalf of.....</p> <p>Date.....</p>
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Appendix 2: Invitation and information for participants

2a. Invitation for participant

Caring Through Clothing is a series of workshops where we share memories and stories around our clothing.

What is Caring Through Clothing?

We are inviting you and your friend or relative to take a look at the clothing in your wardrobes and revisit them as items of importance. We will then invite you to take part in four workshops where you bring your own clothes to explore stories and memories together.

Can I bring a friend?

We hope that you will bring a family member, carer/friend with you to take part also.

What does Caring Through Clothing involve?

We will meet 4–6 times over a 3–6 month period to share and explore stories and develop new ideas around our clothing together. We will talk about how our clothes help to shape us into the people that we are

How can I take part?

We are holding an informal meet and greet on *[insert date]* at *[insert location]*.
This will be a good opportunity to find out about the research and ask any questions that you may have.

If you require more information about what is involved, please contact Tara Baath Mooney.

2b. Participant Information Leaflet

Information Leaflet: Caring Through Clothing

You are being invited to take part in a research study. Please take time to read the following information carefully and discuss it with friends/ relatives. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

This study is looking at using clothing and textiles as a way to explore a sense of self and interrelationships for persons living with dementia and their carers or partners.

Why have I been chosen?

You have been chosen with your primary carer and four other couples to take part because both you and your primary carer might benefit from the study.

Do I have to take part in this research?

It is up to you to decide. If you decide to take part, you will be asked to sign a consent form but you are still free to withdraw at any time up until data collection without giving a reason.

If I take part what will happen?

The research will take place over a 3–6 month period. There will be four sessions. During this time you will be asked to partake in a number of short activities including: a general questionnaire about yourself; a questionnaire relating to clothing and your sense of self; and two informal sessions where you will be asked, along with your partner, to share your experiences relating to your own clothing and to create your own visual map of your lived experience.

Will the sessions be recorded?

We would like to video or photograph you and your family member and to record your voice during the sessions. The purpose of this is to supplement our understanding of the stories you tell us and your reactions to some of the materials. In addition, we will use clips of recordings and photographs for the PhD submission, which will be seen only by the examiners of the doctoral thesis. Finally, any short clips of recordings videos or photographs used when presenting the work at conferences, workshops and seminars to highlight key points will be anonymised through facial blurring. Please be assured that only the members of the research team will be able to store and use the videos in this way and they will never be shared in an unauthorised manner. You have the right to opt out of having your sessions recorded but still take part in the study as normal if you wish. Please speak to the researcher about your preferences or if you have any questions or concerns.

What are the possible advantages and or risks of taking part?

It is hoped that the discussions will be informative to you and generally of interest. Additionally, the results will be analysed and written up, which may inform the direction for future research in the area.

There are no risks to you in taking part outside of those you would experience in everyday life. However, by taking part, you may remember things that you may find upsetting. If this occurs, the researcher will ask you if you want to continue to participate in the interview. Any decision you make will be followed and no information about the incident will be given to relatives or third parties whose identity or relationship to the participant cannot be verified as this could breach assurances of confidentiality.

If I notice or uncover anything during an interview that would indicate that you are in need of help or support and that this may need to be disclosed, I will explain to you that I have a duty of care to inform an appropriate contact. All of these records will be passed on to the appropriate contact and will not be held by this researcher.

Who is organizing and funding the study? This study is being conducted by Tara Baath Mooney to fulfil requirements for a Doctor of Philosophy at the University of Wolverhampton.

What will happen when the study ends?

The data collected will be analysed by the researcher. All raw data (audio, paper and photographic) will be kept securely for analysis.

What will happen to the results of the study?

The results will be written up and will form part of the final PHD thesis. The results will also be written up and disseminated as a paper. If you would like a copy of the results we will be happy to provide this for you.

Will my taking part be kept confidential? Yes. All the information about your participation in this study will be kept confidential. The transcription of the interview you participate in/the surveys you completed will be stored on a password protected computer in a locked room. All raw data (audio, paper and photographic) will be kept securely for analysis. Only the researcher will have access to the raw data. You will be assigned a number and your name will never be used. All videos will use facial blurring.

Who has reviewed the study?

This study has been reviewed and approved by the University of Wolverhampton Research Ethics Committee.

Who should I contact if there is a problem or I wish to make a complaint?

If you have a problem with the research and wish to make a formal complaint please contact: Prof. Fiona Hackney, Faculty of Arts.

2c. One-page overview

This study uses clothing and textiles as multisensory triggers for those living with early-stage dementia to increase a sense of personhood and well-being.

Introduction:

This research proposes to investigate the use of clothing and textiles as an intervention to explore lived experience personhood both for people with dementia and their carers or family members.

Context:

Realistic goals for amelioration of the symptoms of dementia lie in both delaying institutionalisation and on improving care conditions that impact the positive well-being of patients and their caregivers. This research is investigating whether textile and garment artefacts can enable the exploration of an individuals' sense of personhood specifically in the context of dementia.

Proposed methodology:

This is a qualitative study that aims to facilitate participants' active engagement with one another through an artefact of clothing or textile while exploring a sense of self and personhood. There will be no reference or access to participants' medical records. The protocol will not interfere with participants' standard of treatment or care. All participants will partake in the same protocol with no control group or randomisation.

Short sessions will be held with the participants, using their own clothing and textiles as a starting point to explore memories, storytelling and the development of a different kind of relationship between the people living with dementia, and their closest carer/family member. There will be a total of four sessions. The first session will last for 60 minutes and each subsequent session will last for 45 minutes. During this time, participants will be asked to share their experiences relating to clothing.

Participants will be selected from an Alzheimer's Café and day care centre, based on their ability to participate. Only people diagnosed as living with early stage dementia will be considered.

Participants must have a close carer and/or immediate family member who may be willing and able to participate in the research project on a regular basis for the duration of the project.

Researcher: Tara Baoth Mooney, PhD Researcher, University of Wolverhampton.

Appendix 3: Session overviews

3a. Session 1. Introduction: For the researcher

Overview: This first session is an introductory session. It contains personal introductions, the signing of the consent forms, an overview and explanation of what will happen throughout the course of the project, an icebreaker and two short semi-structured interviews containing questions about the participants and their relationship to their garments.

- The consent forms will be signed.
- Icebreaker: The researcher/facilitator will show the participants a photograph of her/himself wearing a garment of personal significance and will bring the garment in for the participants to see. The garment will also be given to the participants to hold. There will be a general discussion around clothing in relation to self – specifically, clothing of significance from the past or present, and photographs that have captured clothing of importance that may no longer be in existence. The preliminary questions will act as an audit to reveal any clothing of significance in the participants' memory/ wardrobe. The researcher will request that the participants bring in any such items and photographs for the next session.

- The 'About Me' questionnaire will be delivered in an informal way as a means to relax the participants and exchange some information about each other. There are prompts in brackets under the main questions.
- Preliminary questions for the participants around their clothing and sense of self.
- Debrief.

(One session of 60 mins)

About Me questionnaire for the participants

Some of these questions may seem to be personal but they are a way to help me to understand more about you both.

- Name of participant & telephone number
- Preferred name of participant:
- Name of carer & telephone number
- Preferred name of carer:
- Are you
 - Male?
 - Female?
- How old are you?

- What is your first language?
- What are good topics for conversation?
 - (Pets, food, hobbies such as sport or craft or reading, etc.)
- How do you think someone who doesn't know you could tell if you are:
 - Unhappy
 - Happy
 - In pain
- Are you comfortable with physical touch?
- Other things to consider:
- Do you have any difficulties that I can assist you with?
 - Pain
 - Mobility
 - Hearing
 - Using the toilet
- Do you wear glasses or contact lenses?
- Do you have any problems with hearing? (Which ear if any is better)
- Do you have any other needs that I should be aware of?

- What are your favourite food and drinks?

Preliminary questions for the participants

The next questions are about your attitude to clothing, your sense of yourself and your personhood:

Clothing and sense of self:

- What are you wearing today?
- Do you like what you are wearing?
- In general, how important are clothes for you?
- Do you prefer to be comfortable or stylish or both?
- Of the clothing you are wearing today what is your favourite garment and what are the properties which make you like it?
 - Fabric type? (softness, hardwearing, feel?)
 - Colour, design, style?
 - Is it fitting well?
 - Are there any other things you could mention?
- Do you think about what you wear every day?
- (Do you think about it in advance?)

- Do you have a favourite article of clothing that you like to wear?
- Do you have a least favourite article of clothing that you have to wear but don't really like wearing?
- Would you ever worry about wearing something inside out?
 - (If so, why?)
- Is it important to you to dress appropriately every day?
- Do you worry about dressing appropriately for special occasions?
 - (What occasions? Wedding, celebration?)
- Are there garments that make you feel good?
- Are there garments that make you feel not so good?
- Do you keep clothes for a long time?
- Do you ever worry about your clothes getting a little soiled or stained?
 - (Like a wine stain or a pen in your pocket?)
 - If so, why?

Past association:

- Do you have a memory of a garment which you wore and loved?
 - (Can you describe the feeling of that?)

- Do you have a memory of a garment which you had to wear and did not like?
 - (Can you describe the feeling of that?)

- Do you have any clothes in your wardrobe that hold significance for you?
 - (Could you bring them in next time?)

- Do you have a picture of any clothes that you particularly like or that have significance for you?
 - (Could you bring them in next time?)

- Debrief

(one session of 45 minutes)

3b. Session 2. The in-depth questions for the participants

Overview: The overall aims of this session are to listen to one another, to interact using the textile object brought by the participant as a focal point and to record the interview.

- Introduction and overview to the session.
- Icebreaker: The researcher will show the participants another photograph of her/himself wearing a garment of personal significance and will bring a different garment in for the participants to see.
- In-depth questions for the participants around a specific item (or items) of clothing will be administered. The item or a photograph(s) of the item(s) of clothing will be brought to the workshop by the participants. The questions have been developed from two areas of importance – Ulrich Neisser’s (1997) outline of the five senses of self and best practice in person-centred care in nursing. The questions fall into sections that explore the ‘sense of self’ and personhood through clothing. These are the interpersonal self, conceptual self, ecological self, extended self and private self. See Appendix 3b. In-depth questions for the participants.
- Debrief

- (one session of 45 minutes)

In-depth questions for the participants

Private self:

- What is the item which you have brought to this session?
- When did you get this item?
- Where did this item come from?
 - Was it custom made?
 - Did you make it?
 - Did you buy it?
 - Was it gifted?
 - Was it passed down?
 - Is it second hand or vintage?
 - Anything else?
- Do you ever interact with this item?
- Do you ever touch it look at it or wear it?
 - Yes

- No
- If so, how often?
 - Once a week
 - Once every 2 weeks
 - Once every 4 weeks
 - Once every 6 months
 - Once a year
 - Once in a blue moon

Questions around sense of self and personhood:

- Why do you like wearing/holding/ touching this item? Is it because the item is?
 - Functional
 - Comfortable (soft, easy to wear)
 - Good quality (durable materials)
 - Do you think that it is in fashion? Stylish?
 - Makes you feel good
 - Nice to touch

- A nice colour
- Smells a particular way
- Easy to clean
- Fits well
- Anything else?
- Is there some sort of meaning attached to the garment?
- What does interacting with this garment bring to mind?
- What prompted you to keep it?

Ecological self:

Sensory and physical connection and 'sense' feelings associated with the item:

- What is it about the physical aspects of this item that make it memorable, special for you?
- Can you try to explain if your body in any capacity REMEMBERS a feeling or sense related to this article of clothing (like your mother's perfume)?
- Is the feeling that you get directly related to one or more of the following physical senses? (Please choose as many as you like)
 - sense of touch?

- sense of sight?
- sense of smell?
- sense of hearing?

Interpersonal self:

These questions are about how we connect emotionally to our clothing:

- This item, was it:
 - given to you as a gift?
 - passed down to you from someone else?
- Do you experience any sense of connection to a particular person through this item?
- Has the item strengthened your connection to anyone
 - through its presence?
 - in your memory?
 - If so, how?
- Other than this emotional attachment is there anything else that you like about this item (such as warmth, the colour, the style, its practicality?)

Extended self:

- What associations do you have when you look at/ interact with this item?
 - Affirming your connection with yourself
 - Sad
 - Nostalgic
 - Happy/positive
 - Family memories
 - Past experiences
 - Good
 - Not sure
- Could this feeling or the feeling of the moment be repeated?
- Does this garment remind you of:
 - A sense of belonging?
 - Something you have achieved?
 - A feeling/sense of importance?
 - A moment of celebration or joy from the past or present

Ongoing sense of self:

- Has the significance of this item changed much over time?
- How do you think about this item that you wore? What strikes you about it now in retrospect?
- What is the significance for now? Future?
- Does it represent something about you or your life or someone else?
 - A time in your life?
 - A place in your life?
 - You as a particular person in the world?

Conceptual self:

- What does interacting with this garment bring to mind?
- Would you ever consider throwing or giving away this item?
- Have you ever changed this item in the past?
 - (Would you change or modify this item to make it last longer?)
- If you could change one thing about this garment what would it be?
- What is the overall story of what this garment means to you? Or another even more special garment?

- Debrief
- (one session of 45 minutes)

3c. Session 3. Creation of the MoM : Caring Through Clothing

Overview: The third session will see the person living with dementia and the carer/partner start to construct their own map of themselves through clothing.

- Introduction to the session
- Icebreaker: The researcher demonstrates their own MoM: Caring Through Clothing using the template and materials that are available for the participants to use.
- The participants start to construct their own map of themselves through clothing. The MoM: Caring Through Clothing draws from their answers in the questionnaires and is enabled by the researcher through the use of drawing, templates, and a sensory swatch library that contains sensory-rich elements such as fabric and yarn. This will enable the participants to capture the MoM: Caring Through Clothing on to an axis that illustrates two concepts:
 1. The running sense of self through time.

2. Personhood represented as points along the axis of time.

- Debrief
- (one session of 45 minutes)

3d. Session 4. Advance intervention for the future of the person living with dementia and their partner/carer

Overview: The fourth session participants will discuss the possibility of an advance intervention for the future of the person living with dementia and their partner/carer. How might the MoM: Caring Through Clothing be utilised in the future to explore the running sense of self through time? What elements of importance in the past and present could be revisited in the future?

- Introduction to the session.
- Icebreaker: The researcher/facilitator checks in on how the participants are feeling about the project so far.
- Revisit the consent forms.
- The participants identify areas that need to be improved and changed.
We discuss the preceding sessions and identify how the sessions might be improved and how the tool could be further developed.
- Debrief

- (one session of 45 minutes)

3e. Adapted from van Manen ‘Lived Experience’

reflective log for researcher

Consider the most immediate outcome from the questions about the clothing – the individuals’ story, the sharing of that story with another.

How can holding, recognising and talking about these items help us to understand lived experience?

Did the participants seem to enjoy sharing each other’s personal experience?

Did they seem to enjoy the facilitator’s experience?

Was there anything else that struck you about the exchange?

1. Describe experience as lived – direct description. No analysis / causal explanations, generalisations, abstract interpretations.

2. Describe experience from the inside,
e.g. state of mind, feelings, mood,
emotions.

3. What aspects of the experience stand
out 'personal meaning' / understanding.
e.g. vividness, first time, unusual qualities.

4. How does body feel – notice physical
experiences.

5. How did things sound, smell, weather etc. – temperatures, other specifics / contexts.

6. Current reflection on above information. Comparison to previous log if similar activity.

Any other particulars / related info, streams of consciousness, links, thoughts to follow up.

3f. Clothing quiz – Ireland and UK

Excerpt from co-created quiz around school days and clothing:

Did you wear a uniform going to school?

What kind of coat did you wear?

Did you wear shoes and socks to school?

Did any of you wear a shawl?

Did you have to wear anything special for sports?

Did you have to bring a fuel or piece of turf to school?

Can you remember? Some Irish words for clothing:

Word: Clothes	Irish: Éadaigh	Pronunciation: ay-dhee
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Word: Dress (frock)	Irish: gúna	Pronunciation: goon-ah
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Word: Skirt	Irish: sciorta	Pronunciation: shkir-thah
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Word: Suit (of clothes)	culaith éadaigh	Pronunciation: kull-eh ay dhee
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Opening ice-breaker questions around school days and general clothing questions:

Did you wear a uniform going to school?

What kind of coat did you wear?

Did you wear shoes and socks to school?

Did any of you wear a shawl?

Did you have to wear anything special for sports?

Did you have to bring fuel or piece of turf to school?

Name three items of clothing that women wear but men don't (skirt, dress, high heeled shoes).

Name two items of clothing that men wear but women don't (tie, men's suit – jacket and trousers)

Name three pieces of clothing that start with the letter s? (skirt, shirt, shoes, socks)

Name two pieces of clothing that start with the letter c? (coat, cravat, culottes)

What do we hang clothes up with? (clothes pegs)

What are the strings for tying shoes called? (laces)

What piece of clothing do you wear around your neck? (cravat, tie or scarf)

Which item of clothing has fingers? (gloves)

What is another name for a woman's shirt? (blouse)

Appendix 4: Example of excerpts from each of the three case studies of transcriptions. A full copy of all recordings and transcriptions are available on request.

Excerpt from Transcription IRIS 2 (example with notes)

Transcription of Recording No 100729_001

I: Interviewer, Annie: Daughter, Tina: Daughter, Iris: Mother.

ITEMS and GARMENTS PRESENT:

PURPLE CHENILLE JUMPER MADE BY Annie

WEDDING DRESS BELONGING TO Iris:

WEDDING ALBUM BELONGING TO Iris:

AN EMERALD GREEN SUIT WITH SHOULDER PADS AND LARGE GOLD
BUTTONS

WHITE CHRISTENING BLANKET MADE BY Annie

PINK TWEED JACKET PERSONAL ARCHIVE TBM

A BOX OF GLOVES PERSONAL ARCHIVE TBM

THE CONVERSTION STARTED WITH A SHORT CONVERSATION ABOUT KNOCK AIRPORT AND THE INTERVIEWER ASKS Iris WOULD SHE HAVE CYCLED TO KNOCK.

I: But did you ever cycle to (Knock?)

Iris: Oh, I did, yes ... VERY SURE

I: From home, was it?

Iris: Yes, from (KilgevrenUnclear)IN CO GALWAAY WHERE iris IS FROM

I: And how long would that take?

Iris: How long would it take? I think about 15 miles to (Knock). One way. About that, I think. She PONDERES THIS WHILE REPEATING THE QUESTION. AND GIVES THE CORRECT DISTANCE

I: Yeah, so that would have been a good old ... (laughs)

Iris: The roads are ...

I: Oh, yeah, they'd be bad for the old bike

Iris: Full of potholes, yeah. And how are you keeping? She AGREES WITH INTERVIEWER ABOUT THE ROADS BEING FULL OF POTHOLES AND

THEN TURNS AND ASKS HOW THE I IS KEEPING-She IS SHOWING AN INTEREST IN THE PERSON THAT SHE IS TALKING TO BUT DISPLAYS COMFORT AS IF SHE REMEMBERS THE PERSON FROM BEFORE.

I: I'm good. I had your 2 daughters rooting around their house for ... (laughs)

For g ... (Unclear)

I: But look what she found; this is gorgeous! You might recognise it.

Iris: Who was looking for g ...

Tina: That was Mia.

Iris: What's that?

Annie: Thats a purple jumper that I knitted. Annie IS TENTATIVE AT FIRST BUT HOLDS THE JUMPER FORWARD TOWARDS HER MOTHERS LAP AND USES IT TO SHOW THAT SHE HAS SOMETHING IMPORTANT TO SAY.

Iris: What is it, a jumper? She IMMEDIATELY SHOWS INTEREST AND STARTS TO SLOWLY TAKE IT INTO HER HANDS

Annie: Yeah.

Iris: Is it home made? FIRST QUESTION ABOUT QUALITY- CONNECTION ETC

Annie: Yeah, I knitted it about 30 years ago, I'd say. A IS PROUD AND HAPPY TO SAY WHEN SHE KNITTED THAT JUMPER

Annie: Do you remember it? ASKS HER MOTHER DOES SHE REMEMBER THE JUMPER

Iris: I can't see it. She CANNOT SEE THE JUMPER BUT STARTS TO FEEL IT MORE WITH HER HANDS

Annie: Do you remember seeing it on me ... holes in it ... it was actually kind of chilly. Annie IS BRINGING HER MOTHER BACK TO THE TIME WHEN SHE WOULD HAVE WORN THE CARDIGAN- ALSO TALKING ABOUT ITS PHYSICAL PROPERTIES- IE THAT IT WAS COLD

I: And it had the blackberry stitch.

Iris: We didn't buy jumpers in those days, we knitted them. STATING A FACT WITH PRIDE.

Annie: Yeah ...

Iris: Very cold and dampish. She FEELS THE JUMPER AND HOLDS ON TO IT WHILE KEEPING IT SLIGHTLY AT A DISTANCE. FEELS IT AND SAYS THAT IT IS COLD AND DAMP.

Annie: It's a cotton kind of a blend or whatever, so it's not kind of wool so it can be kind of cold. It was in the boot of my car, so that's why it feels cold.

I: So, Annie probably would have worn that a lot.

Annie: Still do

I: Yeah, oh that's lovely. The blackberry stitch – can you feel the blackberry stitch?

Iris: Oh, Yeah ...

I: It's nice, isn't it?

Excerpt from Transcription VIOLET 3

Transcription of Recording No 101014_001

Jim: Husband, Violet: Wife, I: Interviewer

ITEMS and GARMENTS PRESENT:

Purple tweed cape

Green tweed cape

Many photographs and memorabilia.

(laughter)

Jim: - about the about the erm I forget what you call them, but the boneen (CI)
clad bombshells

Violet: yeah

Jim: isn't there a story around that about wasn't didn't your manager

Violet: that's

Jim: trying to dress you up or

Violet: no she might have called us the boneen clad bombshells but as she was English that mightn't have er bothered too many Irish people. V LAUGHING AND TWINKLING SO HARD DURING THIS SESSION

Jim: inaudible

I: yeah did she wear boneen a lot?

Violet: I don't remember

Jim: didn't you get them to go on The Late Show? J IS SO PROUD OF HER

Violet: oh we may have done we were on The Late Late Show

Jim: well when Byrne was only a lad like

I: oh wow

Violet: yeah

Jim: and the youngest sister still is in the annals of The Late Late Show

Violet: she was playing the spoons on his head on the show

Jim: she gave Gay Byrne a haircut

Violet: with her spoons

I: no way oh that's fabulous

Violet: laughter

I: wow that's great. So you had to wear boneen to go on *The Late Late Show*?

Violet: yes

I: probably

Violet: I suppose if we hadn't they would have asked us to. I don't know if I went on it even I don't think I did

Jim: well you didn't but they were on twice I think they were on it twice but

Violet: but I was in England at the time so I didn't come home

I: yeah

Violet: for it

I: did you dress differently to the two girls anyway?

Violet: when we were singing together er and no we could all of dressed the same more or less but erm

Jim: you didn't have a uniform

Violet: no we didn't have a uniform

Jim: they all dressed up themselves

I: yeah

Jim: that's my impression of it when I met you was that you all looked great but they were very different J IS SO ATTENTIVE TO V AND HOW SHE WAS IN THE PAST.

I: yeah

Jim: and but I remember so much about Violet, mm her earrings

I : oh

Jim: she had very big earrings and this long hair

Violet: long curly hair, yes V IS ENTERING INTO HER MEMORY VIVIDLY. AS J IS PROMPTING HER

Excerpt from Transcription ROSE 1

Transcription of Recording No 100305.001

I = Interviewer, Rose = mother, Linda = daughter, Larry = father

Interviewer: I'm going to talk to you first about what you are wearing today and tell me a little bit about...

Rose: That was when I was a nice girl. ROSE ACTS AS IF SHE IS HIDING A SECRET

Interviewer: What? That was when you was a nice girl! What happened, Rose?

Rose: He doesn't do what he's told, at all! ALMOST AS IF SHE IS HAVING ABOUT 3 CONVERSATIONS WITH 3 DIFFERENT PEOPLE

I: Really? That's terrible! Did he ever do what he was told?

Rose: ...because his mum had three lads, and he was the naughtiest...

I: OK and why did you pick the naughtiest one?

Rose: We lived with his mum when we first got married and he was never, never, out of trouble

I: Oh, no!

Rose: ...you're doing this, and he wouldn't do it.

I: Ah, (laughs). Did I see a hat in there?

Linda: Yeah, you know when you said a piece of clothing that reminded me of me dad? That's from when I was little. He always wore a cap, didn't he?

I: Do you still wear it, Larry?

Larry: Now and again...

Rose: When it's cold. He used to be a miner, at one time, and my dad was a miner...

I: Right...

Linda: And my grandad always wore a cap...

I: OK

Linda: And that's even from early years, when I was really young, I'd recognise my dad, because you've always had a cap, haven't you? Always ...

Rose: It's always in the back, in the garage, on the...

I: Why did you like that one, Larry? Why did you like that hat?

Linda: Probably me mum chose it...

Larry: ...particularly, it's one of about three that I've got...

Linda: Mum would choose it, but he's always wore a cap like this...

I: ...yeah...

Linda: The majority of the time, as a little one, I'd remember him walking from work with his cap on, but now, when it's raining or it's cold...

I: And would you consider that cap to be for work, or for every day or for a special occasion?

Larry: Just special occasions.

I: Just special occasions.

Linda: Not every day, when it's cold...

I: Yeah, yeah, yeah ... And er, have you ever washed it?

Linda: No, it's for dry clean, that would.

I: Oh, it's Paris tweed...the fabric is beautiful!

Linda: You've got another one like this in the garage, haven't you? He used to have like a water-proof one when he was working. I mean, years ago, you hadn't got a car, had you, like, years ago...gas work on his bike...old porous thing...

Larry: Yeah...

I: So, do you wear it much now, Larry?

Larry: Yeah...

Linda: When it's cold or it's raining, all through the winter...

Appendix 5: A small sample of existing ecopsychosocial interventions for persons living with dementia and carers

Tara Baoth Mooney ©

<u>Name of Intervention</u>	<u>Creator and Source/reference (where possible)</u>	<u>Description</u>	<u>Intended Users</u>	<u>Impact</u>
<p>Music memory box 2011–present</p>	<p>Chloe Meineck, designer, maker and inventor https://studiomeineck.com/methodology/</p>	<p>A customisable box filled with person's favourite objects. When an object is put in the centre of the box an individual piece of music or audio content plays. It features the same technology that is used in Oyster cards around London.</p>	<p>Patient family and carers, volunteers</p>	<p>Improves patients' emotional well-being and communication skills.</p>

<p>RemPad 2013</p> <p>Reminiscence Enhanced Material Profiling in Alzheimer's and other dementias</p> <p>Design Intervention</p>	<p>Julia O'Rourke 2013</p>	<p>RemPad allows you to put in a profile of each person, with details such as where they have lived and when they lived there, plus if they have particular interests, explains O'Rourke. 'Then you bring together a group and the RemPad system's classifiers and algorithms profile the people within the group and [the technology] recommends content from our digital archive accordingly.'</p>	<p>Health care professionals, activity co-ordinators, family carers, volunteers, patient.</p>	<p>To be decided.</p>
<p>E-textile Eindhoven 2016</p>	<p>Pillow</p> <p>Tactile dialogues is a collaboration between Eindhoven University of Technology (Martijn ten Bhömer), De Wever (Borre Akkersdijk, Optima Textiles BV and Metatronics. Design for dementia: A design-driven living lab approach to involve people with dementia and their context</p> <p>Rens Brankaert 2016</p>	<p>Tactile Dialogues is an e-textile pillow constructed with touch sensors and vibrating motors. The pillow is used to generate a positive interaction between a caregiver and an individual suffering from severe dementia.</p>	<p>Person living with dementia.</p>	<p>An earlier prototype of the blanket has been tested with five pairs of each a care receiver and a care giver. These tests showed that the object has potential for often difficult visits when</p>

				<p>conversation is not possible. However, long-term testing is required to find out the true impact of the product.</p>
<p>Buddi – 2011</p> <p>Living Well with Dementia</p> <p>Launched in 2011, Living Well with Dementia was a Design Challenge run in partnership with the Department of Health, to improve the lives of those affected by dementia.</p> <p>buddi.co.uk</p>	<p>Design Council</p> <p>34 Bow Street London WC2E 7DL United Kingdom</p> <p>Tel +44(0)2074205200</p> <p>info@designcouncil.org</p> <p>uk.designcouncil.org.uk</p>	<p>Buddi band for people living with dementia. At home the device communicates via a base-station that is also the charging dock and displays the power level. In an emergency, the user can communicate with the monitoring centre staff through two-way audio on the base station. O</p>	<p>Person living with dementia,</p>	<p>Online monitoring successful to date; allowing carers to keep an eye on activity levels without being present</p>

<p>2012</p> <p>Ode, one of the five innovative solutions developed as part of The Mains-powered unit releases three food fragrances a day, adjustable to coincide with the user's mealtimes.</p> <p>Fragrances are released in short sharp bursts, acting as a strong appetite trigger and then dissipating rapidly so users won't become inured to the effect. A subtle light indicates the device is working and also communicates when</p>	<p>Design Council</p> <p>34 Bow Street London WC2E 7DL United Kingdom</p> <p>Tel +44(0)2074205200 info@designcouncil.org uk.designcouncil.org.uk</p> <p>2014</p>	<p>This discreet system is less stigmatising and more inspiring than an alarm or constant reminders from carers to eat. Scents are pleasant and evocative and aim to improve mood as an additional effect.</p> <p>The scents have been developed specially for ode, in conjunction with a leading fragrance laboratory and in response to workshop patient feedback in the Living Well with Dementia Design Challenge,</p>	<p>Person living with dementia.</p>	<p>Initial research suggests it can stimulate real hunger subliminally</p>
<p>2011</p> <p>Custom- made Mosaic Weighted Blankets®</p> <p>Often as dementia progresses, insomnia can become an issue. Sleeping for one or two hours during the night, then awakening</p>	<p>Founded by Laura LeMond.</p> <p>https://mosaicweightedblankets.com/</p>	<p>PLWD can benefit from the sleep-inducing qualities of a Mosaic Weighted Blanket®. Weighted enough to give deep pressure touch stimulation without being too heavy to remove on their own. 'The blankets work by providing input to the deep</p>	<p>Person living with dementia.</p>	<p>May assist with a full night's rest can be an effective therapy for loss of sleep and relaxation.</p>

<p>only to wander around the house, is a common experience.</p>		<p>pressure touch receptors throughout the body,' Moore says. 'Deep pressure touch helps the body relax. Like a firm hug, weighted blankets help us feel secure, grounded, and safe.'</p>		
<p>2018 HUG by LAUGH®</p>		<p>HUG by LAUGH® is a sensory device designed to be cuddled and has a beating heart within its soft body. can play music that can be easily changed to a favourite playlist</p>		<p>Customisable and bring pleasure and comfort to people living with dementia.</p>
<p>2020 - Virtual Singing for the</p>	<p>21https://alzheimers.org.uk/get-support/your-support-</p>	<p>Singing for the Brain - online development from</p>	<p>PLWD and carers.</p>	

<p>Brain?</p> <p>Ring and sing online singing.</p>	<p>services/singing-for-the-brain</p>	<p>singing for the brain from the Alzheimer's Society which uses singing to bring people together in a friendly and stimulating social environment.</p>		
<p>2011</p> <p>Six views in a box.</p> <p>The tangible result of the co-design course, the Dialogue box, contains visual games, books and a documentary video. The material was developed in a dialogue with people who have Alzheimer's, their families, and professionals in the care sector. In the future it will be used as a tools to facilitate the dialogue with and among these groups.</p>	<p><i>Royal Danish Academy of Fine Arts, School of Design.</i></p> <p>Danish Alzheimer's Association and the multinational pharmaceutical company Johnson & Johnson.</p> <p>Mind Design #42, October 2011 volume 5</p>	<p>The project resulted in a book containing a book and six specific, designed tools for facilitating dialogue with and between people with Alzheimer's and their families.</p> <p>Designed in a co-design environment – users and stakeholders create and develop ideas in collaboration with the designers. 'In the process, the participants' collective knowledge and experience are brought into play.'</p>	<p>Person living with dementia and carers</p>	

<p>Effects of multisensory stimulation on cognition, anxiety levels and well-being of early stage Alzheimer's</p>	<p>Ozdemir and Akdemir Hacettepe Universitesi Hemsirelik Yuksekokulu Samanpazari, Ankara 06 100 Turkey</p> <p>E-mail address: leylaceyran@yahoo.com</p>	<p>Collective application of activities related to music, painting and time-place-person orientation.</p> <p>Use of instrumental music with a light tempo that took into consideration the preferences of the participants, was combined with inanimate and animate object picture painting.</p>	<p>Health care professionals, activity co-ordinators, family carers, and volunteers, patient.</p>	
<p>2007 Comparison of two psychosocial treatments for their effectiveness in reducing the frequency of physically and verbally agitated behaviours in nursing home residents with dementia.</p>	<p>Prof. Daniel O Connor Kingston Centre, Warrigal Road Cheltenham, Victoria 6192 Australia</p> <p>E-mail: Daniel.Oconnor@med.monash.edu.au</p> <p>Garland, K., Beer, E., Eppingstall, B. and O'Connor, D. (2007), <i>American Journal of Geriatric Psychiatry</i>, 15(6), pp. 514–521.</p>	<p>Fifteen-minute audiotapes of (1) simulated family presence (a conversation prepared by a family member about positive experiences from the past), and (2) music preferred by the resident in earlier life were compared with a placebo tape of a reading from a horticultural text. Researchers were blinded to the tape contents.</p>		

2008 Multisensory stimulation (MSS)	<p><u>Dept of Psychiatry</u></p> <p><u>Queen's University</u></p> <p><u>Ontario</u></p> <p><u>Canada</u></p> <p><u>Email:</u> <u>milevr@providencecar</u> <u>e.ca</u></p> <p>Milev, R.V., Kellar, T., McLean, M., Mileva, V., Luthra, V., Thompson, S. and Peever, L.</p> <p>Multisensory Stimulation for Elderly With Dementia (2008). <i>American Journal of Alzheimer's disease and other Dementias.</i></p>	<p>Multisensory stimulation</p> <p>Snoezelen room included objects such as textured balls, a wall projector, different musical selections, fibre-optic cables, and a colour-changing water column.</p>	PLWD and carers	Sensory stimulation for the five senses.

<p>Time Slips</p>	<p>Anne Davis Basting</p>	<p>Time Slips uses creative storytelling to engage participants and help them communicate with each other and their caregivers.</p>	<p>Health care professionals, activity co-ordinators, family carers, and volunteers, patient.</p>	
<p>2020</p> <p>Caring Light is designed to help caregivers of someone with Alzheimer's disease and related dementia to cope with the difficulties related to caregiving, reduce stress, and improve patients' quality of life.</p>	<p>Bruno K. Kajiyama, MS Photozig, Inc. NASA https://clinicaltrials.gov/ct2/show/NCT04517877</p>	<p>Caring Light mobile app with a self-paced program to enhance the quality of life, it incorporates relaxation techniques, and coping skills</p>		<p>This is an intervention to help caregivers by reducing stress</p>

<p>2014</p> <p>Memory Suitcases</p>	<p>For use as part of group reminiscence sessions. The suitcases contain photos, memorabilia and objects.</p>	<p>Part of the Liverpool based House of Memory project</p> <p>https://liverpoolmusseums.org.uk/house-of-memories/memory-suitcases</p>	<p>Health care professionals, activity co-ordinators, family carers, volunteers, patient.</p>	<p>Improves and promotes conversations about memories.</p>
<p>2015</p> <p>Sensory textiles</p>	<p>e-CARIAD</p>	<p>Sensory and tactile aprons and other textiles with embedded electronics.</p>	<p>PLWD and carers</p>	<p>Calming and soothing for late-stage dementia</p>
<p>2019 Giggle Balls</p>	<p>Cathy Treadaway, Jac Fennell, Aidan Taylor and Gail Kenning (2019) Designing for tilt sensor, playfulness through compassion</p>	<p>Balls that contain electronics comprising a small tilt sensor, speakers and microcontroller with sound files of children's laughter. When turned over in the hand the</p>	<p>For carers and PLWD</p>	<p>Useful for changing the mood.</p>

		balls 'giggle'.		
Aromatherapy Efficacy of aromatherapy as an intervention for people with Alzheimer's	Ballard, C.G., O'Brien, J. T., Clive Ballard, M.D., Wolfson Research Centre, Newcastle General Hospital, Westgate Road, Newcastle upon Tyne, United Kingdom NE4 6BE Reichelt, K. and Perry, E. K. (2002). Aromatherapy as a safe and effective treatment for the management of agitation in severe dementia: the results of a double-blind, placebo-controlled trial with <i>Melissa</i> .	Melissa oil applied twice daily to arms and faces. Aromatherapy is considered adjunctive therapy in this study, since 92 per cent of the participants in both groups were taking at least one psychotropic medication. The biological effect from the lotion is through skin absorption and olfactory (smell).		Most people in this study had advanced dementia and had lost their sense of smell, so emotional associations and/or like/dislike of the fragrance was not a confounding variable.

<p>Scented Sound</p>	<p>Rompa 01246211777 customer.service@rompa.com</p>	<p>Multi-sensory die – tactile, aromatic and with a bell inside for auditory appeal. Colours/aromas include green/mint, pink/strawberry, blue/aniseed and yellow/lemon.</p>		<p>Improves sense of smell and is a multisensory game. Improves patients' emotional well-being and communication skills.</p>
<p>1989 Le Loto des Odeurs A game of scent recognition</p>	<p>https://sentosphere.fr/gb/about-us</p>	<p>Set of scents, complete with colour cards to match aromas for visual identification. The sense of smell promotes visual recognition.</p>		<p>The sense of smell promotes visual recognition encourages hand movements</p>
<p>2013 Augmented</p>	<p>Design Council Future</p>	<p>As a means to combat symptoms of loneliness</p>		<p>Not developed for older</p>

<p>Quilt</p> <p>Augmented Quilt opens up an additional line of communication between the child and their loved ones.</p>	<p>Pioneers.</p>	<p>experienced by children staying long periods of time in hospital. Each animal illustration on the quilt can be linked to a friend or family member, who can in turn leave digital messages.</p>		<p>people but important intervention</p>
<p>2012</p> <p>House of memories suitcase and memorabilia packs</p>	<p>National Museums Liverpool 0151 478 4240 or email learning@liverpoolmuseums.org.uk.</p>	<p>As part of the House of Memories programme at National Museum Liverpool, participants can borrow a 'memory suitcase', which contains objects, memorabilia and photographs to help carers and patients engage</p>	<p>Carers, volunteers, patient.</p>	<p>Improves patients' emotional well-being and communication skills.</p>

<p>2012-present</p> <p>House of Memories app</p>	<p>National Museums Liverpool</p> <p>https://liverpoolmuseums.org.uk/house-of-memories/my-house-of-memories-app</p>	<p>Ongoing project that collates hundreds of inspirational objects from the 1920s–1980s to stimulate memory and conversation</p> <p>Fascinating facts and background information about the objects</p> <p>An easy to use design with simple touchscreen controls</p> <p>A toolkit for carers, with tips and hints on additional memory activities you can do together</p>	<p>Carers, volunteers, PLWD.</p>	<p>Improves patients' emotional well-being and communication skills.</p>
<p>Vibe-ing 2013</p>	<p>Vibe-ing is a collaboration project between TU/e, TextielMuseum, TextielLab Tilburg, and Metaromics. As part of Smart Textile Services (CRISP) project Eunjung Jeon, Kristi Kuusk, Martijn Bhömer and Jesse Asjes have developed an improved version</p>	<p>Vibe-ing is a self-care tool in the form of a garment, which invites the body to feel, move, and heal through vibration therapy. The merino wool garment contains knitted pockets, embedded with electronic circuit boards that enable the garment to sense touch and</p>		<p>By integrating vibration actuators in textile pockets the design enables us to program the exact areas and the way of stimulation on the body depending</p>

	from Tender.	vibrate specific pressure points on the body.		on the specific person's need for rehabilitation and healing.
2020 Memory Haven	https://assistivetechologyblog.com/2020/10/memory-haven-dementia.html	Memory Haven has face and voice recognition abilities to help patients recognise their family and friends. Using the same facial recognition ability, the app can detect the person's mood and play music for them.	Activity co-ordinators, family and carers, volunteers, patients.	Improve cognitive abilities and delay the effects of dementia.
Musical Positioning Cushion A bean bag that gives tactile and aural	Rompa 01246211777 customer.service@rompa	A bean bag that gives tactile and aural stimulation while providing comfortable	Family and carers, volunteers, patients.	Tactile and aural stimulation No room for personalisa

stimulation.	a.com	support. The bean bag envelopes the user so the vibrations and the music from the special speakers within the cushion seem to soak deep into the body offering a truly profound sensory experience.		tion
Talking Mats	.talkingmats.com	A visual framework that uses picture symbols to help people with communication difficulty express themselves more clearly.		Aid for communication.
2012–present Music Mirrors build on	Heather Edwards Heather and Lisa	Here, people with early-stage dementia are helped to create	The concept was developed by a voluntary organisation (Come	Improves patients' emotional well-being

<p>and take further the accepted potential of music to unlock autobiographical memory and support relationships.</p>	<p>Breame.</p>	<p>their own resources of brief written life-story prompts linked to digitally-recorded music in a form that is easily 'portable' throughout the dementia journey and particularly useful at times of change and transition in care.</p>	<p>Singing) and Norfolk and Suffolk Foundation Mental Health Trust and has most recently been adopted by the Norfolk and Norwich University Hospital and the South London Health Initiative</p> <p>ALZHEIMERS EUROPE CONFERENCE</p>	<p>and communication skills.</p>
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Appendix 6: Log of all case study interactions

#	A	B	C	D	E	F	G	H	I	J	K	L	M	N
		Type of Session	Column1	Date	Location	Number	Num	Number of Ca	Dur	Inter	Conse	Purp	Primary Ob	
	CODE	Events		Date	Location	Number of I	Number of C	Duration	Interview	Consent	I	Purpose	Primary Observations	
1	MMDIR	Meeting with management, IRE		27/06/2016	Alzheimers centre, Dunally IRE									
2	CAT	Vulnerable adults Course, IRE		15/07/2016	Alzheimers centre, Dunally IRE									
3	MMMUK	Meeting with management, UK		21/07/2016	Alzheimers Caf�, Molyneux, Wolverhampton,UK								Tara B Mooney	
4	OSDIR	Observation Session, UK		21/07/2016	Alzheimers Caf�, Molyneux, Wolverhampton,UK								Tara B Mooney	
5	OSDIR	Observation Session, IRE		22/07/2016	Alzheimers centre, Dunally IRE								Tara B N	0
6	DBSUK	UK DBS CHECK START PROCESS		10/08/2016										
7	GCIRE	IRE Garda CHECK START PROCESS (Nursing Homes)		10/08/2016										
8	IGSDIRE	Introductory Group Session Dunally IRE		10/08/2016	Alzheimers centre, Dunally IRE	2							Tara B N	0
9	IGSMUK	Introductory Group Session 1 UK		18/08/2016	Alzheimers Caf�, Molyneux, Wolverhampton,U	2							Tara B N	0
10	MMCI	Meeting with management, IRE		05/09/2016	Carrageens Day Care Centre, IRE	2							Tara B N	0
11	MMCI	Meeting with management, Dunally IRE		05/09/2016	Alzheimers centre, Dunally IRE								Tara B N	0
12	MMDIR	Observation Session		06/09/2016	Carrageens Day Care Centre, IRE								Tara B N	0
13	IGSDIRE	Introductory Group Session Carrageens Day Care Centre		07/09/2016	Carrageens Day Care Centre, IRE			2 (Kate)					Tara B N	0
14	GS2MUK	Group Session 2 'Caring Through Clothing' UK		15/09/2016	Alzheimers Caf�, Molyneux, Wolverhampton,U	16	5		11	110 min			Tara B N	0
15	GS2CIRE	Group Session 2 'Caring Through Clothing' Carrageens		21/09/2016	Carrageens Day Care Centre, IRE								Tara B N	0
16	MMATIRE	Meeting with management, IRE		01/10/2016	An Teaghlach Uilinn, Galway, IRE								Tara B N	0
17	ACIRE	Alzheimers Caf� IRE		14/10/2016	Alzheimers Caf� IRE								Tara B N	0
18	CTC1,2MUK	Caring Through Clothing session 1&2 UK		20/10/2016	ROSE SESSION 1&2 after Alzheimers Caf�, Molyneux, Wolverhampton,UK								Tara B N	All
19	DBSUK	UK DBS granted		25/10/2016										
20	ACIRE	Alzheimers Caf� IRE											Tara B N	3
21	MMATIRE	Meeting with management, IRE		17/11/2016	An Teaghlach Uilinn, Galway IRE	2							Tara B Mooney	
22	GCIRE	IRE Garda CHECK Nursing Homes Ireland GRANTED		12/12/2016										
23	CTC3MUK	Caring Through Clothing session 3 UK		rescheduled	Alzheimers Caf�, Molyneux, Wolverhampton,UK								Tara B Mooney	
24	CTCOCIRE	Caring Through Clothing Observation session, IRE		15/12/2016	Clontarf, Dublin, IRE								Tara B Mooney	
25	CTC1,2 CIRE	Caring Through Clothing session 1&2 IRE		20/01/2017	Clontarf, Dublin, IRE								Tara B Mooney	
26		Caring Through Clothing Observation session and family		22/01/2017	IRIS An Teaghlach Uilinn, Galway IRE								Tara B Mooney	
27		Caring Through Clothing Observation session, IRE		03/02/2017	IRIS An Teaghlach Uilinn, Galway IRE								Tara B Mooney	
28		Caring Through Clothing Family meeting session, IRE		04/02/2017	IRIS An Teaghlach Uilinn, Galway IRE								Tara B Mooney	
29		Caring Through Clothing session 1&1/2 IRE		DOUBLE CIRIS	An Teaghlach Uilinn, Galway IRE								Tara B Mooney	
30		Caring Through Clothing session 2		17/04/2017	IRIS An Teaghlach Uilinn, Galway IRE								Tara B Mooney	
31		Caring Through Clothing session 3		24/05/2017	ROSE HOME								Tara B Mooney	
32		Caring Through Clothing session 1		30/05/2017	VIOLET HOME								Tara B Mooney	
33		Caring Through Clothing session 3		27/06/2017	An Teaghlach Uilinn, Galway IRE								Tara B Mooney	
34		Caring Through Clothing session 2		29/06/2017	VIOLET HOME								Tara B Mooney	
35		Caring Through Clothing session 4		TBC	An Teaghlach Uilinn, Galway IRE								Tara B Mooney	
36		Caring Through Clothing session 4		11/07/2017	ROSE HOME								Tara B Mooney	
37		Caring Through Clothing session 3		04/07/2017	VIOLET HOME								Tara B Mooney	
38		Caring Through Clothing session 4		28/07/2017	VIOLET HOME								Tara B Mooney	
39		Caring Through Clothing session 5		25/09/2017	VIOLET Nursing HOME								Tara B Mooney	
40														
41														
42														
43														
44														
45														
46														
47	MM	Meeting with management,												
48	DBSUK/GC	DBS Check / Garda Clearance												
49	OS	Observation Session												
50	IGS	Introductory Group Session 1												
51	GS2	Group Session 2												
52	CTCO	Caring Through Clothing observation session												
53	CTC1,2,3,4	Caring Through Clothing session 1,2,3 &4												
54	CAT	Courses Trainings												
55	ACIRE	Alzheimers Caf� IRE												
56														
57														
58														
59	DIRE	Dunally, IRE												
60	MUK	Molyneux, UK												
61	CIRE	Carrageens, IRE												
62	ATUIRE	An Teaghlach Uilinn, IRE												
63	ACIRE	Alzheimers caf�, Sligo IRE												
64	CIRE	Clontarf, IRE												
65														

Appendix 7: Incidental findings forms and checklist

7a. Caring Through Clothing: Template log and letter for Incidental Findings

Dear _____,

The purpose of my writing to you is to provide some information on a patient who is under your clinical supervision.

Name of patient:

DOB:

The above-named patient has taken part in a research study involving a one-to-one interview. This research has ethical approval from the University of Wolverhampton, and the Director of Studies is Prof Kristina Niedderer, University of Wolverhampton. A copy of this letter has been sent to the patient.

During the course of our research we have noted incidental findings, which may warrant medical attention, and which we are ethically obliged to report. These are detailed in the below table.

Date	Test completed or event	Outcome of test/symptom presentation

Should you wish to discuss this further, please contact me here:

Best wishes,

Tara Baoth Mooney

Event Log

Date		How would you	<input type="checkbox"/>	Distress
Time		Describe the event?	<input type="checkbox"/>	Disclosure of harm to others
Site / site code			<input type="checkbox"/>	Disclosure of harm to self

Participant code			<input type="checkbox"/>	Disclosure of criminal activity
Researcher initials			<input type="checkbox"/>	Incidental findings
			<input type="checkbox"/>	Illness

			<input type="checkbox"/>	Fire/evacuation
			<input type="checkbox"/>	Other

Describe in detail what happened:

Ensure anonymity is held using codes for participants and sites.

Action plan:

Activity & evidence	Date Completed

Follow up:

What is the plan to follow this up? Include timescales, key contacts, and action required.

7b. Caring Through Clothing: Site-specific checklist

Items on this checklist to be compared before data collection. Each site needs a separate checklist. The checklist should be stored as confidential data and only codified data about the participant should be included.

Codes for participants

Name/code of site

Name /code of researcher

Proposed time frame for data collection*

From (date) _____ to

*You are advised to check accuracy and currency of information if you are away from a site for more than one month.

Distress

In the event of participant becoming distressed, who should be contacted?

Name

Role in organisation

Or relationship to participant

Contact information (room where they will be, or extension number)

Who should the event log be shared with?

Disclosure

In the event of a participant disclosing **harm** to themselves, who should be contacted (this may be self-harm or abuse from another)?

Name

Role in organisation

Contact information

Who should the event log be shared with?

In the event of a participant disclosing **criminal activity**, who should be contacted?

Name

Role in organisation

Contact information

Who should the event log be shared with?

Incidental findings

In the event that the research process uncovers evidence of a previously undiagnosed medical condition or concern, who should be contacted?

Name

Role in organisation

Contact information

Who should the event log be shared with?

Illness

Familiarise yourself with the organisation's policy for dealing with these situations.

In the event of the participant becoming ill during data collection, who is the person to be contacted within the organisation?

Designated First Aider

Contact room/phone number

Health care practitioner

Contact room/phone number

Fire or evacuation

Familiarise yourself with the organisation's procedure for dealing with these situations.

Query whether there are any planned fire alarms or evacuations while your research is taking place.

Planned fire alarms/evacuations: Date/Time

Name of fire marshal

Contact room/phone number

Who would be responsible for evacuating your participant if they are (a) from a vulnerable population or (b) use a wheelchair (c) required assistance with mobility.

Name

Role in organisation

Contact information room/phone
number_____

Appendix 8: Letter of support from Alzheimer Society of Ireland



6th May 2015

To Whom it May Concern

Re: Ethical approach for ‘Caring Through Clothing: Textile artefacts as multisensory triggers for memory and narrative to enhance personhood for people with early-stage dementia (ARTS)’

This letter is to confirm that the Alzheimer Society of Ireland, the leading dementia-specific service provider and advocacy organisation for people with dementia and their carers in Ireland, will support Tara Baoth Mooney’s PhD research. This support will include facilitating sample recruitment in one of our service sites and is dependent on full ethical approval being given for the study.

Please do not hesitate to contact me if you have any queries or concerns.

Yours sincerely



Dr Emer Begley PhD, Policy and Research Manager

Appendix 9: Ethics letter of approval and ethics document



Date 23.03.16

Tara Baoth Mooney
University of Wolverhampton
FEHW Research

Dear Tara Baoth Mooney,

Re: "Caring through clothing: Textile artefacts as multisensory triggers for memory and narrative to enhance personhood for people living with early stage Dementia and their carers (ARTS) submitted to The Faculty of Education, Health and Wellbeing Ethics Panel (Health Professions, Psychology, Social Work & Social Care)

The Faculty Ethics Panel (Health Professions, Psychology, Social Work & Social Care) has considered and reviewed your re-submission.

On review your Research Proposal was passed and the Panel believes that the ethical issues inherent in your study have been adequately considered and addressed. Therefore the Panel is giving you full ethical approval for your study (**Code 1 - Approved**). We would like to wish you every success with the project.

Yours sincerely

H Paniagua

Dr. H. Paniagua PhD, MSc, BSc (Hons) Cert. Ed. RN RM
Chair – Ethics Panel

Richard Darby

Dr Richard Darby PhD, BSc
Chair – Ethics Panel

Appendix 10: DBS and Garda clearance



21st June 2022

Alzheimer's Society
Part Ground Floor
Castlemill
Burnt Tree
Tipton
West Midlands
DY4 7UF

Telephone
[REDACTED]

Email
[REDACTED]

Website
alzheimers.org.uk

Dear Sir/Madam

I am the Group Coordinator for the Alzheimer's Society in the West Midlands, and I am writing to confirm that Tara Baoth Mooney worked with us over a period of a year from 2016 – 2017.

Tara came to the centre to find suitable participants for her PHD studies on clothing memories and dementia.

We had several meetings to discuss the best approach and after a few weeks, we consulted with the group, and everyone agreed they would like Tara to visit. After meeting with the group, Tara developed two wonderful clothing reminiscence sessions, something we still talk about as it was such a wonderful experience for the participants and staff. From this, Tara did one to one work with some of the group members and their extended families, which they valued very much.

We verified Tara's ID and DBS status at the time, but do not have access to any of our documentation as our local office has closed and many of our systems have changed since then.

Yours faithfully,

[REDACTED]
Group Coordinator
Black Country Alzheimer's Society
[REDACTED]

Alzheimer's Society is a registered charity in England and Wales (296645) and the Isle of Man (1128)
A company limited by guarantee, registered in England and Wales (2115499) and the Isle of Man (5730F)
Registered office: 43-44 Crutched Friars, London EC3N 2AE.

An Garda Síochána

Bíúró Náisiúnta Grimmhiosrúcháin,
Bóthar an Ráschúrsa,
Durlas,
Contae Thiobraid Árann.

Teilcefón / Tel: (0504) 27300
Facs / Fax: (0504) 27373

Bi linn/Join us  



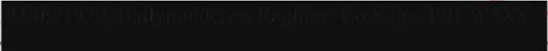
National Vetting Bureau,
Raccourse Road,
Thurles,
Co. Tipperary.

Láithéan Gréasain/Web Site: www.garda.ie

Luaig an uimhir tagarta B.N.G. a leanas le do thoil/
Please quote the following N.V.B. Ref. No: ASI001-20161202-01323

Vetting Disclosure

Rosemary Collier
The Alzheimer Society of Ireland

Re: Tara Mooney, 

Decision	Date
Accepted	9/12/10
Referred	
Rejected	
Appealed	

Pursuant to your application within the provisions of Section 13 of the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016 in respect of the above named, the herewith vetting disclosure is issued to you within the provisions of Section 14 of the National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016.

Searches were conducted on the 09/12/2016 .

Criminal Record

NIL

Please Note: If the above-named asserts that this criminal record is inaccurate, the Liaison Person should address the matter in writing to the National Vetting Bureau.

Specified Information

NIL

 Superintendent



