Architecture and Dementia Care: An Ethnographic Study of the Everyday Life of a Secure Dementia Care Environment

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DECLARATION

I declare that I have composed this thesis myself and that the results are of my own research. I also declare that none of the work contained within this thesis has been submitted for any other degree at any other university.

Claudia L. Cruz de Salgado

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To my mother, whose journey with dementia inspired and motivated my own academic journey. To my father, who taught me to challenge the given. To my husband and son, who are the reason for all.

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ABSTRACT

The irreversible nature of dementia eventually affects the individual's ability to perform daily living activities, strongly predicting the person living with dementia will move to a specialized dementia care environment. The architectural production of these environments often disregards their and other users' input. With limited empathic understanding of dementia, and of how the body experiences the environment through embodied knowledge, there is a disconnect between design intent and environmental experience. Acknowledging the impact of the physical environment on individuals, this thesis advances knowledge of how the production of architecture and the conceptualization of space affect the user experience in a dementia care environment.

Adopting an ethnographic approach to inquiry and using multiple data collection tools, this qualitative study researched the user experience from different perspectives of those involved in the dementia care experience: residents, staff, and family members. Fieldwork relied on participant observation, interviews, walk-along chats, and social encounters which provided rich personal narratives illustrating how individuals adapt, adopt, or resist the care home. This study reaffirmed the importance of space in enabling or limiting the individual's ability to feel in place. It also highlighted the different tensions stemming from the care home's hybrid typology: home, workplace, and healthcare. It critically discussed the gaps in the design process which arguably result in essentializing the individuals living with dementia. Persons living with dementia were presented as individuals with embodied biographies, capable of communicating and asserting their identity. The social aspect of space was found to be critical in understanding the potentiality of the physical environment in bridging past and present biographies, effectively acknowledging the body's tacit potential of expression and recollection. These findings prompted a construct of place – a milieu - as unfinished space; concrete yet abstract; social, with plural relations; performative, and always in the process of becoming.

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Chapter I

INTRODUCTION

Architecture and Dementia, two fields I am immersed in. The first by intention; a vocation fed by my passion for the arts. The latter, an unexpected life-changing encounter; forced upon me when my mother was diagnosed with Alzheimer's. Both fields have collided in my world, contributing to my identity and lived experience. The first is commonly associated with dreaming, creating and building; the second is typically associated with loss, impairment and deterioration. This research work was motivated and inspired by the convergence of these two experiences.

Given the prevalence of dementia and recognizing the inescapable nature of the physical environment as the material context and background of every interaction (Imrie and Luck 2014), this study acknowledges the environment as a key enabler and significant determinant of how people will perform (Lawton, M. P. 1974). It aims to contribute knowledge on the experience of people living with dementia in a specialized dementia care environment, and on the resulting tensions of domestic and institutional cues emerging from the care home's hybrid typology. It probes how the conceptualization of space, user, and assumptions of function during the design process arguably result in the essentialization of the individual, ultimately affecting their experience. It proposes architecture as a domain that transcends the material, situating it as a potential harmonizing enabler of imagination and embodied memory, capable of transforming anonymous space into relatable places of personal significance (Pallasmaa 2007). Individuals living with dementia contributed to this study, ably conveying their embodied knowledge and experiences, asserting their identity, suggesting how memories are associated not only to events, people, feelings, and emotions, but also to place.

Similar to a mnemonic exercise that involves superimposing images and places that become symbolic parts of a larger evoked memory (Katz, S. 2012), this study explored ways in which memories of place are held, and of how embodied experiences can be retrieved through social interactions and sensorial cues facilitated by the environment. The environment's potential to prompt embodied memory was found to be even more significant for people living with dementia, providing insights of how past biographies could be bridged with the present. The individual narratives and experience of space supported the stance that architecture can enable or disable environmental experience (Innes et al. 2011), stressing the specificity of this experience. The social aspect of place-making, where diverse relations took place over time, rendered space as always in the process of becoming place. These findings informed the proposed construct of a care milieu, constituted by the physical and social dimensions of the dementia care setting, underscoring the environment as a dynamically evolving and performative place; essential to the quality of life of those involved in the dementia care experience (Simmons 2011).

The Context

Dementia is an umbrella term used to describe a set of conditions caused by neurodegenerative and vascular diseases or injuries (World Health Organization 2021). Associated with a progressive decline across the domains of memory, language, executive functioning, perceptual-motor function, and social cognition, it affects everyday life (Scales et al. 2017). Incurable, dementia is a progressive condition extending its effect beyond functional ability loss to emotional issues and logical reasoning (Simmons 2011); compromising the individual’s ability to execute daily activities such as eating, toileting, and grooming (Public Health Agency of Canada 2019). The cognitive deterioration associated with dementia can limit the person living with dementia from being able to undertake activities that require even a modicum of skill, often causing disorientation even in the most familiar places (Kitwood 1990). A progressive condition, where care needs can demand round-the-clock attention that often exceed homecare capacity, dementia is a strong predictor for institutionalization (Falk et al. 2013).

Widely associated with stereotypes and stigma - exemplified by expressions like 'the person who used to be there has already gone', or 'a death which leaves the body behind' (Kitwood 1990) - reported projections contribute to perpetuating dementia as a fearful state (Gilleard and Higgs 2011). Current estimates suggest there are more than 55 million people living with dementia worldwide (World Health Organization 2021). In Canada, where this study was undertaken, dementia is one of the main causes of disability in later life. More prevalent than cancer or cardiovascular disease (Population Health Expert Panel 2016), it is estimated that more than 419,000 Canadians aged 65+ are living with diagnosed dementia (Public Health Agency of Canada 2019). With projections suggesting that by 2031 that number will be approximately 937,000 (Alzheimer Society Canada 2019), dementia is often described as an epidemic (Dudgeon 2010), a tsunami (Muthara 2018), a rising tide (Dudgeon 2010). Data from the last five years for Ontario - the province where research took place - substantiates these projections, as 64% of long-term care residents report having dementia, with 86% of them needing extensive help with daily living activities (Ontario Long Term Care Association 2019). With approximately 35,000 people currently wait-listed for care home placement (Ontario Long Term Care Association 2019), the accelerated rate of demand for long-term placement poses a tremendous strain on Canada’s health system, directly impacting the demand for specialized dementia care living environments.

The Memory Care Opportunity

Basic market dynamics link demand and opportunity. Industry experts predict that due to the incoming ‘silver tsunami’ and the prevalence projections of dementia, demand for memory care environments will steeply rise, identifying memory care as a ‘hot’ market (Senior Housing News 2016). In Ontario, the projected shortfall to meet this demand has been identified as critical, resulting in a market opportunity for private care home operators (Ontario Long Term Care Association 2019). Consequently, private operators are responding to this opportunity, building care homes at a fast pace in order to capitalize this care market opportunity (Senior Housing News 2016). Given the impact the physical and social environment has on the users’ quality of life (Simmons 2011), this rapid acceleration of development pose design challenges and opportunities for architects. In addition, the complex nature of design and construction of these care homes make it extremely challenging to retrofit buildings to incorporate new standards, or correct design errors once completed (Barnes 2002). Therefore, acknowledging the high cost of construction and the expected performance longevity of these care environments, the need to advance knowledge of how the production of architecture impacts the dementia care experience is critical.

Research Aims

The correlation of environment and quality of care for people living with dementia has been recognized (Popham & Orrell 2012), with evidence suggesting that the physical environment can potentially support remaining skills, arguably influencing wellness and quality of life by providing opportunities for the individual to assert their personhood (Davis, S. et al. 2009; The WHOQoLGroup 1998). Nonetheless, as the global population ages the risk of developing dementia increases, with projected capacity of current infrastructure resulting in national health systems being caught off-guard, struggling with escalating needs and inadequate preparation (Chan et al. 2020; Hlavka et al. 2019; Kitwood 1993; The Global Coalition on Aging and Alzheimer's Disease International 2017). Moreover, there is limited evidence that designers planning dementia care home environments have identified a design process in which design criteria reflects the needs of those most affected with the experience of living with dementia. This knowledge gap suggests there is a risk of prioritizing the physical environment, disregarding a person-centered context which acknowledges the rich and powerful emotional life of the person living with dementia (Kitwood 1993; Popham and Orrell 2012); an undercurrent concern informing the aims of this work.

Through self-reflection on my professional practice, values, and a review of existing literature, this research project was framed within the context of person-centered care principles - reflective of culture change and the radical departure from the institutional models of care in the late 20th Century (Simmons 2011) - establishing the following research questions:

1. Who is the 'user' in the architectural production of dementia care environments? How does the production of architecture and design process conceptualize the 'user'?
2. How does the embodied experience and use of space differ from design intent? What is the embodied experience of the person living with dementia in a care home environment? How is space adapted, appropriated, or resisted?

These questions were researched from a unique perspective; as an architect whose practice has focused on seniors housing design, and as a sociology researcher trying to understand the lived experience in a dementia care setting. According to Kitwood, the fact that I was already immersed in that which I sought to investigate, allowed me a 'privileged access' (Kitwood 1993), facilitating the contribution to knowledge of how the physical environment influences the experience of living with dementia in a care setting.

The structure of this thesis mirrors the evolution of thought and discovery experienced during the study. The literature review on dementia was undertaken within the context of architecture and sociology, resulting in a theoretical framework which reflected the most relevant concepts. These were contextualized with appropriate research methodologies, leading to adopting an ethnographic approach to the inquiry, relying on different data collection tools to enhance the robustness of the data. The rich data was analyzed, discussed, and presented using vignettes and case studies, providing valuable insights and answers to the research questions. The thesis ends by suggesting future areas of development and inquiry.

Chapter II

DEMENTIA CARE AND THE ENVIRONMENT: A LITERATURE REVIEW

Introduction

This chapter provides an overview of how the aims of this study were informed by existing theories, and of how relevant literature was used to develop the theoretical framework. It explains the process of how the research questions were distilled into key concepts, and of how knowledge gaps were identified. It also provides insights of how ongoing critical debates influenced adoption of stance, establishing the theoretical knowledge foundation on which knowledge was advanced.

Search Strategy

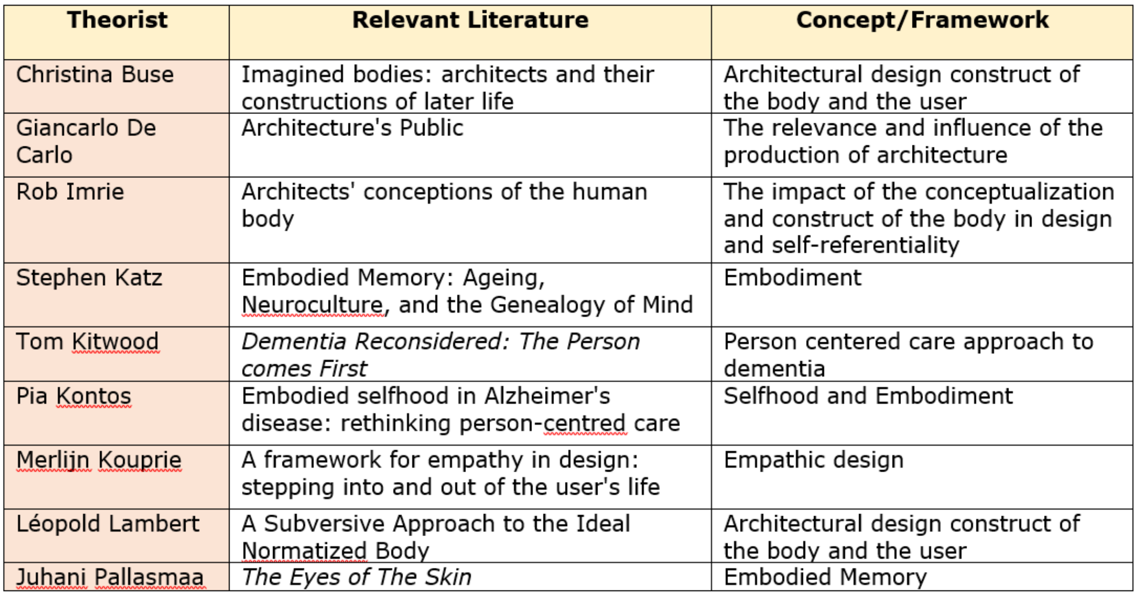
A narrative approach was adopted to review, assess, and synthesize literature into a descriptive account (Gilbert 2008). This approach allowed for the flexibility of a wider scope of review, suggesting key concepts and identifying knowledge gaps (Ferrari 2015). The comprehensive narrative syntheses of existing literature provided a broad perspective of theory and context (Green et al. 2006) relative to the research aims, prompting ideas of new areas of study.

The following keywords were initially searched: dementia, dementia and the environment, dementia care home living, design and dementia, dementia-friendly environments, person-centered care and the environment, homelike environments, dementia and architecture, dementia care settings, neighborhoods, community living. The search was conducted online, using Stirgate, which provides access to the following relevant databases: MEDLINE, Science Citation Index, BASE, Scopus, Academic Search Index, British Library Document Supply Centre Inside Serials & Conference Proceedings, Complementary Index, PsycINFO, Academic OneFile, Social Sciences Citation Index, ScienceDirect, CINAHL Complete, General OneFile, InfoTrac Health Reference Center Academic, JSTOR Journals, Arts & Humanities Citation Index, SocINDEX, Networked Digital Library of Theses & Dissertations, World History in Context, SAGE Research Methods, Sage Premier. When certain articles were not available, using the WebBridge, other search engines like Google Scholar and OAIster were used. The search was restricted to sources in English, focusing on literature from ‘developed’ countries, where dementia care home environments are more common. Discipline filters relating to Anthropology, Architecture, Psychology, Human Sciences, Humanities, and Sociology were applied. Unless researching a specific theoretical concept, date filters from 2000 to present were used, thus ensuring philosophical debates concerning person-centered care principles, culture change, and communal housing expressions reflecting aging-in-place constructs were included (Hrybyk et al. 2012).

The results generated by these parameters were screened to determine relevance to the research questions. Literature was selected based on the applicability and transferability of concepts to the overall architectural and environmental focus of the work, and of the lived experience of dementia. Citation indices were reviewed, providing understanding of how other researchers had incorporated different topics in their work (Robson 2011). As the literature review progressed, my search terms gradually evolved to include: design process, design production, sense of place, personhood, enabling environments, disability, home, belonging, attachment, emplacement, embodiment, environmental experience, reflective practice, empathy.

Developing a Theoretical Framework

Based on the recurrent topics from the literature reviewed, a theoretical context compatible with the proposed research aims was developed to include affect and attachment of place, embodied experience of space, empathy, personhood, production of architecture, and reflective practice. The following table was generated as a tool to contextualize the research aims with recurring themes and applicable empirical works, identifying influential theories used in establishing a theoretical framework for this research.



Theorist	Relevant Literature	Concept/Framework
Christina Buse	Imagined bodies: architects and their constructions of later life	Architectural design construct of the body and the user
Giancarlo De Carlo	Architecture's Public	The relevance and influence of the production of architecture
Rob Imrie	Architects' conceptions of the human body	The impact of the conceptualization and construct of the body in design and self-referentiality
Stephen Katz	Embodied Memory: Ageing, Neuroculture, and the Genealogy of Mind	Embodiment
Tom Kitwood	*Dementia Reconsidered: The Person comes First*	Person centered care approach to dementia
Pia Kontos	Embodied selfhood in Alzheimer's disease: rethinking person-centred care	Selfhood and Embodiment
Merlijn Kouprie	A framework for empathy in design: stepping into and out of the user's life	Empathic design
Léopold Lambert	A Subversive Approach to the Ideal Normatized Body	Architectural design construct of the body and the user
Juhani Pallasmaa	*The Eyes of The Skin*	Embodied Memory

Table 1 - Theoretical Context

These concepts were influential in generating ideas throughout this study, with the following section providing a synthesis of how they were critically associated to key constructs of this work.

Dementia, Memory, and Personhood

Some of the organizations that are considered dementia field authorities publish literature that can be alarming and distressing and which read as catalogues of horrors, documenting dread and loss (Kontos 2004): Dementia is a global epidemic (World Health Organization 2015); Dementia is an illness that robs people of their personality, cognitive ability, independence, and well-being; essential traits that make a person who they are (CARP 2014). With 1.6 million deaths occurred worldwide in 2019 due to dementia, it is the seventh leading cause of death (World Health Organization 2021). These statements are not only discouraging but provide a pessimistic view of dementia as an incurable disease of epic proportions which slowly erases person’s abilities and identity, suggesting the condition leads to the eventual dismantling of the self, until there is nothing left of the individual (Davis, D. 2004).

These constructs are based on the strong 'Western' discourses and metaphors that identify memory as the guarantor of civilized personhood (Katz, S. 2012). Affirming that selfhood is exclusive to the dimension of cognition is a result of the western philosophical tradition that separates mind from body, with the mind being superior to the body (Kontos 2004). Philosophers such as John Locke theorized that memory is the guarantor of rational personhood and identity, affirming that if a person cannot remember past experiences, they are not the same individual as before. For Locke, consciousness is solely that which makes the self, equating loss of memory to loss of personhood (Locke 2000). This Lockean conceptualization of personhood, memory, and consciousness is the philosophical pillar of contemporary frameworks of the aging mind, self, and dementia (Katz, S. 2012) which assume that the effects of the condition on memory and cognition result in the loss of selfhood; a position that resonates with the biomedical model of dementia (Kontos 2004).

One of the catalysts in cementing the idea of dementia as an illness of the brain was the 'anatomo-clinical gaze' that emerged after the Enlightenment (Merleau-Ponty, M. 1962). Once the body was anatomized, 'the gaze' now revealed that disease resided in the body (Armstrong 1981). Today, western biomedicine identifies dementia as a cognitive psychiatric disorder (Davis, D. 2004), a disease of the brain treated through biomedical means. This conceptualization of dementia traces back in North America to 1974, when the National Institute on Aging (NIA) - in an effort to destigmatize 'ageism' and to prioritize funding for research - designated dementia as a disease not linked to normal ageing (Ballenger 2006).

The challenge to research a cure for dementia, a disease that now incorporated the senility of old age, steered the medical community to focus on biomedical means of treating the condition (Davis, D. 2004). The construct of dementia as a brain disease focused research on the relationship between pathology and dementia, attempting to decipher the distinctions at a pathological and clinical level between a brain disease and natural aging. Unfortunately, although public and political support for researching a cure for dementia positively impacted advancing scientific knowledge, it had less impact on reducing the stigma associated with old age and dementia (Ballenger 2006).

Nonetheless, with dementia on the forefront of medical research and academic discourse, theorists were engaging in provocative debates regarding ageing, prompting a social movement. Butler first coined the word ‘ageism’ to denounce how societal attitudes stereotyping and discriminating against the old posed a threat to well-being (Butler 1975). Kitwood theorized on the depth of influence social psychology had on a person living with dementia’s ability to preserve their status of a valued, sentient being (Kitwood 1990), criticising how they were often subjected to ageism (Kitwood 1997). Different discourses advocated for a more empathic and socially responsive experience of ageing and cognitive impairment. It is within this context that a social movement emerged, championing the inherent human and social rights of people with dementia. This new construct asserted that personhood could be maintained despite decline; demanding a new social psychology that recognized and acknowledged this. A different person-centered care approach was advocated; one where care resulted from a cooperative and reciprocal engagement between individuals that held the same social status (Kitwood 1993); a clear departure from a biomedical to a more socially-holistic model. This study drew inspiration from Kitwood’s construct of personhood (Kitwood 1990; Kitwood 1997) which maintains that personhood perdures in spite of cognitive impairment, acknowledging that a person with dementia maintains their identity throughout their journey (Davis, D. 2004).

Embodiment

Kitwood’s conceptualization of the maintenance of personhood throughout the dementia journey within a relational and social context, where human life is understood as interconnected and interdependent, is derived from his definition of personhood:

> *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, pg. 8)*

Kitwood posits that people exist affectively in relational contexts, arguing that the perpetuity of selfhood correlates with how the physical and social environments facilitate the expression and production of self (Kitwood 1997). Detractors of this stance accuse Kitwood of operating within a pseudo-scientific model by interchanging neurological impairment and social psychology, and of trying to preserve a personhood that lacks memory and awareness of their 'being', whose self has eroded (Davis, D. 2004). His argument that personhood is unimpeachable has also been criticised for ignoring the possibility of a social death, where the individual loses the attributes which constitute their identity, and which are deemed necessary for others to recognize them as a person (Lawton, J. 2000). This criticism echoes Locke's stance that personal identity can be placed in nothing but consciousness, and that it is that alone which constitutes the 'self' (Locke 2000).

Contrary to this position, Merleau-Ponty's theory of embodied connection (Merleau-Ponty, M. 1962) proposes an outward engagement with our surrounds where the body-schema is not defined by a cumulus of atoms and cells. What defines this embodied connection is a lived experience that creates an inherent knowledge of being in the world and which by extension, the spatiality of the world is recorded from the spatiality of the body (Davis, D. 2004):

> *The phenomenological world is not pure being, but the sense which is revealed where the paths of my various experiences intersect, and also where my own and other people's intersect and engage each other like gears. It is thus inseparable from subjectivity and intersubjectivity, which find their unity when I either take up my past experiences in those of the present, or other people's in my own. (Merleau-Ponty, M. 1962, p. xxii)*

In his unified view of mind and body, Merleau-Ponty challenges the Cartesian way of understanding the body, which presupposes a duality of mind and body. Advancing the assumption of embodiment, he theorizes that there is a unity in which all parts of the human being are recognized as integral, where the body cannot be separated or objectified, but is recognized as the unique source of information to our lived experience (Wilde 1999). Merleau-Ponty further asserts that an individual is more than just 'a consciousness' endowed with zoological characteristics, suggesting that our life experience depends less on cognition and relies more on bodily perception, effectively challenging the position of a fundamental passivity of the body, and rejecting that cognition alone is an indicator of selfhood (Merleau-Ponty, M. 1962). This perspective challenges the Lockean idea which caged Western thought into a position where the key attribute of personhood is to express human identity solely through unforgivingly unforgotten memory (Katz, S. 2012). Embodiment advances Kitwood's construct on selfhood beyond a bio-psychosocial approach that relies on social nexus and confines selfhood to the brain; it recognizes the body as a source of agency in the constitution and manifestation of selfhood (Kontos 2005). It is a concept that supports the position that personhood and identity persist throughout cognitive deterioration, as it is conceptualized as an embodied dimension of human existence (Kontos 2004). Embodied selfhood captures the construct that essential aspects of selfhood are revealed in the way the body moves and behaves (Kontos 2005); a philosophical underpinning critical to this research work. Acknowledging embodied experience directly challenges Locke's construct of conceptualizing a person as an intellectual creature, where if memory is wanting, the rest of faculties are deemed useless and the status of a person as a thinking being is lost (Locke 2000).

This framework of embodiment stresses the significance of body and experience, and theorises experiencing the world through bodily perceptions, emotions and movement in space (Merleau-Ponty, M. 1962), suggesting that the physical environment is in constant construction and dialogue with the user of space, with the body and its senses critical to its use and interpretation (Negus 1998; Pallasmaa 2005). When describing the field of human perception, Merleau-Ponty highlights how it is filled with a play of colours, noises, tactile sensations; all elements of the physical environment that can arguably be used by the body to help connect meaning of place and continuation of embodied practices (Kontos 2005; Milligan 2005; Örulv 2010). This connection with the physical environment, where the body forms part of the milieu, and where embodied experiences of space help make sense of the surrounds, placed the body as a preserver of agency and identity, with body expressions capable of asserting embodied selfhood (Kontos 2012), further confirming the need to advance knowledge on the relevance of design and the production of care environments.

Architecture Matters

Building typologies are associated with specific human activities, influencing behavior, embedding in our psyche unwritten rules of use and comportment, which through time become entrenched in our actions (Barker, R. G. 1968). It is therefore posited that society's norms influence the built environment, becoming a reflection of a specific culture. Conversely, the built environment impacts the individual in a dynamic interplay of 'modified–modifier' (Misra 2002), a back and forth similar to the sentient and sensible aspects of the body, or "double reference", used by Merleau-Ponty to describe how subject and object relate in the world; the ability to touch and be touched by one's surroundings (Wilde 1999).

Even though there is limited systematic research into the design process of care home environments, literature recognizes the salient role the physical environment has in care settings in enhancing quality of care practices, residents' quality of life, and overall well-being (Barnes 2002; Chaudhury et al. 2018; The WHOQoLGroup 1998). Likewise, the environmental context of aging has played a significant role in gerontological theory, research, and practice. In particular, environmental gerontology has focused on the explanation of the relation between elderly persons and their sociospatial surroundings, emphasizing the role of the physical environment for aging processes and outcomes (Wahl and Weisman 2003). Some of the most salient theories are Weisman's (1997) 'model of place', in which the interaction of people with dementia, their social and organizational contexts and the physical setting are argued to shape the therapeutic dimensions of the environment as experienced by the person living with dementia (Calkins and Weisman 1999; Weisman 1997). Hall and Buckwalter's (1987) 'progressively lowered threshold model', which argues that every individual has a stress threshold, whereby the person living with dementia is argued to have lower threshold tolerance to stressors like changes in routines or environment, amongst others, which contribute to anxious and dysfunctional behaviours. This model theorizes on the influence the environment has on behaviours, with a distinct applied orientation by suggesting strategies to caregivers for identifying these triggers so they can be modified in order to prevent stress responses manifested in behaviours (Chaudhury and Cooke 2014). And Lawton's (1973) 'individual competence and environmental press' or 'environmental docility hypothesis', arguably considered a central theory in environmental gerontology (Wahl and Weisman 2003).

Lawton argues that when the relationship between person and the environment is congruent, the environment has a positive impact, elevating the physical environment as a determinant of human quality of life (Lawton, M. P. and Nahemow 1973); a relationship especially significant for people living with dementia, who are considered more vulnerable to the environment (Regnier 2003). The World Health Organization has consolidated this argument by acknowledging the physical environment as one of the domains that influence quality of life (The WHOQoLGroup 1998). It is therefore argued that design interventions have significant effect on people's lives, situating the architect as a lead actor in determining people's experiences of designed surroundings (Jones 2014). The acknowledgement of the critical role the physical environment has in the care experience, along with empirical evidence of how environmental stressors and cues are linked to sensory stimulation, has led to the development of various design guidelines (Fleming et al. 2016) and environmental assessment tools (Fleming 2011), attempting to identify the characteristics of what constitutes a 'quality environment'. These tools have typically focused on design and environmental elements which have the potential to positively influence the resident's experience, encompassing domains such as homelike décor, use of colour, lighting and acoustic levels, scale of space, spatial layouts, wayfinding, ambient temperature, among others (Brawley 2005; Day et al. 2000; Fleming and Purandare 2010).

Nevertheless, while there is consensus of the importance of the physical environment in the care experience, there is acknowledgement that a singular optimal environment cannot be defined (Fleming and Purandare 2010), given the close yet unforeseeable relationship of the organizational, social, and physical aspects of the care setting (Chaudhury et al. 2017). Likewise, the individual's dementia journey is unpredictable, making it difficult to establish definitive design parameters. Critics have also argued that there is often misalignment of what residents living with dementia and proxies would characterize as ideal (Fleming et al. 2016). This study aimed to address this gap by positioning the individual living with dementia as the expert on their experience, while gaining insight from different user groups which constitute the care milieu. It extended beyond the physical attributes of the built environment to the abstract aspects of place.

The Architect

The role of the architect cannot be underestimated, as they shape the settings where different activities take place - care included - and thereby, have the potential to reformulate cultural philosophies that affect society (Buse et al. 2017).

By designing physical spaces and helping create places, architects participate in the perpetuation of certain societal practices, yet are tasked with the challenge to innovate and reformulate ways in which people use and inhabit the spaces they envision. This places the architect in a privileged position; as an agent of change capable of influencing societal constructs and experiences.

The status of the architect has varied through time, depending on the political and power structure of the era (De Carlo 2005). It is only recently that the profession has been demystified, becoming more relatable through the internet, media, specialized television programs, magazines, and architectural design software programs designed for popular consumption (Misra 2002), changing the context of the production of architecture. As society becomes increasingly media-based, the architect is under closer scrutiny, with the public demanding a more socially-sustainable architecture, with users more sensitive to how buildings affect the way they live, work, and play (Jacob 2014).

As significant agents of influence in the way people experience designed environments (Jones 2014), architects help determine what others do by moving people through spaces in a preconceived way (Kouprie and Visser 2009). And while the user of space may not necessarily connect the social and behavioural implications of design, they will positively perceive and identify dysfunctional design (Misra 2002). Architecture is therefore posited as the material connection between people and places, creating settings where identities converge to produce lived experiences (Lees 2001). This interaction becomes a symbiotic relationship, where the person modifies space and space modifies the individual, suggesting a co-produced experience by the built environment and the perception of the individual (Jacobs and Merriman 2011). And although each space has functional demands, physical constraints, and artistic objectives, there is no best response for a specific design problem; each architectural design may have multiple solutions (Parsaee et al. 2016).

Critics argue that throughout the design process, the architect relies on personal interpretations of design parameters and on their own experiences to create solutions before being able to test them (Parsaee et al. 2016). This self-referentiality has been criticized as a narcissistic approach to design, with an inherent risk of imposing design solutions based solely on personal criteria (Imrie

2003). This self-imaging approach to design echoes Kitwood's concerns regarding the numerous impositions made on people living with dementia by enforcing surrogate frames of reference (Kitwood 1993), leading critics to contend that architecture is too important to be left to architects alone (De Carlo 2005).

These critiques capture an evolution in understanding the architect's role from omniscient master creator, to an agent of influence that must continuously focus on the relationship between architectural design, the user, and their individual needs; open to dialogue within the context of a more socially-involved and demanding society (Andersson 2015). This evolution in role offers an alternate explanation to self-referentiality, where the architect's approach is not necessarily a narcissistic posture, but an empathic design approach. The designer attempts to get closer to the lives and experiences of the people that will be using the space by anticipating their needs, attempting to make situations more comprehensible by contextualizing the design problem within their personal experience and knowledge; a typical approach to everyday problem-solving (Kouprie and Visser 2009).

A nascent literature on the sociology of architecture, particularly in the field of care, explores the architect's participation in shaping care through their design propositions (Prior 1988), identifying tensions around conflicting priorities where empathic objectives often concede to the driving forces associated with the marketisation of care (Brennan et al. 2012). Design solutions often reflect compromise, evolving the architect's role to negotiator (De Carlo 2005; Sharrock and Anderson 1994; Yaneva 2008), making it critical to understand how designs of care environments contribute to the atmospherics of care (Buse et al. 2017), as they influence contemporary interpretation of the social perspective of care, where architectural forms become spatial interpretations that express societal values, often becoming prototypes that help steer social policy (Andersson 2015). Through architectural practice, prevailing ideals of care that influence the lived care experience are reproduced (Prior 1988), situating the architect as an interpreter of certain narratives of care (Buse et al. 2017). Hence, acknowledging the architect's influential role in the design, interpretation, and reproduction of caring practices, critics have argued for a better understanding of how architects derive their knowledge (Buse et al. 2017; Imrie 2003).

The architect is ultimately responsible for proposing a solution to a specific design problem (Parsaee et al. 2016), with relative creative freedom to suggest important aspects like shape and form. Critics assert that every design commission is an opportunity for the architect to produce unusual designs, driven not so much by user satisfaction, but by the desire to produce a distinct oeuvre (Misra 2002). They question whether the architect's aesthetic motivation subjugates function to their desire of achieving 'high art' (Imrie 2003). Arguably, such criticisms reflect an unawareness of the typical role the architect assumes in the design process and of the negotiation context in which design solutions are created, offering an alternate interpretation of the architect's role as being one which demands negotiation and rational decision-making (Parsaee et al. 2016).

A Negotiated Process

Design problems are multi-faceted, requiring multi-disciplinary expertise. The architect must manage multi-relations, and more often than an artist populating an empty canvas with creations, the architect acts as an analyzer and negotiator of competing priorities, often relenting to other driving forces that impact design (Parsaee et al. 2016). The architect is mostly a coordinator, manager, and mediator who amalgamates many disciplines into one solution, integrating differing demands and preferences (Horst Rittel 1971). Much of the design process is shaped by profitable values and commodification of care delivery, making decisions within a fiscal context, thus influencing the overall development (Imrie and Luck 2014). Needs and design criteria are defined by a range of functional goals, reviewed under the lenses of project costs and efficiencies, making philosophical debates about the environment more challenging to undertake, with functionally-driven demands often taking priority (Imrie 2003). Unlike popular belief, the production of architecture is not a capricious and artistic endeavor, it relies on visual arts, but also on building engineering, cost management, and logic studies (Parsaee et al. 2016). Researchers on the sociology of conception have argued that design is a negotiated process (Yaneva 2008) in which often-competing issues are not necessarily resolved, but are incorporated into design solutions through a process of collaboration, bargaining and concession (Sharrock & Anderson 1994). It is an interactive process between different stakeholders, an exercise of analysis and mediation; a balancing act of technical factors, user groups, fiscal targets, special interests, organizational policies, legislative and normative guidelines, and lastly, aesthetic preferences.

Albeit having a lead role, the care-based architect is far from the sole protagonist of this process, nor is the built form a direct result of personal creation and interpretation. There is no single prescribed and unique design method; yet all approaches rely on multi-disciplinary knowledge. It is a nonlinear process of constant evolution and revision, adapting design solutions to specific criteria (Sharrock and Anderson 1994), with different stages of this process offering the architect creative intervention opportunities to mold the design. This formulation of design problem-solving illustrates how the architect cannot unilaterally control the architectural design process, likening the architect's role to that of a juggler who persistently must address an array of demands (Latour and Yaneva 2008). Nevertheless, albeit best efforts to capture all functional and operational requirements, the building will inevitably be a physical representation of a snapshot in time, of the vision of care the owner/operator had at the time it was commissioned.

The Production of Architecture

Dissecting the design process and its inherent challenges provides context to how space is conceptualized and created into architectural form (Parsaee et al. 2016). It is argued that critics accusing architects of producing buildings that simply chase a poetic expression of high art or of having a limited understanding of how the human body should influence the design process (Imrie 2003), lack insight and practical knowledge of this process. Design is not a self-absorbed creative expression; it is a process fed by interaction and multi-relations (Misra 2002), with different stakeholders and actors leaving traces of their specific agendas (Yaneva 2008). Therefore, space provides a glimpse of the cultural, social, economic, and political factors that have influenced its design (Horst Rittel 1971). Therefore, space must be contextualized within the process which creates it, and the forces and ideologies that prescribe it. It is not the void and the air framed by walls for objects to rest and people to use nor a determined factor of social life (Prior 1988). Space is a determinant of social life (Massey 1999). It is social and political, organizational and discursive (Imrie 2003; Misra 2002; Prior 1988).

Architectural space should then be read as a socio-political statement that defines spatial frameworks within an ideological view on how to carry on a specific activity (Andersson 2015). Buildings express a discourse, and architectural form and space provides a record of such discourse, thus asserting that space is also ideological (De Carlo 2005; Lefebvre and Enders 1976; Lefebvre 1991). Therefore, architectural plans can be acknowledged as manifestos of operational philosophies, and the resulting built form as discursive enunciations that convey information and meaning (Martin et al. 2015; Prior 1988; Whyte 2006; Yaneva and Guy 2008). This further stresses the importance of advancing knowledge on the production of space and the role the architect plays in confirming the correlation of architectural design and philosophies of care and the ways in which bodily experience is anticipated (Buse et al. 2017; Hall, P. and Imrie 1999). Leading the design process, and acting as the interpreter of the client's vision of how users should navigate the environment, the architect must imagine the space before designing it; assuming and guessing how people will circulate through the space and how different activities will be carried out (Horst Rittel 1971; Yaneva 2008). This imagination process has become more accessible due to the ongoing global digital transformation. Recent technology, ranging from virtual reality to Building Information Modelling (BIM), is influencing architectural practice by providing tools to bring conceptual designs to life, enabling virtual exploration and assessment of design choices, with supporters of this approach hailing the benefits of improved collaboration, productivity, and efficiency (NBS Research 2018). The full impact of digital design tools on design processes is to be determined. Nevertheless, digital exploration and assumptions of form and space cannot be confirmed without validation of their functionality by actual users, or without understanding the embodied experience the space will enable.

The Imagined User

Contributing to this gap is the fact that most projects are commissioned by clients who are not the intended users of the buildings they are developing, exacerbating the divide between designer, client, and user (Parsaee et al. 2016). This results in architects relying on different strategies for imagining users, relying on their personal constructions of ageing, while amalgamating the interpretations of imagined bodies conceived by other stakeholders involved throughout the design process (Buse et al. 2017). Often having to rely on their client's vision of care, expected to deliver environments that facilitate the operator’s intended performance of the building, the predictive and prophetic demands of the architect to design a space according to how use and care delivery are imagined, is a challenge in the care home design process. This gap is aggravated when considering that ‘the client’, typically the care home operator, will not use the space being designed, contributing to critics’ concerns that the architect’s search to reconstruct and anticipate the daily experience of the user potentially results in reducing people to bodily needs and functions (Buse et al. 2017; Heylighen 2013). Therefore, design decisions made by different stakeholders during the design process, help shape both the physical environment and the experience of future users, who in all likelihood will be different to those making these decisions (Kouprie and Visser 2009). Thus, the need to critically reflect on the strategies used by the architect, client, design team and other stakeholders to conceptualize and define who ‘the user’ of the designed environment is.

Throughout the design process, the architect tries to anticipate and ‘imagine’ the bodies that will navigate the space (Buse et al. 2017), foretelling use and performance, mentally running through different scenarios to implement the appropriate design solution. Critics argue that most architects have no conception of the human body, or if they do, they often conceive it in reductive terms (Imrie 2003). It may be suggested that these detractors often dismiss the different conceptualizations the architect undertakes to be in tune with the anticipated embodied, multi-sensual and affective understanding of buildings as experienced by its occupants (Jacobs and Merriman 2011). Designers, aware that the architectural spaces produced will be inhabited by others, do try to anticipate the multi-sensory encounters that the environment will prompt. Throughout the process, the architect continuously seeks to understand the impact of design choices, taking calculated risks in evaluating the potential outcome and impact of specific decisions on the overall success of the design, hoping to positively affect a segment of society (Horst Rittel 1971). As it relates to dementia care environments, the architects’ strategies for imagining bodies, or users, is equally influenced by their constructions of dementia and the aged, and by the constructs held by other stakeholders involved in the design process; operators, consultants, legislators, marketers, investors, and others (Buse et al. 2017). Their individual constructs influence design decisions, arguably contributing to the disconnect between user and designer.

A unique spatial embodied experience

Embracing Merleau-Ponty's views on how one's perception of the world is dependent and inseparable from one's personal past (Merleau-Ponty, M. 1962), suggests that each one of us will experience space differently. Each social actor will somehow have their own unique embodied experience with the designed environment, generating different feelings, attachments and affects from their milieu. They will each demand from it, as well as modify it; a process in which they become everyday designers, as they navigate, manipulate, and re-interpret the designed space to meet their needs (Jacobs and Merriman 2011), predicting different experiences within the same environment.

This individual and unique spatial experience informs the criticism that architects think in terms of 'categories of users', predetermined and associated to the building typology being designed, which risk undermining the individual body (Imrie 2003). Arguably, it is not the architect's intention to typify the user into categories, but a practical consequence of the use of precedents in the design process; grouping people and assigning predetermined functions to help the efficacy of design (Bay 2001; Moraes Zarzar 2003). The challenge with this imagined choreography has been identified in the reviewed literature as problematic, arguably ignoring human plurality and undermining the diverse ways in which bodies can potentially interact with the environment (Imrie and Luck 2014). This generalization, often results in conceptualizing the imagined user exclusively as abled-bodied, rarely regarded as an organic, fleshy entity (Imrie 2003); faceless individuals, whose embodied experience is dismissed, forced to live and interact in a world designed for them without their input or reported environmental experience.

Therefore, understanding the architect's conceptualization of the 'user' is critical, given their contribution to the reproduction of caring practices through their design assumptions (Buse et al. 2017). Recognizing the varying occupations of the environment, and assuming different kinds of embodied engagement, it is argued that different types of users will demand different functionality of space. Therein the need to reflect on the sources that shape architectural conceptualizations and on how the relationship between user and space is expressed (Imrie 2003), as enabling different experiences of inhabitation could potentially sensitize the architect to acknowledge a more pluralistic experience of space (Jacobs and Merriman 2011).

The Body as a Design Tool

Classical analogies of how the human body relates to architectural proportions, and theoretical exercises explaining architecture as a mathematically-based science which relies on geometry (Merrill 2013), have long been part of design conceptualizations. Using the human body, believed to be created in God's own image, and therefore a perfect model of the cosmos, as the key to decode harmonious design that is derived from a perfectly-proportioned male ideal (Lester 2012), have traditionally been part of architectural and design discourse. This numeric, Cartesian, and essentialized approach to the body has a long-standing architectural academic tradition in which the body is the reference for ideal design proportions and composition (Buse et al. 2017; Imrie 2003; Imrie 2004). This hard-coded design approach has influenced architects for generations and resonates with Imrie's concern that the body is often used in an objectified manner, only as a dimensional tool to gauge proportion and scale (Imrie 2003); a modular anthropomorphic reference unit.

Da Vinci's L'Uomo Vitruviano (Figure 1), exemplifies this tradition, immortalizing the mechanistic reduction of the human body. In this illustration, art and mathematics merge into one statement, attempting to decipher the laws of the universe around the image of a perfectly symmetrical and balanced male figure; conceptualizing the human body as an instrument of movement governed by mechanical laws (Katz, S. 2012; Keele 1964).

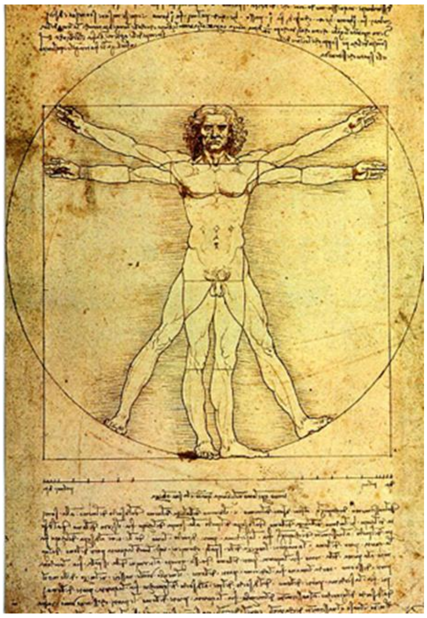


Figure 1 - L'Uomo Vitruviano. Leonardo Da Vinci (c.1487)

This image is a vision of the human ideal, a model of the universe, the promise of a godlike ability to understand the laws of nature. With its shifting centers of square and circle, and the series of suggested poses, it was not only a solution to an architectural theorem; it was the representation of the perfect relationship between man and geometry (Lester 2012). Decoding a canon that apparently regulates the human body, it illustrated the Renaissance idea of man as a symbolic microcosm. At the center of the universe, the iconography of the perfect creation of God proposed a blueprint of geometry and proportions as tools for designing the perfect building, and achieving the perfect relationship of the body to architecture (Murtinho 2015).

Le Corbusier, like other modern architects, drew inspiration from it, developing the Modulor scale (Figure 2). Based on what he considered the ideal human figure (a six-feet-tall Englishman), it proposed ergonomic principles as design guidelines to achieve the perfect fit and relationship between man and architecture (Corbusier 1961; Steyn 2012). He associated physical activities to the dimensional criteria of the 'ideal' human body, theorizing that implementing these proportions would prompt the human psyche to aesthetically and psychologically associate with space (Steyn 2012). This mathematical conceptualization of the human body, condensed in normative design standards (Schön 1988), has dramatically influenced how architects conceptualize movement and spatial relationships.

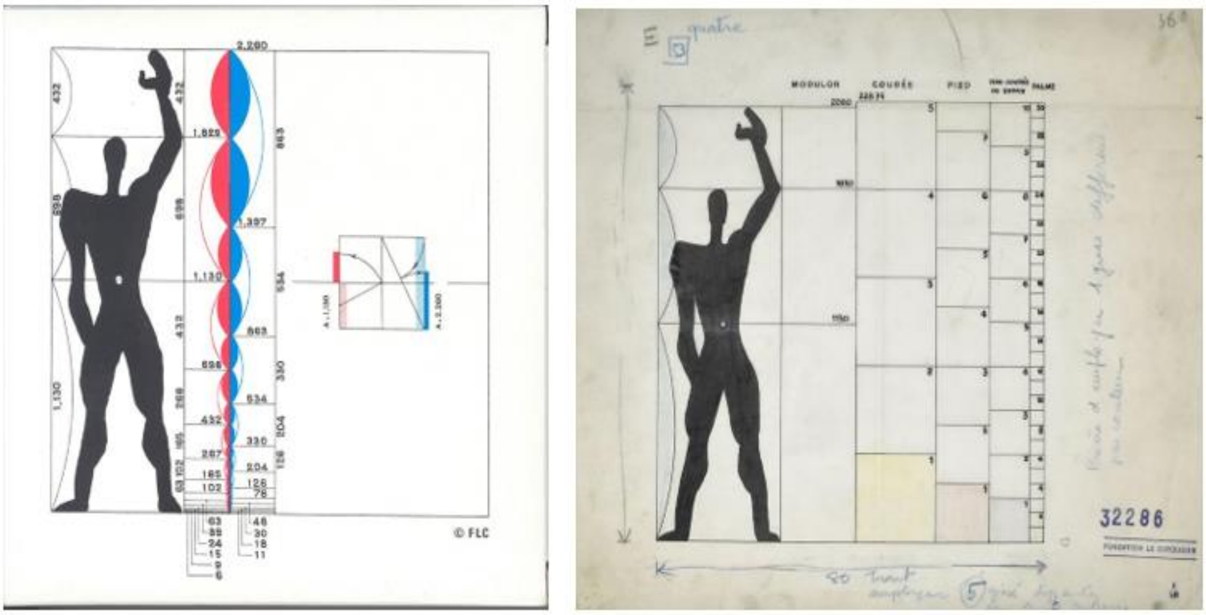


Figure 2 - Le Modulor. Fondation Le Corbusier. ©FLC-ADAGP

The academic attempt to decipher how the body relates to architecture exemplifies the deeply-rooted academic discourse of searching for a standardized and normative approach to design (De Carlo 2005), still engrained in current design processes. The risk of this mathematical rationalization to the body-environment relationship is that the body becomes a dimensional unit to be understood in geometric terms only, a 'Cartesian, geometric and essentialized body' (Imrie 2003), which dismisses all other embodied and qualitative aspects of the body. Nonetheless, such mechanistic logic serves as the foundation for the development of widely applied ergonomic design standards where bodily dimensions are normalized based on the assumed space required by the user to perform certain functions, as illustrated in Figure 3. Once established, these dimensions are used as reference throughout the design process, responsive to the stance that if architecture serves the body, design should obey mathematical truths. This construct approaches design as a system of technical goals, favouring programmatic functionality of space over the sensual qualities of space which relate to a body-centred experience (Bloomer and Moore 1977). It conceptualizes space as a rational production, similar to a machine, that can be designed by adhering to specific dimensions associated with specific functions and user type;

a discourse that has largely influenced the architect's conceptions of the human body (Imrie 2003).

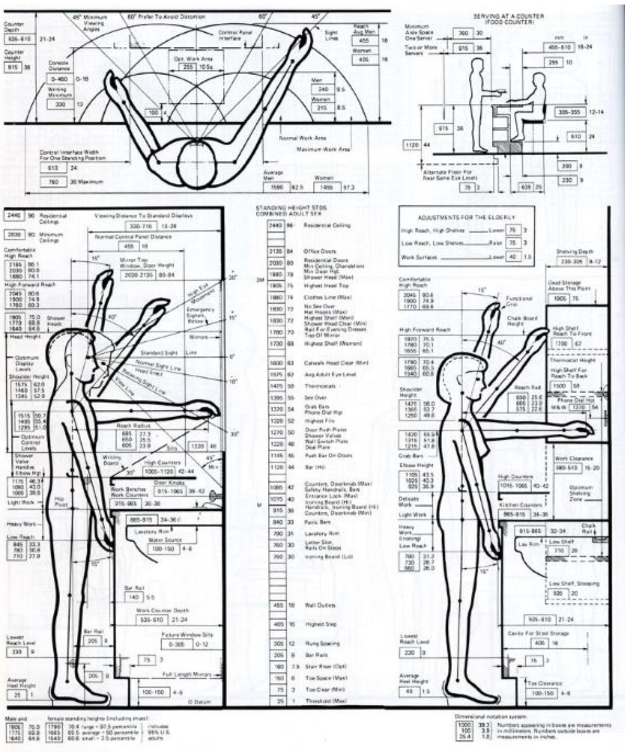


Figure 3 - Architectural Graphic Standards. Wiley, 2008.

Design standards directly respond to this modernistic quest of a universal scale that encompasses all human tasks and which can be used as a spatial design reference, meant to attain an ideal relationship between man and the built environment (De Carlo 2005). This anthropocentric approach establishes the abled, 'normal', youthful male body as the base unit of architectural design and proportion, capturing the mechanics of motion associated to this 'ideal' body for space optimization, arguably reducing the body to a series of normative dimensions, also reflected in prescriptive design codes (Printz 2013). And while the intent is to produce architecture that perfectly adapts to the human body, it essentializes the body, conceptualizing it to an unreachable state of normality, arguably resulting in spaces that are discriminatory (Lambert 2012), exclusionary, and unrelatable.

These rationalistic conceptualizations, advanced as universal design solutions, have had the opposite effect, with detrimental implications on the experience of space (Horst Rittel 1971; Sharrock and Anderson 1994). Normalising the human body and the illusionary formulations of a universal scale for all human actions (De Carlo 2005), often inform the construct of an imaginary user (Lambert 2012), infusing the subconscious with architectural rules and configurations, arguably resulting in environments where not everyone has an equal opportunity of fitting (Agrest 1988). Consequently, architectural design is reduced to a mechanical exercise, where utility and function are disassociated from experience and embodiment, contributing to the production of architecture that is desensitized, abstracted, and dismissive of the intricacies of body interactions (Imrie 2004).

As previously discussed, and consistent with Imrie's research (2003), architects rely on self-referentiality and their own experiences during the design process (Kouprie and Visser 2009); role-playing the lived bodily experiences of others to help them infer spatial experiences (Buse et al. 2017). Contributing to the architect's construction of the imaginary user, this approach has been criticized for being a reflection of the designer's ego, as it invariably imagines the user's body in relation to their self-image, orchestrating movement based on personal bodily interactions with the environment (Imrie 2003). Nevertheless, Lawton theorizes that incongruent designs are not necessarily the result of the architect's ego, arguing that design gaps are a consequence of innocent errors of judgement, where the unforeseen side effects of certain design decisions are due to ignorance (Lawton, M. P. and Nahemow 1973); an argument I support based on my professional experience. Albeit not always successful, designers endeavor to empathize with the users they are designing for (Kouprie and Visser 2009). Arguably, this imagination exercise, which seeks to relate and understand those who will use the space, could be framed as an empathic, user-centred design strategy (Mattelmäki et al. 2014) which albeit flawed, attempts to relate to the potential user's motivations, emotional needs, and personal preferences (Kouprie and Visser 2009).

Also influencing this approach is the individual constructions of ageing held by other stakeholders involved in the design (Buse et al. 2017; Gilleard and Higgs 2011; Yaneva 2008). Consequently, how the body is conceptualized, and the resulting mental image of the potential resident of a care home, will be prejudiced by personal experience with older people, influenced by exposure to the mediatic representation of old age (Blythe and Wright 2006; Twigg 2012), and biased by the personal values and truths of the envisioned constructions of ageing (Imrie

2003). Hence, this self-referentiality will render different constructs for consideration, with architects proposing new spatial solutions and meanings for care environments, assuming the critical role of cultural intermediaries; influential in shaping and interpreting social constructs of ageing through the material production of space (Twigg 2012).

Therefore, the way in which designers imagine older people is critical, not only because the human body and architecture are conjoined in coproduction (Imrie 2003), but because spaces will be shaped based on the embodied biographies habitually informed by familiar generational images (Buse et al. 2017). This approach is ultimately exclusionary, as the designer will consistently define the human body in relation to a self-image (Imrie 2003), failing to incorporate direct input from the actual users, potentially dismissing individual needs specific to particular conditions, such as dementia, where the designer may lack empathetic reference to contextualize design solutions (Sharrock and Anderson 1994). The role of the body, theorized as the primary interface with the environment (Merleau-Ponty, M. 1962; van Hoof et al. 2010; Wilde 1999), must also be considered within the natural ageing process and associated sensory changes that occur (van Hoof et al. 2010).

While the ageing process is inevitable, it is not a universal trajectory (Hertzog et al. 2008). Evidence suggests that each of us ages differently, a consequence of our individual lifestyle choices and of our natural, social, and physical environments (Hertzog et al. 2008; The National Institute on Aging 2020). Therefore, ageing is proposed as the consequence of culture, environments, lifestyle, past illnesses, and heredity dispositions (Chaudhury and Cooke 2014); lifelong influences and practices that become embodied as part of our biography and identity. Furthermore, there are distinct pathophysiological and behavioral manifestations of different forms of dementia (Calkins 2018), suggesting that the individual's neuropathological changes will also influence how the person living with dementia interprets their social and physical environments (Bakker 2003), making their perception of stimuli unique to their condition. The unpredictability and plurality of experience, and the individuality of the ageing process and dementia journey, makes establishing overarching design, therapeutic, or functional guidelines and objectives a challenging enterprise.

Therapeutic Goals and Design Guidelines

Kitwood's (1997) influential work initiated a shift in dementia care in the 1990s, where the individual was the centre of all care discourses (Davis, D. 2004). This novel approach to dementia care prompted a social movement, referred to as 'culture change', which was based on person-directed values and practices and which embraced person-directed values like choice and dignity (Pioneer Network 2023), emphasizing the correlation of quality of life, wellbeing, and the caregiving environment (Garre-Olmo et al. 2012; White-Chu et al. 2009). As a result, the role of the physical environment in supporting dementia care emerged as a critical aspect of quality of care (Barnes 2002; Chaudhury et al. 2018; Davis, S. et al. 2009; Imrie and Luck 2014; Kitwood 1997; The WHOQoLGroup 1998).

Influenced by this new perspective on dementia care in the mid-1990s, environment-gerontology designers and researchers pivoted to empirical studies to explain the human experience in relationship to the environment (Calkins 2018). Attempting to bridge the gaps of the mechanistic approach of earlier codes and standards by addressing emotional and behavioral outcomes related to quality of life for people living with dementia, therapeutic goals and objectives were identified and associated to environmental features, developing evidence-based design guidelines and frameworks as reference for designing dementia care environments (Calkins 2018; Chaudhury and Cooke 2014; Chaudhury et al. 2017; Chaudhury et al. 2018; Lawton, M. P. 2001; Lawton, M. Powell et al. 2000; Marquardt et al. 2014; Schwarz et al. 2004; Zeisel et al. 2003). Amongst the environmental attributes identified as influencing behavior and performance were: unit size and layout, residential versus institutional character, sensory stimulation (lighting levels, acoustics, thermal comfort), ambiance, and design of key amenities like dining spaces, resident rooms, bathing and toilet rooms, and outdoor areas (Chaudhury and Cooke 2014; Marquardt et al. 2014).

This refinement of approach to design guidelines has been a valuable contribution to the advancement of understanding the different factors that contribute to the environmental care experience of people living with dementia. More recent studies have widened their initial focus on behavioural and functioning outcomes to include emotional well-being and social interaction as critical contributors to the individual's quality of life (Chaudhury et al. 2018). These guidelines are often presented to the designer in abstracted formats like matrices or checklists, meant for easy visualization, consumption and implementation, as exemplified in the tables below.

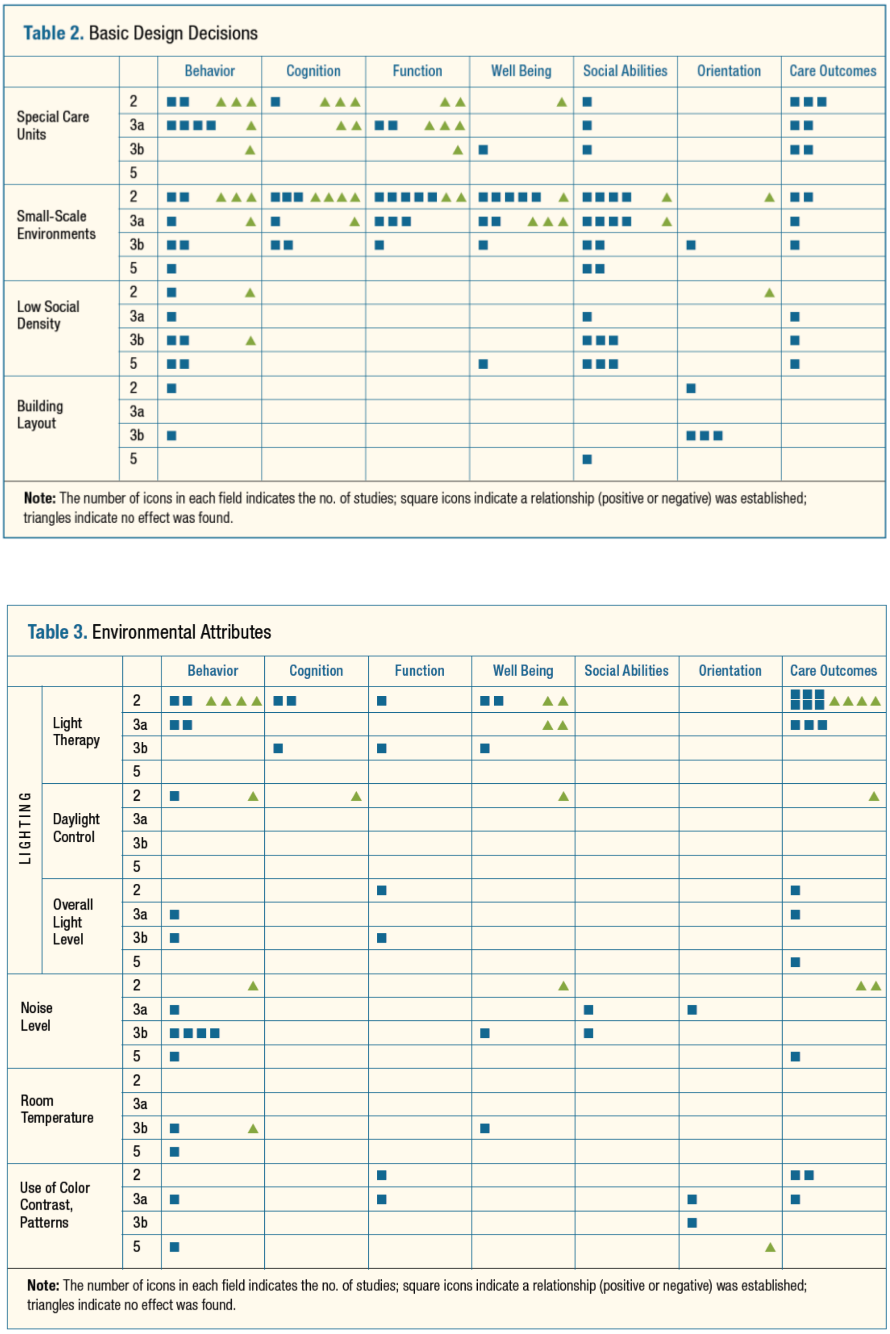


Table 2. Basic Design Decisions

		Behavior	Cognition	Function	Well Being	Social Abilities	Orientation	Care Outcomes
Special Care Units	2	■■ ▲▲▲	■ ▲▲▲	▲▲	▲	■		■■■
	3a	■■■■ ▲	▲▲	■■ ▲▲▲		■		■■
	3b	▲		▲	■	■		■■
	5							
Small-Scale Environments	2	■■ ▲▲▲	■■■ ▲▲▲▲	■■■■■ ▲▲	■■■■■ ▲	■■■■ ▲	▲	■■
	3a	■ ▲	■ ▲	■■■	■■ ▲▲▲	■■■■ ▲		■
	3b	■■	■■	■	■	■■	■	■
	5	■				■■		
Low Social Density	2	■ ▲					▲	
	3a	■				■		■
	3b	■■ ▲				■■■		■
	5	■■			■	■■■		■
Building Layout	2	■					■	
	3a							
	3b	■					■■■	
	5					■		

Note: The number of icons in each field indicates the no. of studies; square icons indicate a relationship (positive or negative) was established; triangles indicate no effect was found.

Table 3. Environmental Attributes

			Behavior	Cognition	Function	Well Being	Social Abilities	Orientation	Care Outcomes
LIGHTING	Light Therapy	2	■■ ▲▲▲▲	■■	■	■■ ▲▲			■■■■■■ ▲▲▲▲
		3a	■■			▲▲			■■■
		3b		■	■	■			
		5							
	Daylight Control	2	■ ▲	▲		▲			▲
		3a							
		3b							
		5							
	Overall Light Level	2			■				■
		3a	■						■
		3b	■		■				
		5							■
Noise Level		2	▲			▲			▲▲
		3a	■				■	■	
		3b	■■■■			■	■		
		5	■						■
Room Temperature		2							
		3a							
		3b	■ ▲			■			
		5	■						
Use of Color Contrast, Patterns		2			■				■■
		3a	■		■			■	■
		3b						■	
		5	■					▲	

Note: The number of icons in each field indicates the no. of studies; square icons indicate a relationship (positive or negative) was established; triangles indicate no effect was found.

Figure 4 - Therapeutic Goals Matrices. (Marquardt et al. 2014)

By translating research findings into design practice, the authors of these guidelines aim to expose the best available evidence in order to 'help architects and designers make the right design decisions on users' behalf' (Marquardt et al. 2014), providing architects credible evidence on which they can 'confidently base their design decisions′ (Pati 2011; Stichler 2010); with results aimed to ‘help designers and building services engineers to create optimal environmental conditions inside the living environments for people with dementia’ (van Hoof et al. 2010). And although these guidelines suggest that they should be critically appraised for their effective application (Stichler 2010), I argue that there is a risk of perpetuating the essentialization of the individual user of space. A risk of dismissing the ability of the person living with dementia to still communicate and convey preferences, of abstracting their embodied experience by proposing design guidelines and therapeutic goals that arguably generalize, categorize, and associate behavior, functioning and performance to environmental interventions, while disregarding the complexities of the individual experience - both past, present and future.

The compilation of environmental design evidence is useful, as are architectural design precedents. Nevertheless, absorbing this information and relying on it as a shortcut to base design decision on, without contextualizing and sensitizing the evidence to the particular situation can potentially render a typified conception of the body and user (Schön 1988), further estranging the designer from the intended user of space. There is a risk of bleaching out significant differences such as gender, disabilities resulting from the individual’s ageing and dementia process, identity and biography (Twigg 2012), ultimately producing generic architecture that is non-relatable. Architects are critical agents who help shape the experience of space and of care practices, thus highlighting the need to build on evidence-based knowledge guidelines, by seeking to evolve these design guidelines to design strategies that recognize embodied knowledge, personal identity, and the plurality of environmental experience (Imrie and Luck 2014; Jones 2014).

The Marketization of Care

The advancement of care delivery markets is part of a broader suite of changes in state–society relations, in which market-oriented policies have conceptualized users as consumers, and care as a commodity to be sold and bought, compelling care providers to compete for business (Brennan et al. 2012). Although Canadians have access to public healthcare services, the availability of these services is inconsistent. Inter-organizational coordination is inadequate and capacity for support services is limited, creating challenges in the delivery of care (Tam-Tham et al. 2016); the demand on staffing and funding is higher than what the public system can absorb (Ontario Long Term Care Association 2019). Different factors have converged in creating a competitive care market; the inability to meet care demand, the growing demographic pressures on inadequate infrastructure, increased pressures on public funding, and the demand to provide options, have all contributed to the commoditization of care, giving way to the creation and acceptance of 'for-profit' care delivery organizations. Each claiming to have the best quality of care services and options, these private care operators compete for a market segment by rationalizing cost of care and by closely monitoring operational expenses; adjudicating the care recipient with the novel role of customer (Greener 2008).

Consistent and reflective of a perceived social and demographic shift in the senior's population, with older people living longer, healthier, and more affluent lives (Twigg and Martin 2015), the aspiration of choice and agency of how ageing can be experienced is reaffirmed (Brennan et al. 2012). Consequently, caught in the midst of different objectives within a competitive market that is ever more demanding, the business of care architecture is reframed as an arena where these commercial motivations must be acknowledged (De Carlo 2005). This has a direct impact on the production of architecture, demanding innovative designs to entice the consumer, influencing the ways in which care is represented and 'sold' to the public by producing marketable environments that can help the care operator sell the attractive lifestyles they are proposing. Therefore, these care propositions are designed to echo residential lifestyles, selling the intangible domestic 'feel' of the care home through staged interiors, showcasing comfortable furnishings and attractive décor; elements that have also been associated with assuaging the guilt relatives often experience when bringing their loved one to the care home, and which have often been interpreted as a cue for quality care (Davies, S. and Nolan 2003). This consumerist model of care pressures the architect to reprioritize design strategies to meet the operator's expectations of designing an environment that will primarily appeal to surrogate decision makers, typically relatives of potential residents, rather than the individual who will be coming to live in the care home (Buse et al. 2017).

This consumerist approach to care design informs the dialogue between the architect and the operator. Hence, marketing objectives introduce a functional tension in the design process by expecting care environments to perform as a market commodity as well as somebody's home (Horst Rittel 1971). The operator, as the commissioning client, provides the lead in terms of resident expectations; type of services, assumed preferences, and routines. Their interpretation of what the target market demands often become the basis for design decisions (Sharrock and Anderson 1994) and design criteria. Critics argue this design approach conceptualizes the 'user' as a 'scenic feature' or conceptual element (Imrie 2003; Jones 2014).

It is a flawed design approach in which the envisioned orchestration of space takes precedent, often resulting in what some detractors identify as the unavoidable disconnect between designer intent and assumptions, and reported user experience (Heylighen et al. 2013; Imrie and Luck 2014). This gap highlights the need to understand the envisaging strategies architects use to establish the structure and order which enables them to develop design solutions (Sharrock and Anderson 1994).

Empathy and the Design Process

Designers are tasked with producing environments that have long-term permanency within a context of functional criteria and financial demands. With limited opportunity to test design solutions by trial and error, and relying on imagination, the architect is forced to creatively anticipate the experience and consequences of design decisions as best as possible (Horst Rittel 1971). The ideal of introducing the user's perspective, although often an imagined one, into the design solution is assumed to guarantee 'good' design (Heylighen et al. 2013). By relying on reflecting strategies like empathy and personal experience, the architect endeavors to be sensitized to user needs (Imrie 2004). This reflective dimension in the design process suggests that it is through the architect's personal and unique experiences that the empathic horizon is defined (Kouprie and Visser 2009).

Arguably, the designer's academic training, professional development, lived experiences, and personal interpretations (Mattelmäki et al. 2014) find their way to the design process the moment pencil meets paper. Drawing upon building precedents to propose new solutions (Sharrock and Anderson 1994) and on referential mental images of older relatives with their associated needs and preferences (Buse et al. 2017), designers develop conceptual ideas typically rooted in personal identification, empathy, and compassion (Pallasmaa 2005). Architecture is therefore produced within this empathic and self-referential context (Kouprie and Visser 2009; Malins and McDonagh 2008), suggesting that empathy and experience are strong sources of influence during the creative process, serving as a nexus between tangible design metrics and subjective user needs.

This empathic pursuit of relating to the identified user's needs, is a genuine effort to discover the anticipated 'happenings' and the experiential understanding of architectural space (Lees 2001). Nonetheless, for empathy to have an effective meaning in the produced environment, it needs to go beyond an emotional feeling to a shared understanding and sensitivity of the user's experience (Kouprie and Visser 2009; Malins and McDonagh 2008). Serving as a precedent that lends validity to the aims of this study, Kouprie et al. (2009) propose an empathic model for design practice, echoing an ethnographic approach in which the designer steps into the life of the user and after discovering, being immersed, and connected to their reality, is able to detach with a deeper understanding of their needs. Often, the architect performs this empathic dance; moving in and out of the imagined world that the envisioned user will inhabit. Regretfully, these empathic efforts frequently fall short, with design solutions often imposing personal values and aesthetics (Buse et al. 2017), producing environments built by 'experts' deciding what users need, thereby restricting the commonplace where things can happen organically (Barker, P. 1999).

During the design process, the architect internalizes design criteria and functional requirements, unconsciously sensing movement and scale through their body (Pallasmaa 2005). It is therefore argued that bodies create architecture for the use and interpretation of other bodies, establishing a symbiotic relationship between bodies and the built environment (Negus 1998). The design process can therefore be conceptualized as a self-imaging approach to imagined spaces that seeks to anticipate use, movement, and experience, drawing not only on personal experiences, but also using one's body as the central point of reference. Consequently, the designer's body - usually a healthy, average-sized, abled body – inevitably becomes the reference for design decisions (Hall, P. and Imrie 1999; Imrie 2003). Critics suggest that design implementations rarely conceive impairment or illness as design criteria when allocating space to functions (Imrie

2004; Jones 2014). This tendency to disregard the complexity of an illness such as dementia during the design process, where sterile environments devoid of disease are envisioned, arguably result in what some call the thaumaturgic ambition of modern architecture; an architecture that miraculously heals all disease in society by normatizing bodies and experiences (Lambert 2011).

How space is structured during design also impacts user experience. Organizing space solely based on associated functions – an area to sit, a space to sleep, a room to bathe – compromises the empathic design goals of bridging experience, time, and place (Buse et al. 2017; Imrie 2004; Prior 1988), contributing to the user's estrangement from the built environment by reducing the human body to an abstracted system of dimensions that ignores diversity, identity, and personhood (Hall, P. and Imrie 1999). Moreover, architecture becomes distant, a disconnected endeavor often likened to a machine-engaging process of normalising anatomical action and user (Imrie 2003; Lambert 2012), ultimately leading to the production of an imagined design world that is unrelatable and inequitable.

Architectural Documentation and Production

Another essential phase of the design process is the production of documents that will technically detail and specify the building project, coordinating all disciplines into one comprehensive set of construction documents. These documents heavily rely on Euclidian, two-dimensional space and geometry (Latour and Yaneva 2008), a collection of vectors and distances, demanding a level of technical precision that often leads the architect to depend on computer software for the efficient and accurate production of drawings, an approach which further distances the architect from the embodied experience of the user (Martin et al. 2020). This graphic representation of the environment is flat and static, unable to convey embodied practices, everyday affects, or materialities (Martin et al. 2020; Nettleton et al. 2018). They are unable to capture the embodied experience of space, movement or the dimension of time, dismissing the eventual transformation of the environment by its users (Latour and Yaneva 2008). Ignoring the sensory qualities of place (Degen et al. 2017) arguably contributes to the essentialization of the user experience and to the disconnect between design intent and eventual use (Ingold 2013; Nettleton et al. 2018). And although three-dimensional digital technologies are influencing architectural practice (NBS Research 2018), virtual realities remain enhanced graphic representations of space, still unable to capture the rich, multi-layered dimension of embodied experience.

Production of architecture has also evolved from pre-industrial societies, where the alteration of space and spatial experience was embodied into the production of vernacular architecture, given the conception, construction and use of the space was typically undertaken by the same individual, thus allowing the 'immaterial' experience of space to be incorporated into the environment (Heylighen and Strickfaden 2012). The embodied experiential learning derived from use was cycled into the next production of space, effectively integrating human action to the built form (Lees 2001). The ongoing pursuit of construction efficiencies, mass production, and cost control, has abruptly interrupted this direct post-occupancy feedback loop, resulting in a separation between the designer, the builder, and occupants of the space (Heylighen and Strickfaden 2012). As previously discussed, the care home was designed for a care operator who will not inhabit the environment. With limited input from the eventual occupants, the designer is disaffected from the embodied immateriality of user experience, contributing to the reductionist conception of users, generating misaligned assumptions of needs (Hall, P. and Imrie 1999); an estrangement which ultimately leads to favouring homogeneity over plurality (Bollnow 1961).

Representation and production of architecture often undermines the fact that architecture is neither static, nor a mere representation of areas; it is performative, encompassing ongoing social practices which persistently shape and define the environment being used (Lees 2001; Massey 1999). Buildings are dynamic, it is where human interaction takes place; they age and are transformed through use (Latour and Yaneva 2008; Massey 2001). Space is more than the receptacle of material objects, it is socially produced; it is an essential constituent of social life (Massey 1999; Massey 2001; Prior 1988). A building is never at rest and never in the form of Euclidian space (Latour and Yaneva 2008; Yaneva 2008). There is a dynamic and performative dimension of architecture which is not captured in drawings or renderings, like motion, preference, identity, sensation, or embodiment (Heylighen and Strickfaden 2012; Latour and Yaneva 2008); yet it remains the dominant approach to architectural representation. This gap in practice merits further understanding, as excluding the messiness of space hints at what is being repressed (Agrest 1988); the embodied experience of architecture. The static portrayal of space and the reductionist construct of the user is analogous to a Lego world, Figure 4, where the user is a two-dimensional character; where action, time, and experience are dismissed, presenting a colourful world that is disconnected from reality.

Figure 5 - Lego World. https://www.flickr.com

Conclusion

This chapter has provided context for the aims of this research work, highlighting knowledge gaps on how architectural design processes and architectural production affect the experience of space. It recapitulates how the literature review identified recurrent topics, gradually evolving the scope and depth of review to explore the relationship between embodiment and experience of space, between memory and dementia, and of how they relate to identity and personhood, showcasing the need for advancing knowledge on the production of a more inclusive, dynamic, and less prescriptive architecture. It established the relevance of architecture in the lived experience, highlighting its dynamic potential, and contextualized the different currents that influence design decisions: self-referentiality, market pressures, and body schema conceptions. It introduced the user of space as an active catalyst that helps shape the environment through time, advancing the stance that space is open, social, always in evolution and never truly completed (Massey 1999). It argued for the rediscovery of corporeality in architectural practice and of the embodied experience of space (Heylighen and Strickfaden 2012). We are embodied beings; we live and experience our world with our bodies (Merleau-Ponty, M. 1962), thus the argument of this thesis that the relationship between architecture and body must be restored (Heylighen et al. 2013), making it critical for architects to acknowledge that they are designing for different types of bodies, of identities, and of conditions such as dementia. Failing to embrace and methodically insert the user as an active shaper of designed environments risks reproducing staged scenarios with the user considered as a scenic prop (Jones 2014), disempowering and stripping them from the richness in identity that heterogeneity ensues.

Chapter III

PLAN OF INQUIRY

Introduction

This chapter provides insights into the methodological rigor that was followed to enhance trustworthiness of findings and on the critical judgements that were undertaken, disclosing the different assumptions and stances that informed the adopted research plan (Rudestam and Newton 2015). Different research design theory approaches were explored to determine the most appropriate strategy for the proposed aims; the research onion (Melnikovas 2018), research outlines, and paradigm diagrams (Guba 1990; Prendergast 2004). Based on the four domains of issues and assumptions engaged in methodological development (Greene 2006) - philosophical stances, the inquiry logics, the guidelines for practice, and the values which influenced this study - the structure of this chapter reflects the sequence of reflections and decisions that informed the adopted methodology.

Research Philosophy

This research aimed to better understand the human experience of living with dementia in a very specific social environment; a secured, dementia care floor within a full continuum of care residence in Canada. It also sought to interpret the singular realities of the different individuals that comprise this social world and how their interactions and experiences within this physical environment influenced their lived experience. Furthermore, the undertaken literature review revealed relevant topics like embodiment, place-making, the co-construction of the care experience, and how those associated with the production of architecture influence this experience. As such, it became evident that what was being researched would be subjective, closely linked to individual interpretations of experience. And given the focus on human experience - their social constructions, and their individual truths - meanings and intentions of their actions and interactions had to be interpreted (Trivedi 2020).

Recognising that different vantage points produce different renditions of what is being observed, it is essential to assert the held ontological and epistemological assumptions about reality and the ways in which knowledge was obtained, analysed and used, to contextualize the adopted research design (Greene 2006).

Firmly believing that the world is socially constructed (Alexander et al. 2008), and that perceptions and actions of social actors create social phenomena (Dudovskiy 2022), this research adopted a subjective ontology. Furthermore, acknowledging that the knowledge being sought would be relative to the interpreted meaning and understanding of the interactions and experiences of all involved in this research (MacIntosh and O'Gorman 2015), an interpretive epistemology was embraced.

Situating Architecture and Experience

Departing from the architectural modern movement notion of the messianic role of architecture of imparting salvific social messages, the philosophical values of this study support the stance that the experience of architecture is informed by its sensuous quality, geometrical form, functional purpose, symbolic connotation and historical context; and that such experience is conditioned by multifaceted embodied dimensions of the space as well as of the user of that space (Haldane 1999). The content of architectural experience is therefore conceptualized as a combination of the cognitive, emotive, and sensual qualities of space, framed by the individual's social, cultural and psychological embodied dimensions (Fisher 2016). This experience goes beyond the physical elements that compose the environment, as the way we experience and judge architecture is a complex multi-sensorial fusion of countless factors. One must move around or within space to perceive and experience it, provoking an immersive relationship between user and architecture.

This experience is not only immersive but holistic. As Merleau-Ponty suggests, we perceive our surroundings in a total way, with our entire body, speaking to all of our senses at once (Merleau-Ponty, Maurice 1964). The experience of architectural space is therefore dynamic, as an immediate judgement of the character of space demands our entire embodied knowledge and existential sense. It also includes the dimension of time, as experience implies duration, where perception, memory, and imagination are fused (Pallasmaa 2014). This adopted stance is supportive of Heidegger's (2006) position that space is not something that faces man, but instead that as we enter space, space enters us; an exchange and fusion of subject and object.

We perceive atmospheres through our emotional sensibility, becoming attached to certain settings and alienated in others (Pallasmaa 2014). Architecture has the potential to move us and affect us by shaping our actual, imagined or embodied knowledge, while concurrently being the basis that informs our environmental experience (Robinson, J. 2012). This belief leads me to embrace the stance of architecture as a domain of embodied meanings and values (Haldane 1999), a congruent stance with the theoretical framework of embodiment. The embraced position of place is therefore associated with embodiment, where there is a fusion of place and self, proposing the self as much of a container of place, as place is a container of self. The environmental experience is thus understood as an exchange of the material properties of space and the abstract and immaterial realms of human perception and imagination (Harrison 2008).

Furthermore, as discussed in Chapter II, the production of architectural knowledge is posited as socially constructed, given design problems and their possible solutions rely on negotiated processes involving different stakeholders and influenced by social relations (Fisher 2016). And while some critics have referred to architecture as a social art form, I believe that architecture also expresses abstract ideas (for example visions of care), aiming not only for aesthetic beauty, but also utility. Kant (1987) refers to it as 'objective purposiveness', suggesting that suitability to intended use and users is essential to the success of architecture (Guyer 2011).

Research Strategy

The philosophical paradigm adopted reflected the intended focus of inquiry; human beings in social situations. The adopted stance of a social world where meaning and knowledge are socially constructed by individuals as they interact and engage, where interactions and language evoke meaning of how they make sense of their world, with descriptions of their lived experience being shared in their own words, and where subjectivity and different perspectives were acknowledged as integral components of this study, suggested a qualitative research approach (Robson 2011). Acknowledging that to produce 'thick description' (Geertz 1973a) and to truly understand the experience of the person living with dementia from their perspective would be to be immersed, observe, and participate in their particular setting (Davidson, Julia O'Connell and Layder 1994; Robson 2011), an ethnographic research approach was adopted.

Ethnography

While the biomedical model of dementia has provided understanding on the pathology of dementia, it has proven limited in providing existential understanding of how people are affected by dementia in their everyday life (McCrae and Banerjee 2011). This research sought to go beyond this biomedical stance by seeking to advance knowledge on how individuals living with dementia experience and make sense of their environment (Robson 2011). It aimed to better understand their social reality by sharing their world and participating in their everyday life, focusing on enhancing awareness and emotional understanding of their embodied experience (Charlotte 2008) within the context of the dementia care setting.

Goffman posits that groups of people develop their own way of life which is charged with meaning, and a good way to learn about their worlds is to submit oneself in their company to their daily life (Goffman 1961). Consequently, ethnography was identified as a method of knowledge production congruent with the aims of studying the everyday practices and use of space by the different user groups within the dementia care floor, and was adopted as a research strategy to explore the co-production of the care environment from both a social and architectural perspective (Lees 2001; Parker 2007). Considered the foundation for social science research (Morse 2016), it provided an approach to understanding the social meanings and activities of this group of people (Löwstedt 2015) and a means to uncovering the shared cultural meanings of their actions and behaviours (Robson 2011). It positioned research as a social process, where social encounters were mined as data, and the voices of different participants helped disclose the 'inside story' of their world (Charlotte 2008). It provided a means of getting close to the reality of the social phenomena in a way that is not possible through other experimental strategies (Robson 2011). It offered a method to understand and make sense of others' experiences providing an approach for entering different social spaces (Kleinman 1999).

Ethnography proved to be a compatible approach, where being close to the natural environment of people living with dementia provided a glimpse to their world by disclosing the narrative of their particular reality (Robson 2011). Nevertheless, critics of ethnographic research have argued it lacks the elements of what is considered ‘quality’ research: validity, reliability, ethical practice, and credibility (Matthews and Ross 2010). They argue that close exposure to the people and setting being researched can lead to results being skewed by personal prejudice, or that data is often manipulated to ensure findings coherence. Such detractors posit that narrative analysis becomes too much like storytelling (Gray 2014).

Ethnography is above all a ‘method of discovery’ (Fielding 2008) and as such, it is difficult to identify a direct way of validating claims given the inescapability of infusing personal experience to the road of discovery. However, understanding is derived from experience, and without reflective interpretations of that which has been observed and lived, ethnographic descriptions would yield hollow accounts devoid of meaning (Fielding 2008). Therefore, in order to provide credible renditions of experience and to enhance validity of the ethnographic approach, words and expressions of participants were used extensively in the development of a systematic understanding of data (Douglas 1976). Hence, supporting the argument that knowledge of social behaviour cannot be grasped unless the ‘symbolic’ world of the individuals involved in the care experience is understood (Fielding 2008), data collection tools were designed to prompt participants to express the meaning of their experience in their own words, while developing understanding through observation. The various data collection tools rendered different perspectives of the same reality, allowing the inference of meaning from social relationships, personal narratives, and observation, thus lending credibility to this research and mitigating potential research gaps associated with ethnography.

Inquiry Logics

Establishing a proper sample group was critical to the validity of this research and in justifying the applicability of findings to a wider context (Sturgis 2008). Adhering to the traditional emphasis of ethnography on depth and richness of context (Fielding 2008), the sample size favoured a small size, thus allowing an in-depth understanding of ‘the particular’ and the situatedness of the participant’s social experience, ensuing a deeper and more intimate understanding of their situation (Mason 2006). This research focused on a very specific population, the contained memory care floor of the care residence. From this population, the sample consisted of three different participant groups: twenty-two residents living with early to moderate stage dementia, management and staff, and family members. Twenty residents consented to participate in this research. Memory care staff – all thirteen of them - and the residence manager and memory care coordinator also consented to participate. In addition, five family members were interviewed, with two of them having more in-depth participation given their availability and their expressed desire to contribute in a more meaningful capacity. Each participant group contributed rich data for analysis, providing a multi-dimensional understanding of the user experience within the memory care floor.

The Setting

The host organization, which shall remain anonymous, is a leader in the private-pay retirement sector in Canada. Providing a continuum of care based on assessed levels of care needs - independent living, assisted living, or dementia care - it currently owns and operates over thirty care homes in three different provinces: British Columbia, Alberta, and Ontario. Located in the province of Ontario, the specific residence hosting fieldwork was proposed by the organization because it was recently built, thus incorporating up-to-date technology, operational and marketing preferences, building systems, and design preferences. Given research took place in the secured dementia care floor of the care residence, the organization suggested it was representative of their most current approach to dementia care. And having been recently inaugurated, management and staff were highly motivated to contribute to this research, willing to dedicate time to discuss challenges and opportunities.

Nestled within a small community comprising of about 35,000 people, conveniently accessible by car, and accessible to amenities such as a park and the town’s main street, the residence is in an affluent community, with over 44% of households reporting an annual income above $100,000. With 63% of residents over the age of 50 years (Statistics Canada 2022), out of which 52% are female, and a very high proportion of residents (64.5%) with third level of education. It is a ‘traditional’ community where over 60% of households reported to be married or common-law spouses. With a homogeneous ethnic makeup (only 6.1% of residents identifying as a visible minority), most of its population is white, with the top five ethnic backgrounds being English, Canadian, Scottish, Irish and German (City of Hamilton 2016).

The context of where this care residence is located is critical in understanding the makeup of the residents, given that most of them came from less than a ten-kilometer radius. As such, the demographics of the memory care floor reflected the immediate community. Most residents were white, average age was 87 years, there were more women than men, with a financial status that allowed them to opt for private pay care versus a government-funded care institution. There were no visible minority residents on the memory care floor, and all of them were either still married or widowers from a presumed heterosexual relationship.

The homogeneous composition of this social world directly influenced how the physical environment was designed. The psychographics of the market segment this care residence was addressing provided cues around statistically relevant preferences and as such, informed interior design principles applied to the setting. The overall feel of the care residence was one of discreet elegance and comfort, with soft colour palettes appealing to the general audience.

Figure 6- Care Residence Common Areas

The memory care neighbourhood, considered the main field of observation, was a contained floor. The exit doors of the floor had specific access control measures, ranging from numeric keypads in which a constantly changing code must be entered, or doors on magnetic locking devices which were permanently closed designed to only open in case of a fire alarm. Exit doors were equipped with roam alert hardware which signaled staff if a resident had exited the floor. The elevator cabins that reach this floor could only be operated with a FOB (frequency operated button), provided only to staff and visitors who had registered at Concierge.

Figure 7 - Access Control Hardware

The secured floor had twenty-two residential suites, six of them were one-bedroom suites; the rest were studios. The suites varied in size (ranging from 580 ft2 to 318 ft2), each with a private bathroom. The provision of memory care was influenced by a hospitality aesthetic; the floor had different amenities including a dining area, a television lounge, an open dining servery, an area for hobbies, and quiet lounges for visiting. The floor was staffed around the clock with personal support workers and trained caregivers, led by a registered nurse. Unlike residents, care staff was more diverse. There were visible minority ethnic workers in the front-line caregivers, with most of the staff being female, and only a couple of male attendants. Management on the other hand, were predominantly white. Over a period of 11 months, this was the setting for the fieldwork, where I visited on a weekly basis, during different times of day and on different days of the week, with each session lasting anywhere from four to eight hours.

Consent Process and Sampling Strategy

The theoretical and ethical frameworks for this research, in which personhood, embodiment, valued identity, and person-centredness were identified as central, also informed the adopted consent approach. Based on Dewing's (2007) Process

Consent Method, and acknowledging appropriate consent can only be achieved through ongoing relationships, the consent process lasted throughout the research (Parker 2007). Designed as an integral element of fieldwork, where the person living with dementia was enabled to participate in meaningful ways according to their individual abilities, facilitated relationship-centred encounters with all participants (Dewing 2008). Most importantly, consent did not specifically depend on cognitive competence, but instead relied on empathy, respect, and in-depth knowledge of the person with dementia; relying on background preparation to gain biographical information of the participant to better explain the process.

In collaboration with management, the Memory Care Coordinator was deemed to have the clinical and ethical background to support, advise and provide insight on everyday routines, staff availability, and resident disposition, advising me on the best times to approach participants to obtain consent, becoming my liaison during fieldwork. Directly recruiting individuals with mild to moderate dementia to participate in this study recognized their lived experiences and right to express their preferences, fulfilling one of ethnography's key roles of creating a more equitable field by bringing to the fore their voice (Murphy and Dingwall 2007). Embracing inclusionary ethics that valued all stakeholders and anticipating that participants would have different abilities to communicate, consent was personalized to individual capacities, resulting in a more dementia-friendly approach to consent (Dewing 2008), sensitive to the fact that disposition in participants was situational, and that communication could be supported through a caring relationship approach (Dewing 2007). This consent strategy complied with the *Policy Preventing Discrimination Based on Mental Health Disabilities and Addictions* (Policy on preventing discrimination based on mental health disabilities and addictions 2014), part of the Ontario Human Rights Code which governs all matters related to mental capacity, recognizing the inherent worth and dignity of each person, regardless of their psychosocial condition.

The consent process assumed close collaboration with staff and caregivers to establish a baseline for capacity and behaviors for each resident, ensuring the participant could understand and agree, as best as possible, to be part of this study, providing them the opportunity to decline participation at any stage of the study. Where necessary, their power of attorney was also contacted to gain consent for both open field observation and interviews. Aims of the study were frequently discussed, repeating the consent approach at each encounter, thus maximizing opportunities for participation (Goodman et al. 2011). Above all, residents' emotional well-being was ensured through a reflective, self-critical, and attentive attitude demonstrating a 'moral sensitivity' which guided each interaction (Heggestad et al. 2012).

The Challenges of Consent

The adopted consent process celebrated inclusion by encouraging full participation of all individuals, demonstrating respect for dignity, autonomy, and self-determination (Policy on preventing discrimination based on mental health disabilities and addictions 2014). Nonetheless, once fieldwork began, it became evident that the commitment to include the person with dementia's direct input had sorely underestimated the inherent difficulties of communicating with a person with cognitive impairment or how challenging obtaining informed consent would be. Locating and getting response back from the different power of attorneys was taxing and took longer than expected due to slow responses to requests for consent, or the desire to have in-depth discussions about the study before consenting. While most people who were contacted provided consent, others categorically denied it, indicating that they were not willing to have their parents be observed or interviewed, reflecting a desire to shelter their loved one from being ridiculed or exposed; a concern that, despite listing the different measures implemented to ensure an ethical and empathetic approach, did not quell. Fearing that their parents were already exposed to enough scrutiny under their current care provision, or sensing their parents were no longer coherent and would be exposed to mockery, were some of the recurring explanations for denying consent. This position was consistent with findings from other studies where family members avoid potential stigma to their loved ones - or by association, stigma to themselves - by managing information and exercising social control, thus pre-empting any interaction that may result in potential embarrassment (Nolan et al. 2006). Therefore, while the field of observation often included individuals who had not consented to participate, no data associated with these individuals was collected.

Once consent from proxies from their power of attorney or their immediate family had been received, I followed the process consent methodology by seeking consent from the resident. This phase of informed consent required a thorough background preparation in collaboration with staff, learning how to identify the individual’s indicators of potential emotional stress or discomfort, gauging the resident’s capacity and ability to communicate, tailoring my approach to communication accordingly. This prompted a sensitive and heightened awareness of both verbal and non-verbal cues, where interaction, mood and disposition of the resident became equally important to infer communication. This process was time-consuming, yet it helped me develop a reflective, self-critical, and attentive attitude to every interaction. Intimate knowledge of these individuals allowed me to deftly accommodate their shifts in mood, capacity, engagement, and availability prompting me to improvise and react accordingly. For example, I had to constantly adapt to residents’ moods which varied from day to day and often impeded scheduled meetings. I had to follow their lead, as an interview would begin in the privacy of their suite, but if the resident decided to get up and start wondering the corridors, I would shadow them and gauge whether we could continue our conversation or leave it for another time. Despite background preparation my ability to understand and make sense of their efforts to communicate was at times difficult, requiring me to devote ample time for every interaction. Similarly, I also had to adapt to staff availability, which was often linked to their workload. If a resident demanded immediate attention or if the care floor was understaffed during our planned session, I had to reschedule our meeting. Overall, ongoing and informed consent demanded time and flexibility to achieve.

The Voice of the Resident Living with Dementia

All too often, the focus on people living with dementia is around statistical projections, with different fields of investigation commonly excluding them from actively participating in research (Dewing 2002), effectively ignoring their potential of expression (Örulv 2010). The dominant culture of dementia care situates the person with dementia as unable to express themselves, either verbally or through their actions, leading to a disempowered position, where the individual’s awareness and ability to process information is seldom recognized. Consequently, studies have favoured proxy points of view, deeming the individual living with dementia unable to act as an agent, or to meaningfully contribute to a discourse due to cognitive decline or memory issues (Dewing and Pritchard 2004). Likewise, research ethic committees have often focused on the responsibilities of the researcher and the proxy, undermining any meaningful role the person living with dementia may have in the process (Dewing 2002), often concerned that the risks to the participant may outweigh the benefits (Dewing 2007). In addition, carers' needs have gained prominence in the past few years, frequently relegating the person with dementia as someone or something that is cared for (Dewing and Pritchard 2004).

It is not until recently that a movement towards greater user involvement and perspective has been advocated (Bowling et al. 2015; Cantley 2007). Evidence indicates people living with mild to moderate dementia can self-report on subjective issues without relying on proxy accounts (Bowling et al. 2015), effectively acknowledging they have a voice (Heylighen 2013), as well as the ability to retain reflexivity despite their condition (Graham and Bassett 2006). Likewise, a person-centred approach to care advocates for participation of persons with dementia in research (Dewing 2002). Consequently, this study acknowledged the person living with dementia as an active contributor and considered their subjective accounts and perceived experiences of the environment as vital (Cantley 2007). It valued the importance of evaluating their embodied experience of the environment through their direct feedback, successfully bringing to the fore their voice, which is often silent or silenced, recognizing them as experts on their spatial experience.

The organization's policy provides different eligibility criteria that must be satisfied when considering a person for residency on the memory care floor, with the Memory Care Coordinator having to confirm that the services and programs offered on this floor will benefit the individual. This process provides the Coordinator with insightful knowledge of residents. Therefore, leaning on her personal knowledge of them, and her close rapport with their families, I worked closely with her in determining which residents would be best suited to actively participate in the study through interviews or walkabouts, who could bear the process, and who would not be burdened during interviews (Bowling et al. 2015). Thus, the sampling criteria for resident participation was purposive and representative of the group being studied (Øvretveit 1998; Robson 2011): residents with mild to moderate dementia, living in a specialized, for-profit, contained, dementia care setting.

Their insights were facilitated by using different data collection tools, observing how they used space and by also documenting their perspective through interviews and walkabouts, prompting them to express their opinions and preferences which provided different nodes of information and a comprehensive insight of their lived experience (Morse 2016). Through these person-centred interactions, it became apparent that the more in-depth knowledge of a resident - their biographical information, their severity of dementia, their particular way of communicating, their individual capacity to comprehend, their emotional triggers, their preferences and habits, and their personal desire to interact with me - resulted in a more positive experience for them. Within this context, rather than randomly interviewing residents, and relying on the Coordinator's insights, I decided to work closely with three residents, adopting a purposeful sampling approach that has been used in similar qualitative studies as a means to collect rich data (Palinkas et al. 2015). Through this collaboration, and a shared ethical approach to sampling, selfhood of the participants was safeguarded, proactively addressing any barriers to seek process consent (Cubit 2010). These three residents were interviewed on different occasions, using different data collection methods, as documented in Chapter IV. The interviews took place on different days and times of day, respecting daily routines and being sensitive to the everyday life of the dementia care floor. All other residents who had consented to participate were part of the observation field, providing a rich description of their social world.

To maintain some consistency in the topics that were discussed, an interview guideline was used to initiate the interviews (Appendix D). One participant was interviewed in the dining area, followed by a sit-down interview in her suite, as well as a 'walk along' interview through the memory care floor. The second resident was interviewed twice as a sit-down interview in her suite, in addition to a 'walk along' interview that followed her daily path of wondering. The third resident was interviewed at length during a sit-down interview in her suite. As I got to know these residents better, the connection that emerged led to a more fluid interaction with them, with interviews feeling more like conversations, and observation sessions turning into social encounters and visits.

Through time, our interaction became less stressful and less intimidating, allowing me to establish a deep personal connection that facilitated communication and ensured an empathetic, ongoing consent process, a tactic which ultimately provided robust data. It helped me engage and build a caring relationship with these participants, while nurturing their personhood by acknowledging them as experts of their own experience, by endeavoring to discover their preferences, by valuing their past biographies and their input. This resulted in unforgettable moments of connection where a genuine closeness was achieved, allowing me to 'be with' the individual (Dewing 2002). It enhanced my awareness and emotional understanding of the embodied experience of people living with dementia; their struggles with confinement, their perduring emotional needs, and the different coping and adaptation mechanisms they resort to make sense of their new relational and environmental reality. This connection was mutual, as I could sense how much these residents valued the personal attention, the time spent with them, and having someone listen to their stories. The opportunity to be immersed in their world, to understand first-hand how some design decisions resulted in spatial challenges was invaluable.

Management and Staff

As fieldwork was undertaken, the bias to focus on the residents' experiences dissipated, given the relational aspect of the environment and the influential role staff play on the use of space. As discussed in Chapter II, and congruent with similar studies, the reciprocal dependence between care giver and recipient, and the involvement of staff in this relationship, became evident (Fine, M. and Glendinning 2005; Milligan 2005). Therefore, the lens of observation widened to also include staff, learning about their routines, informally chatting with them, thus gaining a more holistic understanding of their milieu.

Having closely collaborated with the Coordinator on the logistics of sampling, and consent helped establish a positive rapport with her. This relationship proved instrumental in recruiting staff participants, as the trust that had been developed with their leader permeated to front-line staff, facilitating obtaining their consent. An information session to explain the aims of the study and the proposed research plan was scheduled during the change of shifts, thus allowing for eleven out of the thirteen staff members to attend. Encouraged to ask questions, they expressed concerns about the amount of time their participation would demand along with concerns of being observed as part of a performance audit, fearing comments would escalate to their supervisor. A viable explanation for these concerns could be their knowledge of my association at the time with the host organization, and the inherent ambiguity of my identity, given I introduced myself as a research student. This perspective would be consistent with findings of studies from academics that research 'lived realities' of their own organizations, where organizational politics become evident and participants expressed fear of potential breaches of trust (Alvesson 2009), and where implicit moral tensions and ethical ambiguities had to be dissipated before authentic encounters happened (Down et al. 2006).

Their concerns were addressed by assuring them the study would be pseudonymised, by reviewing privacy protocols, by stressing that they were at liberty to decline participation at any time, and by explaining how valuable their perspectives were. This last argument seemed to resonate with them, as once the interviews took place, it was evident they had much to say about what was not working for them, yet they often preferred to remain safely silent. This was congruent with research in organizational settings, where staff sense defensive routines and powerful norms that discourage employees from sharing their perspectives, and where willingness to voice concerns or suggestions depend on how approachable and responsive their manager is perceived to be (Milliken et al. 2003). Therefore, being invited to participate in this study was received as an opportunity to express their own views and experiences of how the designed space enabled or challenged their daily routines. During the 90-minute session information sheets were handed out (Appendix B), as well as the ethical participation consent form (Appendix C), making myself available for any further questions. The following week, all thirteen front-line staff members consented to participate in the research.

However, earning their trust demanded careful actions and attitudes, where all armour, both professional and academic, had to drop, conveying accessibility, and demonstrating a genuine interest in their views. This process took some time and was aided by my gradual immersion in the field through the initial observation sessions. Part of dissipating any potential concerns or distrust involved mindful strategies to drop any defensiveness (Down et al. 2006), such as adopting a submissive attitude to protocols, informal policies; even influencing how I dressed and spoke. I relegated my usual business attire for a casual look, ensuring I expressed myself amicably. I adopted some shared routines, like having coffee together in the morning, enabling a gradual emotional engagement with staff.

Being able to observe staff as a group, connecting with them during my observation sessions, and being able to have informal chats rendered valuable data. Individually, two staff members were interviewed at length and on multiple occasions, conversing with them while I shadowed their routines. These two participants were selected due to their observed passion for care and their genuine desire to do what was best for the residents. Both were eager to share their challenges, their ideas, and frustrations regarding their daily routines. One of them was a natural leader, while the other one had a very quiet demeanor, yet both were equally committed to the wellbeing of residents. To provide a well-rounded context of this group's user experience, the Memory Care Coordinator and General Manager were also interviewed in depth on different occasions. This strategy provided both the perspectives of front-line caregivers who perform the daily care routines, and of the managers charged to ensure the successful operation of the residence, generating data of the same environment yet approached from a different angle, thus providing the opportunity for convergence of information (Morgan and Stewart 2002).

Family Members

Dementia is a condition that affects not only the individual living with it, but also their loved ones, as unexpected changes in behaviour and the relentless cognitive deterioration can be extremely stressful to manage (Tirado et al. 2009; Tremont 2011). Including the perspective of family members in the research provided a biographical context to the residents, serving as a link to their past biographies (Robinson, L. et al. 2005), allowing a better understanding of the individual by looking beyond their current condition (Kellet et al. 2010). Their contributions to this study also rendered a more comprehensive understanding of how dementia affects family life and the concept of home.

While all the resident's family members were invited to participate in this study, only five family members responded, consenting to participate. This was not surprising, as the Coordinator had already shared that some family members rarely visited their loved ones, and that for the most part, her interaction with them was via conference calls. Those who had agreed to be part of the study were all frequent visitors to the dementia care floor, thus allowing me to observe their interactions and chat with them. From this group of participants, two stories shared by spouses whose wives were living in the memory care floor, were used to develop more in-depth vignettes. One spouse lived in the care home although on a different floor, while the other spouse was still living at his home nearby.

Both these participants were interested in the study and eager to contribute, hoping their particular experience would prompt changes to improve the experience of not only their spouses, but of future residents. Having established a connection with them, I was allowed a glimpse of their own internal challenges in dealing with a loved one who has dementia. Their perspective proved to be insightful and helped bring to life Kitwood's construct of relational context. It demonstrated how the person living with dementia's personhood and identity were reaffirmed, albeit their cognitive condition, by recognizing their individuality, their past life, their interconnectedness and interdependence to their loved ones (Kitwood 1997). While a topic guideline was drafted for consistency and to facilitate the start of our interviews (Appendix A), arguably, the most insightful data came from allowing the semi-structured interview to feel more like a visit or like a friendly conversation. Being able to listen to their specific challenges and having them share their own emotional journey around their loved one's experience with dementia shed light to the importance of people existing affectively in relational contexts within the built environment.

Ethical Considerations and Guidelines for Practice

Social research strives to understand human behavior and experience hence requiring researching social settings, processes and personal experiences (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada 2014). Nevertheless, any research involving people is bound to face ethical dilemmas and challenges (Robson 2011), especially given the added complexity of doing research with a vulnerable group, such as older adults living with dementia. New legislation on data protection and privacy, legislative changes regarding human rights, and growing public awareness and debate on the limits of research inquiry, has resulted in a heightened concern for ethical accountability (SRA Ethical Guidelines Working Group 2003). Consequently, ethical accountability and a solid ethical framework were used to ensure research was undertaken in a morally defensible manner (Gray 2014), guiding all interactions with a principled sensitivity and respect to the rights, human dignity, and integrity of participants (Bulmer 2008).

Through the literature review, different standards and guidelines applicable to very specific domains were assessed; these were often inconsistent and contradictory in approach, yet were useful in identifying potential ethical issues affecting the individual with dementia, their social network, and their caregivers (Nuffield Council on Bioethics 2009). Once identified, these issues informed the ethical framework, see Table 2. Based on the six main components of the Nuffield Council on Bioethics ethical framework, which specifically addresses dementia-related ethical issues (Nuffield Council on Bioethics 2009), it was used as reference for the everyday application of ethics, associating ethical values to personal judgements and beliefs, while underscoring their applicability to fieldwork.

ETHICAL VALUE	JUDGEMENT and BELIEF	FIELDWORK APPLICATION
Case-based approach to ethical decisions	Situational, context-specific issues	Facts were identified, interpreting, and applying ethical values according to similar contexts and situations. Action was determined in consultation with management and appropriate internal parties.
Nature of dementia	Dementia is a form of disability; personhood should be supported	Communication and interaction acknowledged the person living with dementia as an equal individual with rights and autonomy to express preferences, with special accommodations provided to enable participation and interaction.
Quality of life with dementia	Appropriate care and support will enable the person with dementia to live well	Engaging people with dementia in data collection affirmed their ability to communicate preferences, arguably contributing to their self-worth and well-being. All participants were equally valued.
Promotion of autonomy and well-being	Independence and freedom should be promoted and respected	Resident participation was encouraged, applying the same moral values to all participants, regardless of their cognitive ability. Ongoing consent process ensured participants did not feel coerced to remain part of the study. Fieldwork was undertaken with sincere awareness to any signs of distress, recognizing emotional responses as a way of expressing self-determination.
Requirement to act in accordance with solidarity	We are all equal, regardless of disabilities	A dutiful commitment to support the individual living with dementia was undertaken, adapting data collection methods and communication to their needs. Continuous engagement with staff and family arguably contributed knowledge to the dementia discourse, helping de-stigmatize dementia by demonstrating effective ways to communicate and engage with people living with dementia.
Recognizing personhood, identity, and value	The identity of the person with dementia remains intact	Having adopted the stance early in the study that cognitive decline does not reduce the value or status of the individual, all interactions with all participants were equally respectful and sensitive. Through collaborations and discussions, fieldwork arguably raised awareness within the residence that the individual remains the same throughout their journey with dementia, with their identity and personhood remaining intact.

Table 2 - Ethical Framework

This framework was developed as a guiding foundation for the research design, and as a way to integrate ethics into ethnography, recognising the inherent potential ethical challenges emanating from the depth, detail and sensitive information that this research sought to uncover (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada 2014). The possibility of potentially uncovering concerns that would need further escalation was also discussed with management from the outset, agreeing to adhere to the incident report protocol of their code of conduct policy. This provided a roadmap to share any concerns surfacing from fieldwork, with clear guidelines of what issues had to be reported.

This framework was a starting point, as the different situations that arose during fieldwork could not have been fully anticipated. As described in Chapter VIII, there were times where I was unsure of how to proceed. For example, the internal dilemma I experienced when residents on the memory care floor continually asked me why they were there, when they would be going home, asking for my assistance to leave the contained floor, or when deception was used to calm an agitated resident. These situations spoke to the complexity of the social world I had entered, and confirmed that ethical dilemmas are constituted by everyday interactions and situations, where ethics is itself enacted in practices which go beyond a written framework (Parker 2007). Mostly, I enacted ethics as an object of concern, problematizing everyday encounters as a subject of deliberation that demanded reflexivity, critical judgement and awareness of the implications of my conduct and actions within the backdrop of my stated values and beliefs (Kleinman 1997; Kleinman 1999); seeking advice from the Coordinator, sharing concerns, and consulting with staff to ensure my actions were ethico-moral.

Me, the Partial Insider

As previously disclosed and discussed, this research work was conducted in a care residence owned and operated by the organization I worked for at the time, placing me in the unique dual role within the host organization of in-house architect and researcher. Analogous to a cultural explorer, ethnography purports an informative status in which, after being immersed in the field, one can 'bring back the news' of what it is like to 'live with and live like' someone else (Van Maanen 2011). My immersion in a dementia neighbourhood provided me with valuable insights on design strategies relating to the user experience. This exposure allowed the opportunity to share insights from the field with my colleagues, lobbying for a different conceptualization of the care environment, with discussions often leading to novel spatial solutions. Nonetheless, the objective of this research was never envisioned to be an audit of practice; its aim was always to gain further understanding of how the person with dementia, living in one of the organization's care home environments for memory care, experienced space. Acknowledging that questions of objectivity, reflexivity and authenticity of this work could potentially be raised due to the proximity (Kanuha 2000) of doing research within my former workplace, existing literature suggests there is no overwhelming advantages to being an insider or outsider researcher (Heslop, Burns et al. 2018), and that assumptions about insider positionality are mostly theoretical, supported by scarce empirical evidence (Chavez 2008). Therefore, to evaluate the degree of the potential effect of this lens on this work, and to better understand the ethical implications of this duality, it is necessary to provide clarity around my day-to-day relationship and interaction with the setting.

As the former in-house architect for the organization, I was tasked with providing direction and oversight on all aspects of the design of their care home residences. For each project, a specific external design team was assembled. This team consisted of an architect-of-record for the residence, and a team of miscellaneous consultants. As an owner's representative, it was my duty to ensure the organization's functional, operational, and aesthetic requirements were incorporated and implemented. Providing design input and feedback to the external project architect, my role during the design and construction process of the different care homes was strictly one of an advisor to the team; acting as liaison between the external design team and the organization's senior management. Once design and construction of the residence was completed, I was part of a group of subject-matter experts that helped operationalize the residence before residents moved in. I worked out of the Support Office, which had its own organizational hierarchy with no connected or dotted reporting lines to the care home management team. Consequently, once the project was handed over to operations, I phased out of the residence and had minimal contact with their everyday life, except in the case of a renovation, a specific design issue that needed attention, a special celebration or event. I did not visit the residences on a regular basis, nor was I ‘on the floor’ or ‘front line’, meaning I did not have intimate knowledge of staff, residents, or family members of any of the residences; the one used as a fieldwork setting included. However, given the undeniable insider’s knowledge of the residence, a closeness to the field other researchers would not have, it is a source of potential bias that needs further consideration.

The term ‘insider research’ is associated with projects where the researcher has a direct involvement or connection with the research setting (Robson 2011). A rich body of methodological literature highlights the advantages and potential dilemmas of conducting insider research regarding ethical issues, value, and robustness (Trowler 2011). I would argue that all research - whether quantitative or qualitative, experimental, or naturalistic - is a human activity and as such, it is equally vulnerable to error and bias with each approach being prone to different sources of error (Norris 1997). Researchers are fallible; no approach is immune to bias, given the lens with which they approach the field and their understanding of it, will be tinged by their existing intellectual dispositions or ‘habitus’ (Bourdieu and Wacquant 1992).

This research responds to the prompt that professionals are encouraged to evaluate their own professional practice to heighten awareness of preconceptions and assumptions, reflective of my role as an ethnographer. This reflective exploration of practice, a merging of my architectural training and my nascent scholarly construct of design, enhanced integration of theory and practice (Siebert, Walsh 2013). Throughout the different phases of the research work, the tension of insider/outsider positionality was felt. At times the narrative benefitted from previous knowledge around the organizational intent of certain design initiatives, while at times the data collected was completely unexpected. Notwithstanding the complex challenge of being both an insider with previous knowledge of the ethnographic setting, and an outsider as an academic scholar undertaking fieldwork (Kanuha 2000), it is argued that insider researchers have an important role in advancing knowledge (Heslop et al. 2018). As such, my proximity to the field enhanced the richness of findings by providing additional context to key issues albeit the possibility that, despite the disciplined methodology that was adopted, my insiderness may have predisposed me to some of the features of the setting, as discussed in Chapter V.

Theoretically, the definition of insider positionality is ambiguous since no single articulation describes what degree of social experience and knowledge would warrant the designation of 'insider' (Chavez 2008). It is therefore argued that 'insiderness' is not a fixed value, as I researched areas of the organization that were unknown to me, collecting data from people I had no intimate knowledge of (Trowler 2011). I submit it would be best to define my role as a 'partial insider', as it should not be assumed that having been part of the host organization automatically provided me intimate knowledge of the particular or situated experiences of all constituents (Kanuha 2000). I have endeavored to conduct credible research through rigor and discipline, by explicit awareness and reflexivity of the possible effects of perceived bias on data collection and analysis, coercion, or access to privileged information (Unluer 2012).

Privacy and Confidentiality

As a private care home residence, the host organization must comply with the privacy and confidentiality regulations set forth by The Retirement Homes Act (Government of Ontario 2017). Furthermore, in the province of Ontario, a licensed private care home operator is considered a Health Information Custodian. As such, the residence must adhere to the Personal Health Information Act (Government of Ontario 2018), a health-sector specific privacy law that establishes the rules for collecting and using personal health information, thus safeguarding privacy of among others, people living with dementia. In order to ensure compliance, the host organization follows the ethical principles established by the National Standard of Canada Entitled Model Code for the Protection of Personal Information (CAN/CSA-Q830-96) - Accountability, Identifying Purposes, Consent, Limiting Collection, Limiting Use, Disclosure and Retention, Accuracy, Safeguards, Openness, Individual Access, and Challenging Compliance (Government of Canada 2018) – as guiding principles for internal policies that are rigorously enforced within the organization. Employed by the host organization at the time of fieldwork placed a higher ethical burden on me and I was held to higher ethical standards, as all actions were examined through the lens of academia and were scrutinised for organizational policy compliance. Therefore, fieldwork was carried complying to the privacy and confidentiality guidelines from the different legislation bodies applicable to this work: The Personal Information Protection and Electronic Documents Act (Personal Information Protection and Electronic

Documents Act 2015) at a federal level; the Personal Health Information Act at a provincial level (Government of Ontario 2018), and The Retirement Homes Act (Government of Ontario 2017). Data was gathered in a confidential manner, it was not shared with anyone, and it was safely stored externally following the University's protocols.

Conflict of Interests

One of the core principles identified as critical by the Social Research Association in their ethical guidelines, is the obligation to funders and employers; citing that the researcher's relationship to these has to be transparent and in no way compromise professional integrity (SRA Ethical Guidelines Working Group 2003). Special attention was afforded to this matter, given my former association with the organization funding this study and the fact that fieldwork was conducted in a residence owned and operated by the same organization. As suggested by the Canadian Secretariat on Responsible Conduct of Research in their ethics guidelines for qualitative research (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada 2014), preliminary visits to the residence and discussions with staff and senior management were used to define research collaborations and to establish my role as an academic researcher.

The sponsor organization has well-established protocols to escalate incidents and concerns, allowing for anonymous reporting, providing a clear path to address any concerns regarding power inequality, as anyone in the residence could have reported anomalies without fearing consequences. Therefore, my status as a researcher was like any person visiting the care, equally bounding me to organizational policy compliance, yet allowing me to act independently, as I was not obliged to share any of the collected data with the organization. Furthermore, this research proposal underwent scrutiny by the University's GUEP panel to ensure there were no conflict of interests.

Conclusion

This research sought to understand the situated experience in a contained dementia care environment by generating thick descriptions of how individuals experience and make sense of their lives and those around them in this setting (Atkinson 2007), understanding and drawing meaning from their specific context (Fox 2004). Therefore, supportive of the stance that in research it is not possible to separate the ‘what’ from the ‘how’ (Parker 2007), the adopted methodology for this study was informed by its aims. Ethnography was identified as a compatible research method to achieve an intimate view of what was being studied, and as “a way of being-in-their-world” to observe, participate in, and understand their experiences from the participant’s vantage point (Fox 2004), even if for a fragment of time.

The established sample provided adequacy and appropriateness of data (Morse et al. 2002) to represent the breadth and depth of the phenomenon (Rudestam and Newton 2015) to make theoretically meaningful inferences of findings (Øvretveit 1998). While this research studied a specific setting and focused on the experience of certain individuals, understanding how social processes and phenomena are embedded within a specific context is a vital part of meaningful social explanation (Mason 2006), as the more particular contexts are understood, the better these can be cross-referenced with similar settings, generating explanations which resonate to a wider context (Mason 2006). Above all, the fact that older adults living with dementia are considered a vulnerable group, careful attention was given to the ethics of ethnography by adhering to frameworks that captured personal values and beliefs, and which informed all interactions.

Chapter IV

INQUIRY STEPS AND PROCEDURES

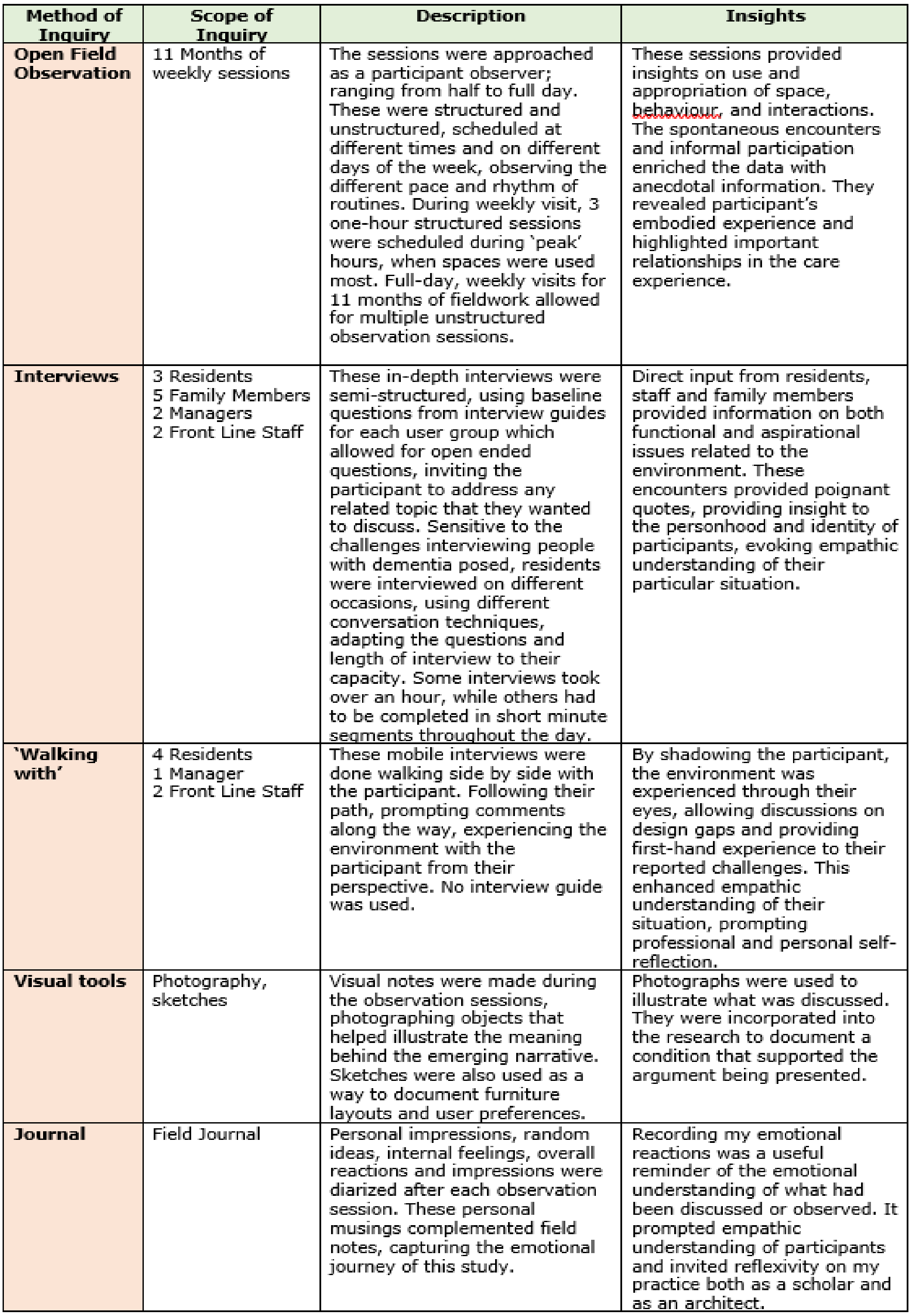
Introduction

More than a method, ethnography is the product of an exploratory iterative process that reveals the depth and intricacy of a social phenomena and as such, there are no distinct steps to follow. The ethnographer simply starts with 'what's there' in its empirical reality and it is only through participant observation and immersion that in time, meaning is derived (Muecke 1994). Because ethnography is created through research practices and always situated in human activity, it is susceptible to both the strengths and limitation of human perceptions and feelings (Richardson, L. 2000). And while there is no infallible way of assuring validity, there are reliable methods and research practices that if followed, could result in similar insights that would resonate with the proposed findings (Fielding 2008; Mason 2006).

Some of the practices used to achieve wider resonance (Mason 2008) in this research were the use of multiple data collection techniques, a nimble research design that reacted to fieldwork and observed relationships, a focus on participant's views, a rigorous approach to data collection, and a layered analysis of data (Robson 2011). This chapter provides insights into the different phases of fieldwork and the ongoing reflexivity with which data was analysed (Morse 2016), mitigating concerns of the risk of privileging an omniscient voice that could suggest a power imbalance with the participants (Gray 2014).

Data Collection

Fieldwork started in May of 2019 and was carried out for eleven months; visiting the dementia care setting, allowing full-day immersions in the life of the residence, collecting data through observation, interviews, walkabouts with residents, acquiring first-hand knowledge of the routines in the everyday life of the dementia care setting. The nature of ethnography, a snapshot in time of situations that are fluid, exacerbated the need to generate explanations from situational contexts and social processes by ensuring there were sufficient data to establish a reliable link between analysis and interpretation (Mason 2006). Consequently, acknowledging that studying the embodied experience of a dementia care home environment would be complex and rich in content, different data collection methods were used to obtain multiple perspectives to both complement and corroborate ideas (Morgan and Stewart 2002), illuminating different dimensions of the same situation, with each collection tool contributing a different layer of information (Morse 2016), thus enhancing robustness of findings (Gray 2014); see Table 3.



Method of Inquiry	Scope of Inquiry	Description	Insights
Open Field Observation	11 Months of weekly sessions	The sessions were approached as a participant observer; ranging from half to full day. These were structured and unstructured, scheduled at different times and on different days of the week, observing the different pace and rhythm of routines. During weekly visit, 3 one-hour structured sessions were scheduled during 'peak' hours, when spaces were used most. Full-day, weekly visits for 11 months of fieldwork allowed for multiple unstructured observation sessions.	These sessions provided insights on use and appropriation of space, behaviour, and interactions. The spontaneous encounters and informal participation enriched the data with anecdotal information. They revealed participant's embodied experience and highlighted important relationships in the care experience.
Interviews	3 Residents 5 Family Members 2 Managers 2 Front Line Staff	These in-depth interviews were semi-structured, using baseline questions from interview guides for each user group which allowed for open ended questions, inviting the participant to address any related topic that they wanted to discuss. Sensitive to the challenges interviewing people with dementia posed, residents were interviewed on different occasions, using different conversation techniques, adapting the questions and length of interview to their capacity. Some interviews took over an hour, while others had to be completed in short minute segments throughout the day.	Direct input from residents, staff and family members provided information on both functional and aspirational issues related to the environment. These encounters provided poignant quotes, providing insight to the personhood and identity of participants, evoking empathic understanding of their particular situation.
'Walking with'	4 Residents 1 Manager 2 Front Line Staff	These mobile interviews were done walking side by side with the participant. Following their path, prompting comments along the way, experiencing the environment with the participant from their perspective. No interview guide was used.	By shadowing the participant, the environment was experienced through their eyes, allowing discussions on design gaps and providing first-hand experience to their reported challenges. This enhanced empathic understanding of their situation, prompting professional and personal self-reflection.
Visual tools	Photography, sketches	Visual notes were made during the observation sessions, photographing objects that helped illustrate the meaning behind the emerging narrative. Sketches were also used as a way to document furniture layouts and user preferences.	Photographs were used to illustrate what was discussed. They were incorporated into the research to document a condition that supported the argument being presented.
Journal	Field Journal	Personal impressions, random ideas, internal feelings, overall reactions and impressions were diarized after each observation session. These personal musings complemented field notes, capturing the emotional journey of this study.	Recording my emotional reactions was a useful reminder of the emotional understanding of what had been discussed or observed. It prompted empathic understanding of participants and invited reflexivity on my practice both as a scholar and as an architect.

Table 3 - Data Collection

This approach also enhanced the evaluative perspectives by enabling a more thorough data analysis (Sandelowski 2000). Acknowledging that ethnographic research requires ongoing analysis and reflexivity (Morse 2016), the versatility of a mixed methods data collection approach, allowed continuous assessment of the quality of data obtained as fieldwork progressed, providing the option to lean on different methods to gather specific information as themes emerged (Davidson, Jane E. 2005).

Converging findings from these different methods of inquiry provided an insider's perspective that depicted the different tensions of each stakeholder group; their needs, their aspirations, their functional requirements, and were critical in establishing reliability of the information that was inferred from the data, as evidence suggests there is often discrepancy between what people say and what they do (Lawton, M. P. and Nahemow 1973). It also allowed knowing, watching, and understanding potential incongruences through the critical analysis of complementary data streams (Scales et al. 2017). To allow for this flexibility in the study, the following sequence of fieldwork was planned:

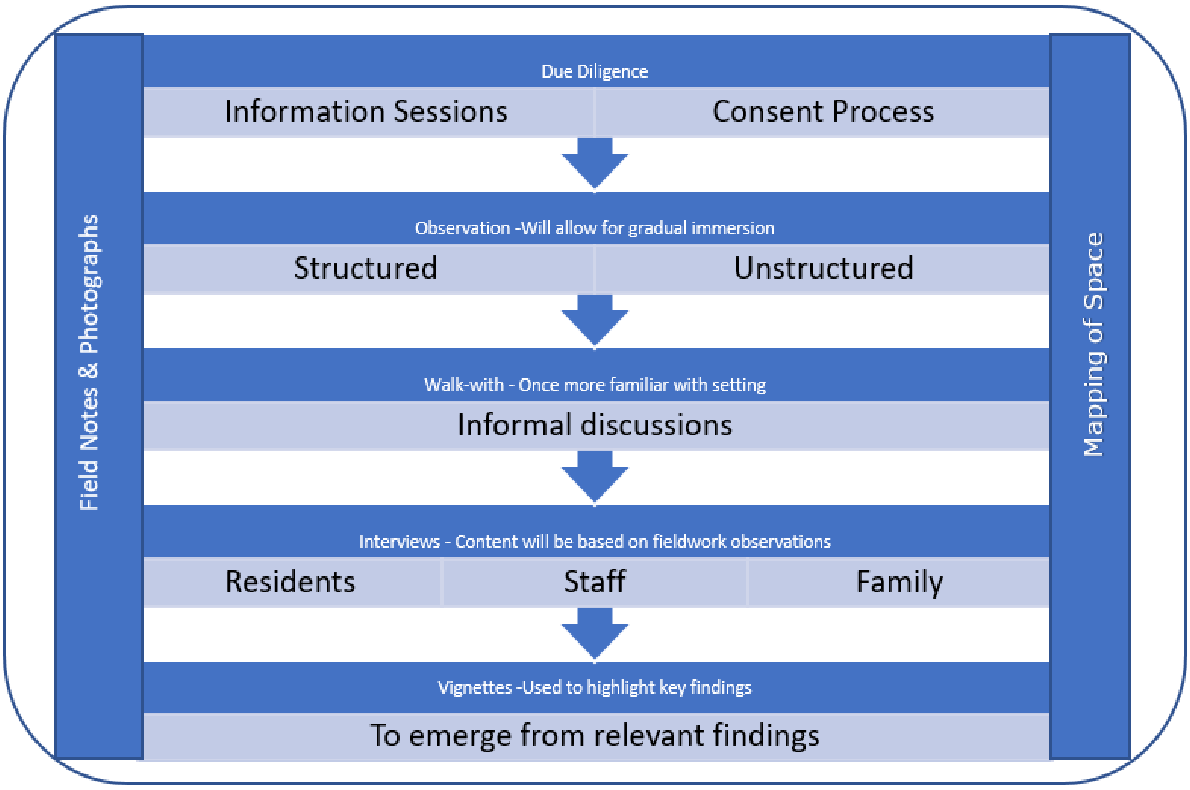


Figure 8 - Sequence of Fieldwork

This plan was effective, as it allowed for a gradual immersion in the social world of the care floor; progressively discovering and understanding the interrelations of the different individuals involved. Uncertain on where to start, I decided to begin my fieldwork with open field observation as a participant observer. I felt that through observation, I would be able to slowly start perceiving the multi-sensory aspect of the environment to the fullest; allowing myself to get acquainted and close to whatever was happening on the care floor (Lee and Ingold 2006). This would also allow for participants to get acquainted with me and to start feeling comfortable with my presence. This approach was congruent with the principles of institutional ethnographic work, where the point of departure is the everyday world as experienced by individuals in a regulated setting (Hogsbro 2020) and the 'entry' to their social world, be it through observation or interviews, is to understand their everyday experiences, tapping into their particular expertise (Carroll 2004). With the aim of understanding the ebb and flow of their daily routines and endeavouring to uncover the invisible aspects of their world by looking beyond their immediate context (Smith 2006), observation sessions were intentionally planned for different times and days of the week.

These sessions were more than visual surveillance. I began to be immersed in people's worlds, providing me with an overarching sensitivity of the embodied experiences and practices of the field by taking notes, photographs of objects and physical space, sketching furniture layouts, and keeping a personal insights journal. They prompted personal reflection on my own practice by discovering the nuances of the environment over time, gaining a clearer understanding of the richness and reality of life on this care floor. By inferring meaning from activities, movements, and language (Kontos 2012; Lee and Ingold 2006), the people I was observing became more than just the stick figures normatized through design, emerging as multi-dimensional individuals (Fine, G. A. 2003).

Once I started feeling more comfortable and familiar with the physical and social environment, I started to schedule interviews, while continuing field observation. All interviews took place on site, providing me with additional time at the residence, allowing me the opportunity to experience the physical environment from the perspective of a visitor, as I felt less pressure to observe and record every detail as I had done during the observation sessions. It provided me time and freedom to experience the place in a social way, spontaneously interacting with people, enjoying informal encounters, as well as experiencing the different spaces within the care floor, becoming more of a participant observer than an outsider looking in. The awareness and immersion process that field observation demanded, became an immersive experience that allowed me to capture, infer knowledge, and begin understanding the lived and embodied experience of people using this space (Robson 2011), providing a sound foundation for the next stage of data collection.

As I started to understand and feel how residents, staff and visitors experienced this space and constructed their immediate world, it became evident that ethnography was the appropriate qualitative methodology. While there is vast research on the biomedical aspects of dementia, insights on the existential understanding of how people are affected by dementia in their everyday life could only be advanced through this ethnographic process of immersion (McCrae and Banerjee 2011). Being able to observe and to chat with the actual users of the environment provided rich data related to their practices and use of space. Understanding the different spatial needs and requirements for each user group allowed first-hand exposure to the co-production of the environment from both a social and architectural perspective (Lees 2001), while providing a deeper understanding of their motivations to effect these changes. Observing this process, in which different users became everyday designers by navigating, manipulating and re-interpreting the designed space to meet their specific needs (Jacobs and Merriman 2011), observing how they interacted, how they used space, furniture, and furnishings, began to suggest different and parallel user experiences within the same architectural space. It also started to reveal tensions resulting from the different functions and meaning demanded by different users from the same environment. For some, the need to recreate home, for others, their place of work. At times a clinical healthcare use, at times a place to redefine new family life routines.

Theory, such as the concept of embodiment, was used to guide fieldwork, influencing how I approached observation. Embodiment recognises the body as a source of agency in the constitution and manifestation of selfhood (Kontos 2005). It affirms the persistence of personhood and identity as an embodied dimension of selfhood, despite cognitive deterioration (Kontos 2004). Also, adopting Merlau-Ponty’s (1962) views on how one’s perception of the world is dependent and inseparable from one's personal past, a personal and individual experience of space was expected during observation. Informed by this theoretical background, it was also assumed during observation that this unique embodied experience of space would be expressed in the way the individual coped, adapted, and modified space. As discussed in Chapter VIII, data collected from observation supported these theories, suggesting that communication was not only verbal, but was also revealed in the way the body moved and behaved (Kontos 2005). Therefore, the theoretical context which informed the decision of starting fieldwork as a participant observer provided a gradual immersion in the dementia care environment, preparing me for the next phase of fieldwork. Interviewing residents and staff, walking alongside people with dementia, keeping detailed field notes, sensitively using photography to complement the emerging narrative, informal chats and being immersed in this environment for prolonged periods of time, started to generate meanings and to unveil the different user's challenges and tensions.

Being able to get close to how people with dementia experience the physical environment provided a glimpse to their world (Robson 2011), revealing the narrative of their particular reality. The often-competing priorities and needs of different users sharing one environment for different purposes at times collided. As described in Chapter VI, this negotiation of function ultimately influenced the embodied experience of the person living with dementia. This phase of fieldwork proved to be a transformative experience. While I had previous knowledge of user needs and anecdotal understanding of their experience, this immersive period in the field shifted my understanding from knowing to feeling; from supposing their experience to sharing it.

Data Analysis

> *…if sociological concepts are to be treated with affection, each must be traced back to where it best applies... Better, perhaps, different coats to clothe the children well than a single splendid tent in which they all shiver. (Goffman 1961, p. xiv)*

This section provides an overview of how collected data was managed, reviewed, and analysed. The process is described in detail to afford understanding of how data analysis was carried out, providing insights on how data was used to make valid and contextual inferences. It describes the iterative and discovery process of abductive analysis, demonstrating the content-sensitive approach used to distill categories and themes, lending credibility of research findings (Graneheim and Lundman 2004; Krippendorff 2018).

Cooperative Production of Data

How meaning is conveyed and shared has been a topic for discussion in other fields of study. Mikhail Bakhtin, a prominent linguistic philosopher, theorized that language is corporeally situated, able to express the abstraction of social relations, serving as a tool for social practice (Majumder 2018). A dialogue in which individuals enter a relationship with someone else's world, where words are charged with social context and populated by intentions, where meaning is co-produced (Zou 2018). Moreover, he posits that it is through the intentions of the message being conveyed that a dialogue is created, with individuals applying their own context and experience to respond, relate, and create meaning (Bakhtin 1986; Öhman 2020). This relational approach to understanding and meaning reflects how data collection was approached, where data was collected with the purpose of exploring the lived experience of those sharing the dementia care environment, identifying themes and patterns that could locate what was being collected within a conceptual framework (Mitchell 2018).

After eleven months of fieldwork, I had collected extensive data from different data points, with thick descriptions of situations which started to capture the richness of the experience that was being observed and lived. Unlike thin descriptions that allude to generalized findings and offer a snapshot of what is being observed, the approach of blending different data collection methods had rendered rich descriptions about micro interactions in the field (Czarniawska 2007). What was being captured as data were the constructions and perspectives of others; of what they said and did, or saw themselves doing (Van Maanen 2011). What people said and how they acted was a means for understanding situations, providing a means of relating experience to theoretical concepts, suggesting potential explanations of the social order being observed (Fine, G. A. 2003).The following passage documents a casual encounter that provided meaning; a social encounter that became data, illustrating the social process of research, supporting the argument that data is a cooperative production (Charlotte 2008).

> As I came to the building, there was a slightly different atmosphere than during weekdays. The parking lot is full, which would suggest there are a lot of visitors seeing their loved ones. I came to the memory care neighbourhood, and nothing seems to be different. Inside, nothing would suggest it's Sunday. I walk in, and as usual, Sally is standing asking about things.
>
> I sat down to get organized in the same corner I sit, she came and sat with me.
>
> - Sally: Today is Sunday? (she overheard someone say it was)
> - Claudia: Yes it is
> - S: Well, I didn't make it to church!
>
> After Sally shares with me how bored she is and that she may be again contemplating jumping, she asks about the weather outside… I invite Sally for a walk and together we walk the floor, where she is pointing out very insightful comments about art, colour, chair rail, and why she likes to sit where she sits.

Observation Notes. November 10, 2019

My encounter with Sally was unplanned, yet we both enjoyed it, becoming meaningful to both of us. Such encounters supported the stance that the relationships crafted in the field helped produce data which were expressed through social interaction, reaffirming that ethnographers help to construct the observations that become their data, and which form the basis of subsequent analysis (Charlotte 2008). The evolution of my relationship with Edith (one of the supervising support workers on the memory care floor) exemplifies this stance, where it took about six months after we first met for Edith to agree to sit down for an interview with me.

> Queen Bee – not sure what her name is *(Edith).* There were times I noticed she was observing me, a couple of times our gaze met. Nonetheless, I just didn't feel comfortable approaching her to ask her to participate in the research and provide consent. In a way, I think she was gauging me – actions and intentions – so I decided to give her space and more time before I approach her. I do think it is critical I get her onboard, as she seems to

> be the one in charge. Again…not sure about the power structures that are in place.

Observation Notes. May 22, 2019

> The demonstration of affection that I witnessed from Jo *(a resident)* with Edith was quite touching. Out of nowhere, she stopped her pacing and leaned over to touch her face and give her a kiss on the cheek, with her hand resting on Edith's chest. Edith was moved to teary eyes and said to me she was her 'grandma'. The affection was quite obvious.

Observation Notes. November 10, 2019

From being observed with distrust, patiently waiting for the right opportunity to ask for consent, and after having built a rapport with different staff members thus proving myself trustworthy, Edith finally allowed me to approach her to ask her to please consider being part of the research work being undertaken. It took a few months, but as my relationship with her developed, my ability to collect rich data also increased. Had I not recognized that the field work I was doing relied on the social process to establish trusting relationships with the participants, I would not have been privy to the beautiful and touching moment I shared with Edith and Jo. Like this shared moment, I had many opportunities to deeply connect with participants, awakening me to the multi-dimensional human beings that I had before shorthanded as PWD; person with dementia. Data was all around me: people, encounters, chats, sounds, silences, empty corridors, doors ajar, bright rooms, dark spaces. The excerpt below captures my evolving understanding of the depth of the human experience that surrounded me.

> As I walk the corridors and see the memory boxes, these take on a different meaning now. I am saddened to see the full lives - at the cottage, with family, younger - that these people have had and to now know how they struggle… Slowly, as I get to know residents, they become more real and more human, with a deep layer of history.
>
> I walked past Ella's memory box, and there she is with her husband, during their 50th wedding anniversary celebration. No wonder she misses him.

Observation Notes. May 31, 2019

………………………….

- Betty: I will need to get back to my place. I don’t know if I will be able to
- Claudia: Don’t worry, I will help you
- B: But I don’t know how to get back
- C: That’s ok…

… Betty held my hand to walk to the great hall. In her frail touch and grasp, I could feel both frailty and fear. We came in, the concert had already started.

Observation Notes. June 19, 2019

This personal connection with participants, the surprising observations and the spontaneous encounters proved to be a critical context during data analysis. They provided stimulating insights and facilitated recognizing their potential relevance when connected to existing theory (Timmermans and Tavory 2012). This connection situated data as more than simple accounts; it ensured data remained rich, detailed, and complex like the people who helped produce it.

Organizing Data

The extent and richness of the data I had collected was overwhelming. I had multiple files of notes, transcripts, photographs, sketches, short-hand memos, audio recordings, reminiscent of a scrap book one puts together after a long journey, where mementos and souvenirs are kept as reminders of an unforgettable experience. In a way, I had been on a professional and emotional journey by being part of the world that I was researching, where some of the others’ experiences had resonated with my own experiences, albeit understanding and valuing them differently (Van Maanen 2011). As I started to make sense of the data I had collected, I decided to attend two training sessions held in Cardiff by the Social Research Association (SRA). Training focused on qualitative data analysis and on strategies for interpreting and writing up qualitative findings, providing me with invaluable strategies on how to organize data. It prompted me to consider data from a dynamic perspective, encouraging me to ‘listen’ to the data; asking questions of it, placing a renewed attention on how words were being used, effectively preparing me for the next stage of analysis.

Motivated by this training, I also completed an online training course on NVivo - a qualitative data management software. This provided me with the basic tools to organize data in a logical way, providing a structure for data management and analysis. The data was organized by files, associating each file with the date of when the data had been collected, differentiating the data by file type, classifying each file accordingly, as conceptually illustrated below.

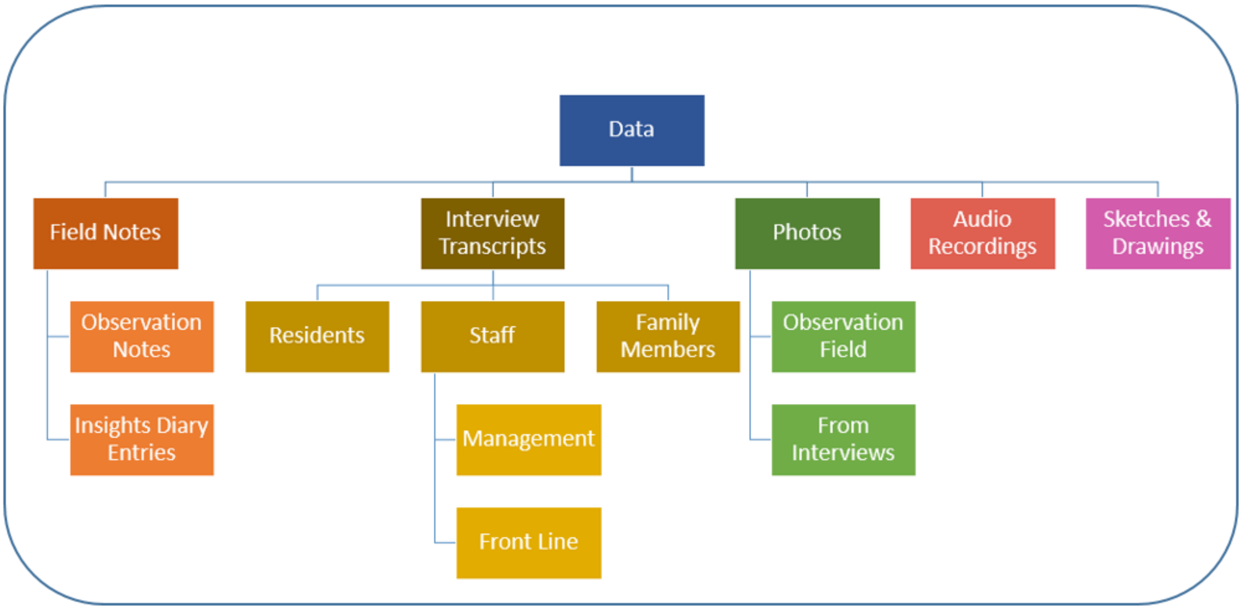


Figure 9 - Data Organization

Sorting data by file type, organizing it by date of collection, and further classifying it by content, provided a structure that was easy to access and manage. This rigorous classification of data also provided a comprehensive review of its content in the process, providing an overarching sense of the information that had been collected for analysis.

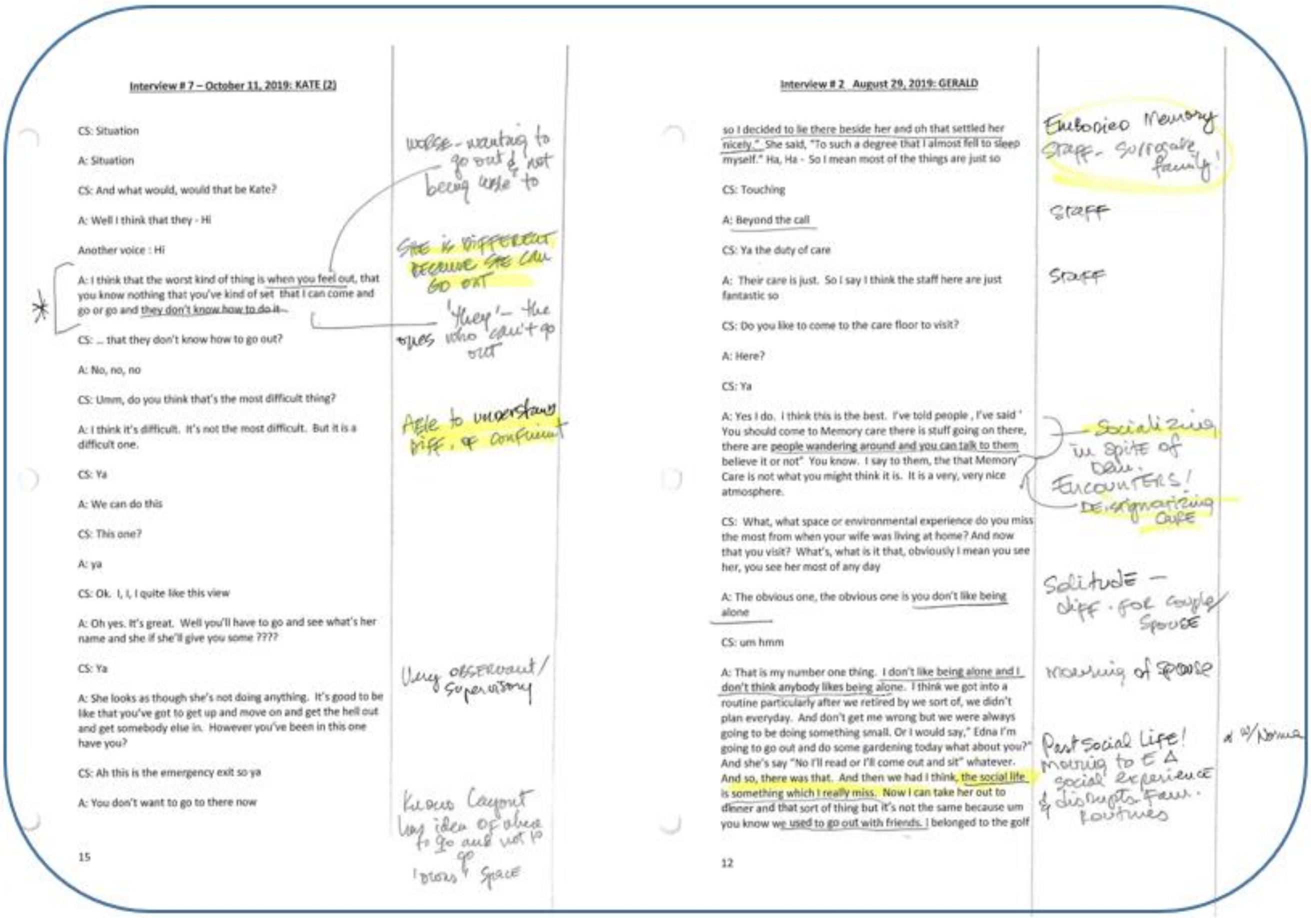
Approach to Analysis

This research phase confirmed what other qualitative researchers have shared; that the most paralysing moment in data analysis is simply getting started (Glaser 1978), demanding a level of tolerance of being fine with feeling uncertain (Elo and Kyngäs 2008). Overwhelmed with the quantum of data, I started reviewing the data by file type, focusing first on the interview transcripts, organizing them by user group: residents, staff, and family members. Listening, studying, and dissecting thoughts, expressions and words directly provided by participants, not generated by me. This approach allowed my immersion in analysis without the immediate bias my observation and insight notes could contain. I relied on the pluralistic approach to data collection, which produced rich layers of information from different data sets, trusting that the meaning emerging from the interview transcripts would resonate with the rest of the data points – verbal narrative, casual social encounters, observation notes, journal entries - analyzing different forms of evidence from a range of perspectives and methods (Kondracki et al. 2002; Pearce 2012). The initial bias to favour the input from residents living with dementia influenced my decision to start data analysis with resident interviews.

Relying on the iterative-inductive data analysis training I received through the SRA, I approached analysis with discipline. I continually read the data, immersing myself in it, gaining a holistic sense of what I had gathered (Tesch 2013). I read the transcripts, intentionally breaking down the paragraphs, so as to read word by word, highlighting the words from the text that seemed to capture key thoughts or concepts. I then annotated my first impressions and thoughts, endeavoring to directly ‘mine’ information from participants’ unique perspectives, avoiding preconceived categories by identifying patterns and grounding knowledge in the actual data, eventually leading to an interpretation of its contextual meaning (Hsieh and Shannon 2005; Kondracki et al. 2002).

I undertook a thorough assessment of the literature review and theoretical framework, revisiting theories on embodiment, memory, and construct of place among others, providing a rich theoretical watermark as context for analysis. I then transcribed all audio recorded interviews into written transcripts, in typical prose format, indicating the ongoing dialogue with tags, and using quotation marks to identify spoken word. After properly organizing these transcripts in NVivo, I re-read the interviews in full, trying to absorb the story each narrative was suggesting. I then printed these transcripts with customized margins that were irrespective of the ongoing conversation that had been captured, effectively deconstructing the paragraph narrative of the interview to phrases. Breaking the narrative this way forced a renewed attention to the words used, examining language intensely and scrutinizing expressions for explicit or inferred communication; associating ideas that were being communicated to the aims of this research (Downe-Wamboldt 1992).

As I reviewed and reread these transcripts, I started analyzing content as if seen for the first time, quickly annotating thoughts next to the line-by-line entry, noting insights that came to mind and that were informed by the context of the recent theoretical framework review, see Figure 9.



Interview # 7 – October 11, 2019: KATE (2)

CS: Situation

A: Situation

CS: And what would, would that be Kate?

A: Well I think that they - Hi

Another voice : Hi

A: I think that the worst kind of thing is when you feel out, that you know nothing that you've kind of set that I can come and go or go and they don't know how to do it.

CS: ... that they don't know how to go out?

A: No, no, no

CS: Umm, do you think that's the most difficult thing?

A: I think it's difficult. It's not the most difficult. But it is a difficult one.

CS: Ya

A: We can do this

CS: This one?

A: ya

CS: Ok. I, I, I quite like this view

A: Oh yes. It's great. Well you'll have to go and see what's her name and she if she'll give you some ????

CS: Ya

A: She looks as though she's not doing anything. It's good to be like that you've got to get up and move on and get the hell out and get somebody else in. However you've been in this one have you?

CS: Ah this is the emergency exit so ya

A: You don't want to go to there now

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WORSE - wanting to go out & not being able to

SHE IS DIFFERENT BECAUSE SHE CAN GO OUT

'They' - the ones who can't go out

Able to understand diff. of confinement

Very observant/ supervisory

Knows layout
has idea of where to go and not to go
'doors' & space

Interview # 2 August 29, 2019: GERALD

so I decided to lie there beside her and oh that settled her nicely." She said, "To such a degree that I almost fell to sleep myself." Ha, Ha - So I mean most of the things are just so

CS: Touching

A: Beyond the call

CS: Ya the duty of care

A: Their care is just. So I say I think the staff here are just fantastic so

CS: Do you like to come to the care floor to visit?

A: Here?

CS: Ya

A: Yes I do. I think this is the best. I've told people , I've said ' You should come to Memory care there is stuff going on there, there are people wandering around and you can talk to them believe it or not" You know. I say to them, the that Memory Care is not what you might think it is. It is a very, very nice atmosphere.

CS: What, what space or environmental experience do you miss the most from when your wife was living at home? And now that you visit? What's, what is it that, obviously I mean you see her, you see her most of any day

A: The obvious one, the obvious one is you don't like being alone

CS: um hmm

A: That is my number one thing. I don't like being alone and I don't think anybody likes being alone. I think we got into a routine particularly after we retired by we sort of, we didn't plan everyday. And don't get me wrong but we were always going to be doing something small. Or I would say," Edna I'm going to go out and do some gardening today what about you?" And she's say "No I'll read or I'll come out and sit" whatever. And so, there was that. And then we had I think, the social life is something which I really miss. Now I can take her out to dinner and that sort of thing but it's not the same because um you know we used to go out with friends. I belonged to the golf

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Embodied Memory

Staff - surrogate family!

Staff

Staff

Socializing in spite of dem. encounters!

De-stigmatizing care

Solitude - diff. for couple/ spouse

Mourning of spouse

Past social life!
Moving to E A social experience & disrupts fam. routines

& w/Norma

Figure 10 - Transcript Work Sheets

These work sheets illustrate the effectiveness of analyzing the interviews line-by-line. The change in print format presented data as incomplete sentences, unveiling expressions that otherwise may have gone unnoticed. These array of thoughts and words were raw material which now had to be interpreted through a creative process; extracting important cues, identifying recurrent topics which suggested meaning (Lipscomb 2012), supporting the argument that a theoretically-sensitized researcher is able to recognize the potential relevance of content, stimulating powerful insights (Timmermans and Tavory 2012). Structuring and organizing transcripts this way also helped mitigate any preconceptions attached to these interviews, allowing the broad qualitative data to hold its own meaning.

Aside from the analytical tools my recent training had provided me, I found the problem-solving skills I had developed as an architect, where information is distilled to its basic unit to understand how a particular segment of data fits in the overall design, were instrumental in helping me approach analysis with discipline and rigour, leading me to uncover critical themes.

It has been posited that any investigator, when faced with rough data, endeavors to detect a pattern, to organize the data using intuition, experience, and knowledge to infer meaning; similar to a detective-like work where the goal is to obtain clues out of data which disclose hidden explanations that eventually translate into meaning (Tohmé et al. 2015). The inductive disposition I adopted to review these transcripts awakened in me the need to note silences, sighs, laughter, or any other expression that potentially influenced the underlying meaning (Graneheim and Lundman 2004). With an open mind and a focus on identifying broad patterns that went beyond the descriptive nature of the text, I identified themes that seemed important and linked to relevant theoretical concepts. And while all data can be ascribed with multiple meanings (Krippendorff 2018), on an interpretative level, common threads to the narrative started to percolate, expressing the latent content of the text, disclosing the underlying meaning (Graneheim and Lundman 2004). As I moved back and forth from the printed transcript work sheets to the NVivo, on-screen version of the same transcript and reading from a monitor in a continuous narrative format, the data almost seemed to be new. The data was not static; each format seemed to stimulate different insights. Nevertheless, the convergence of themes was evident, as similar topics and themes emerged from the different formats. Analyzing interviews in this manner gave me confidence to do the same with the field notes and personal insight entries I had kept.

As this process evolved, and all written data points had been analysed in a similar way, initial themes and categories were used to further structure the data by making initial 'fair guesses' about the emergent meanings (Lipscomb 2012; Peirce 1934). This analytic process stimulated ideas, suggesting relationships and correlations from different data points. Encouraged by these evolving links, I was motivated to tap into my creative training as an architect. Relying on my ability to conceptualize complex problems into visual diagrams, I started to capture related ideas and concepts that resided in the different data entries. These conceptual diagrams, see Figure 10, visually aided me to amalgamate information derived from interviews, notes, observation, photos even, identifying relationships and correlations of themes, providing me yet a different way to understand data.

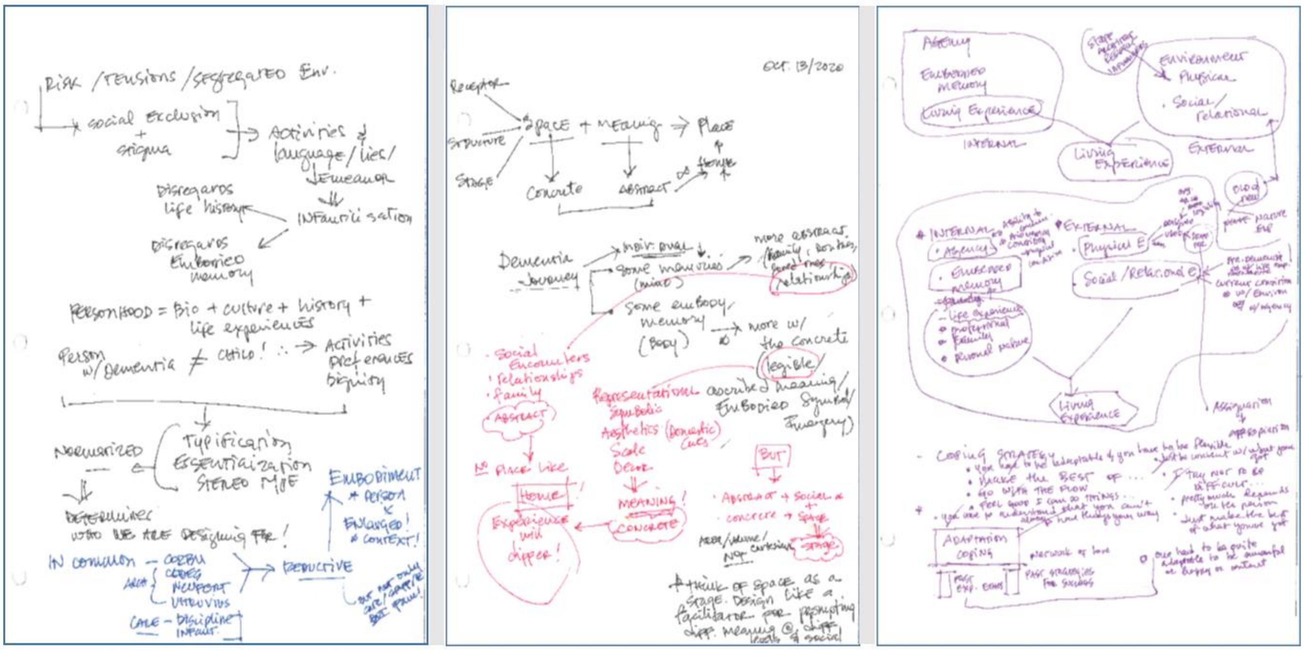
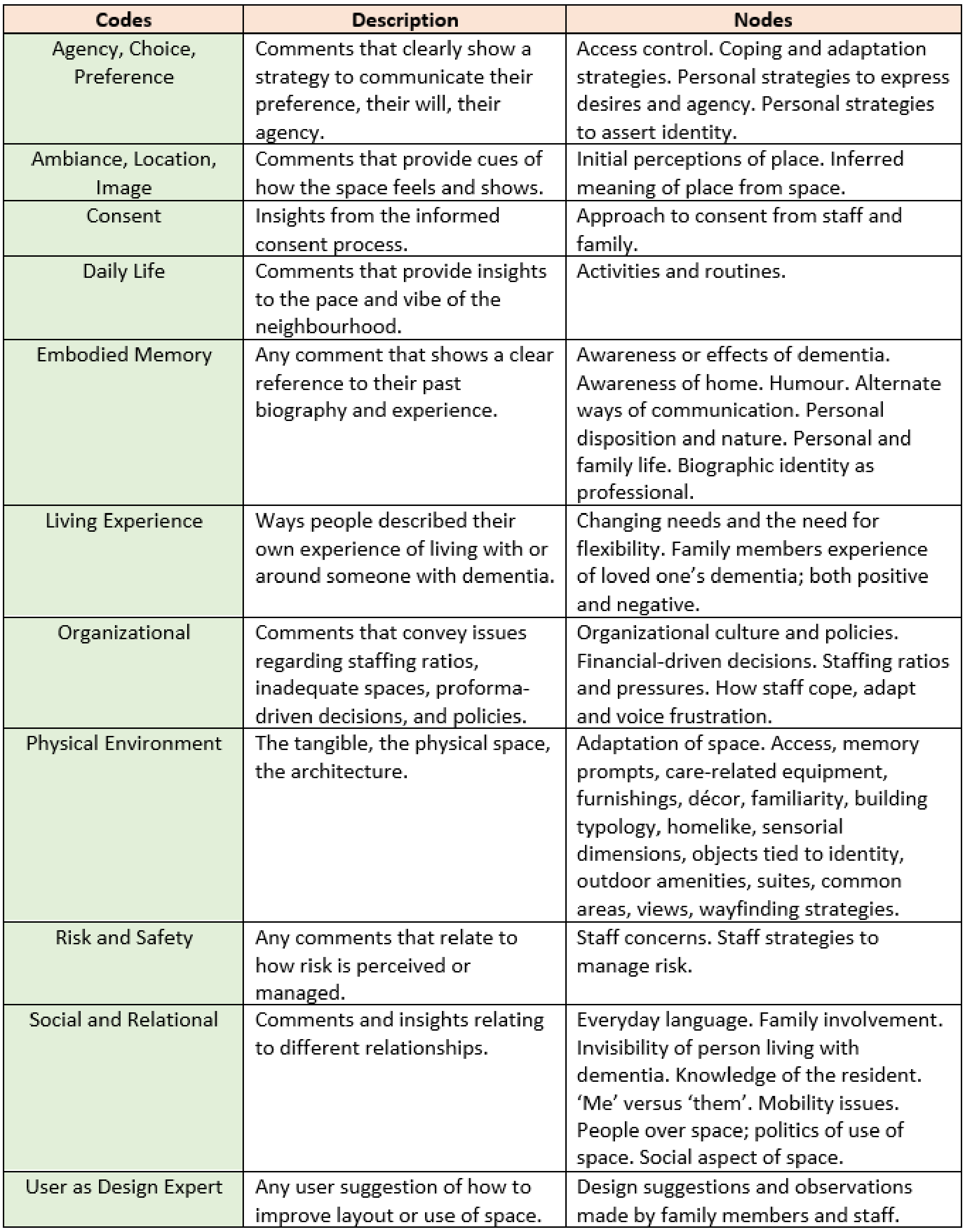


Figure 11 - Conceptual Diagrams

This graphic representation of the different data formats allowed me to compare information and to start weaving a more cohesive tapestry of information. At times I grouped ideas under a general category, sometimes an initial topic had to be expanded to include new information, on occasion a discarded topic made its way back to the central analysis after witnessing its recurrence through the different data entries. Gradually, each insight, every meaningful idea, and 'fair guess', found a place under a specific node, presenting a puzzle that needed a cohesive explanation of how the different pieces fitted together. Reflection and critical thinking had to be furthered to extract meaning and significance from the data, demanding a process where explanations associated findings to supportive theory.

Codes

As illustrated in the previous diagrams, the real-world social phenomena are too complex to extract a well-ordered, neat description (Tohmé et al. 2015), with analysis demanding flexibility, alternating between the whole and parts of the text (Graneheim and Lundman 2004). Once raw data had been organized, interpretive constructions were made by associating information to common nodes, noting insights that helped identify themes and patterns, see Table 4, associating meaning to the ideas being explained (Mitchell 2018).



Codes	Description	Nodes
Agency, Choice, Preference	Comments that clearly show a strategy to communicate their preference, their will, their agency.	Access control. Coping and adaptation strategies. Personal strategies to express desires and agency. Personal strategies to assert identity.
Ambiance, Location, Image	Comments that provide cues of how the space feels and shows.	Initial perceptions of place. Inferred meaning of place from space.
Consent	Insights from the informed consent process.	Approach to consent from staff and family.
Daily Life	Comments that provide insights to the pace and vibe of the neighbourhood.	Activities and routines.
Embodied Memory	Any comment that shows a clear reference to their past biography and experience.	Awareness or effects of dementia. Awareness of home. Humour. Alternate ways of communication. Personal disposition and nature. Personal and family life. Biographic identity as professional.
Living Experience	Ways people described their own experience of living with or around someone with dementia.	Changing needs and the need for flexibility. Family members experience of loved one's dementia; both positive and negative.
Organizational	Comments that convey issues regarding staffing ratios, inadequate spaces, proforma-driven decisions, and policies.	Organizational culture and policies. Financial-driven decisions. Staffing ratios and pressures. How staff cope, adapt and voice frustration.
Physical Environment	The tangible, the physical space, the architecture.	Adaptation of space. Access, memory prompts, care-related equipment, furnishings, décor, familiarity, building typology, homelike, sensorial dimensions, objects tied to identity, outdoor amenities, suites, common areas, views, wayfinding strategies.
Risk and Safety	Any comments that relate to how risk is perceived or managed.	Staff concerns. Staff strategies to manage risk.
Social and Relational	Comments and insights relating to different relationships.	Everyday language. Family involvement. Invisibility of person living with dementia. Knowledge of the resident. 'Me' versus 'them'. Mobility issues. People over space; politics of use of space. Social aspect of space.
User as Design Expert	Any user suggestion of how to improve layout or use of space.	Design suggestions and observations made by family members and staff.

Table 4 – Coding

The emergent themes and insights were structured into eleven different nodes or categories, serving as umbrella to related topics, a process aided by the data management capabilities of the NVivo software. This categorization of data provided a conceptual structure for associating common threads of information. It was also useful in identifying the underlying theoretical relationships, and rather than using it to identify patterns of generalizable explanations, it established a departing point to begin seeking comprehension and specific reasons to help unravel the complexities of the experience being studied (Graneheim and Lundman 2004; Megías et al. 2017). To achieve this, theory was linked to the emergent narrative, critically analysing the dilemmas and tensions they posed with other theoretical constructs, extracting meaning from apparent contradictions and convergences (Bochner 1997).

Abduction

> The abductive suggestion comes to us like a flash. It is an act of *insight*, although of extremely fallible insight. It is true that the different elements of the hypothesis were in our minds before; but it is the idea of putting together what we had never before dreamed of putting together which flashes the new suggestion before our contemplation. (Peirce 1934, p. 113)

Dissecting data to better understand content, recognizing patterns around topics, identifying recurring ideas or issues, and trying to make sense of how the emerging topics were interrelated started to suggest the multilayered complexity of the social context under research. Understanding the experiences of people in the real world was complex (Tohmé et al. 2015), as illustrated above with the attempt to diagram ideas and how these supported different constructs. Given that this research work was my first incursion into the field of social research, I gravitated to my cultivated knowledge and training as an architect which relies on creative and critical thinking to understand the different layers of a design problem. Staring at my notes and diagrams, I decided that the process used when trying to distill information from multiple sources into a cohesive design approach, could be mirrored in trying to create meaning from data. The creative thinking used in design could be likened to the creative approach of abductive inferences proposing meaningful explanations that made sense to explain the observed situations (Richardson, R. and Kramer 2006). This led me to adopt abduction as a method of explanatory reasoning; a dialectic process in which proposed arguments are constantly validated by inductively and deductively relating ethnographic data to existing theory (Pearce 2012; Wilson and Chaddha 2009), an approach resonating with my architectural training.

The design methodology used in architecture to understand the design problem at hand heavily relies on the knowledge of similar or related design precedents, on related architectural theory, comparable building typologies and models (Buse et al. 2017; Martin et al. 2015). By studying, understanding, and inferring design strategies applied in past projects, the architect infers design principles that can be transferred and applied to a new design problem (Heylighen et al. 2013; Pallasmaa 2011). Similar to the composition of music, which relies on a set number of notes, the formal language of architecture relies on a set number of geometric forms. It is through the creative interpretation of theoretical and precedent insights, composed in a manner that has never been done before, that the architect proposes a novel design solution to the problem at hand. Drawing a parallel to this familiar creative process, one which draws inspiration, knowledge and meaning from past models, I decided to apply a similar abductive inference approach to the data, using explicit theoretical insights that have been previously argued (Richardson, R. and Kramer 2006). As suggested by the Latin etymology of abduction, which speaks to being led away (Timmermans and Tavory 2012), fieldwork and the insights drawn from the data felt as if I was being led away from old assumptions of user constructs to new understandings of what the experience of a person living with dementia in a care residence was truly like.

It has been argued that the best qualitative research is steeped in various literatures, and that ethnography and theory are complementary and not opposing; with the best strategy to strengthen the former being to strengthen the latter (Timmermans and Tavory 2012; Wacquant 2002; Wilson and Chaddha 2009). This suggests that effective qualitative research is permeated with theoretical context in order to help dispel the most salient criticisms of ethnographic research; validation and generalization. I posit that by using theoretical sampling, where the assumptions derived from ethnographic data were linked to established theoretical arguments (Wilson and Chaddha 2009), addressed this potential gap. Failing to contextualize findings with existing scholarship would have risked disregarding well-developed concepts and domains (Timmermans and Tavory 2012). Therefore, aware of the direct correlation of reading sociological theories, exploring relevant topics, studying different ethnographies, and having a diverse theoretical context to relate findings to, relevant theory was associated to the different discussions. A range of theoretical precedents were used as reference to support the adopted abductive process, informing insights as data was analyzed. Some of the most salient standpoints were theory on design production and its construct of the body; on how embodiment, memory and identity relate; on how meaning is communicated; on the different constructs of space and place; and on affinities of objects and the physical environment. This theoretical grounding allowed me to associate findings that were being constructed from the data with relevant theory; a process consistent with the dialectic nature of abduction (Pearce 2012; Wilson and Chaddha 2009).

Adopting this abductive method for analysis proved to be a great fit for the data sets that were collected. It allowed for logical inferences from the observed social reality, which was often complex and 'messy', by seeking to associate the best theoretical explanation to the findings; prompting critical thinking that illuminated plausible explanations (Mitchell 2018). Therefore, abduction provided a creative way of identifying themes, as well as a means for continuity and generality of knowledge. It also recognized the value of intuition and experience in exploring the possible explanations of observed patterns by relating these to existing frameworks, leading to insightful understandings (Lipscomb 2012; Yu 1994).

Format

> *People shape their daily lives by stories of who they and others are… Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. (Connelly and Clandinin 2012, p. 479)*

The creative inferential process used to abduct meaning from data has a distinct creative parallel to my training as an architect to unpack complex user needs that must be interpreted into a cohesive design solution that captures the design intent, and that addresses the design brief provided. Both require a cultivated theoretical sensitivity and both demand the broadest theoretical repertoire in order to generate a creative proposition (Timmermans and Tavory 2012) that can hold as a valid interpretation of multiple data points. This creative endeavor of associating data to ideas ultimately contributed to crafting a meaningful story of the phenomena being understood (Richardson, R. and Kramer 2006), much like a building design attempts to create an environment which can be positioned as the ultimate story that captures the needs and voices of those who commissioned it. Nevertheless, despite this creative affinity during data analysis, a tension started to emerge as I evaluated ways to best represent the experience of fieldwork into the next stage of writing. This tension is shared by other researchers as one moves away from the close relational work with participants, to considering effective ways to present findings to a larger audience (Connelly, Clandinin 2012), as it has been argued that rich and vigorous presentation of the findings enhances transferability (Graneheim and Lundman 2004). Therefore, deciding what form to use to retell the tales that were captured in the field and the overall experiences of both the ethnographer and participants (Cunliffe 2010) was deemed critical. The experience of being immersed in this social world had made an affective impression in me and as such, I wanted findings to be presented in a sensed and felt format that reflected the impact of the stories that had been entrusted.

Having coded data, I had to consider what to omit, as it became evident it was not possible to include everything, yet I was concerned about discarding key ideas. A selection process that has in the past been referred to as "the agony of omitting" (Genzuk 2003), required a sensitivity to the risk of losing meaning of the text through the process of condensation and abstraction (Graneheim and Lundman 2004). In considering what to exclude, and acutely aware that one of the essential qualities of ethnography is detailed description, I had to discern how much description and direct quotations from participants to include. I wanted to provide the reader enough information to enable the full understanding of the research setting and the thoughts of the people represented in the narrative, endeavoring to achieve a balance between description and analysis that could then lead to interpretation (Genzuk 2003). Above all, I wanted to present findings in a form that could emphasize that participants had contributed with their knowledge of their social reality and their particular perspectives of their social world through the accounts of their experiences (Megías et al. 2017); sharing their joys, frustrations, challenges, sense of loss and outlook on life. I wanted to capture the depth and richness of not only the participant’s experience, but mine as well.

I initially focused my research work on the experience of the person living with dementia only to understand that their experience was a social one that could not be abstracted from the experience of the other user groups that constituted their social world. I entered the field intending to be a detached observer, only to discover that participants found a way to my heart as I became immersed in their world, acknowledging that good ethnographic pursuit is both about finding the voices of those being researched as much as finding my own voice (Cunliffe 2010). Therefore, I wanted to present my findings in a sensitive way, showcasing participants not as observed subjects only, but as biographic individuals capable of action; who retained an embodied outlook on the world and their milieu, where their words were the data that spoke to a specific and individual experience and truth.

One of the fundamental units that reflected this desire, one of the means by which identities were shaped (Rosenwald and Ochberg 1992), that described the understanding of said experience, was the use of story (Clandinin 2006; Clandinin 2007). Using narrative description to describe ‘lived time’ allowed capturing the thoughts and emotions that were interpreted as part of the shared experience, emphasizing the individuality of each encounter (Bruner 2004), where both the individual who entrusted me with their experience and I as the listener, produced the tale (Megías et al. 2017). As such, findings were composed of different stories and voices, interweaving in the text excerpts from conversations, field notes, personal insights and accounts that helped convey the richness and meaning of the different encounters by particularizing what was noticed (Cunliffe 2010) and the meaning constructed from the data. The different stories invite the reader to enter the horizon of the human experience of a person living with dementia in a specialised secure care floor, explained within the context of existing theory, given that as in most instances, the theory was already there before the story was heard (Bochner 1997).

Conclusion

This chapter summarized the different steps used in data collection and analysis, providing insights of the reflexivity invested in the gathering of data and the rigour in which it was analysed, while noting the judgements and self-awareness used in adopting methodologies to produce different data points. It described the strategies applied to enhance trustworthiness of findings, illuminating different dimensions of the same situation, with each method contributing a different layer of information (Morse 2016). And while the personal stories that were shared did not render undebatable facts, they opened an opportunity to further the dialogue (Bourdieu and Wacquant 1992; Ellis et al. 2011) around the environmental and embodied experience of living with dementia in a secured care environment.

Chapter V

REFLECTIONS ON FIELDWORK

Introduction

I started this research work as a continuation of a personal and professional journey that was prompted by my mother's diagnosis of Alzheimer's. Faced with the incurability of her condition, distressed by the anxiety and uncertainty of how this diagnosis would affect her, and our family, led me to explore ways in which I could further my knowledge about dementia. Therefore, my personal circumstance had already prompted reflections on how a person living with dementia experiences the physical environment. Attesting to the suggestion that we all have lives inside us competing to be lived (Bochner 1997), this personal encounter with dementia prompted my incursion in academia in the midst of a mature career as an architect. The following are some reflections on how this journey influenced this research.

My Sociological Gaze

Ethnographers have long admitted that 'who' the ethnographer is, influences 'what' is said and 'how' it is said (Jarzabkowski et al. 2015), suggesting that the ethnographic experience is innately personal (Cunliffe 2010; Jarzabkowski et al. 2015; Van Maanen 2011). It has also been argued that ethnography is fundamentally self-understanding; an interpretive enterprise which cannot be extricated from personal values (Geertz 1973b). Consequently, it is posited that once we enter to observe a social world, we inevitably introduce our perception of it; a bias (Bourdieu and Wacquant 1992). This link between my personal experience and the social context in which I have existed, constitutes my sociological gaze (Germov and Poole 2019).

Reflexivity implies that our personal inclinations are shaped by the values and interests that the different socio-historical locations we have experienced have bestowed upon us, thus rejecting the idea that social research can be undertaken insulated from our particular biographies (Atkinson 2007). This research was motivated by seeking to better understand the experience of someone living with dementia in a care environment, and by trying to explicate how design professionals conceptualize and design these environments in the hopes of contributing knowledge to how their production can enable and contribute to relational, user-centric dementia care environments. Therefore, my motivation, my past experiences, my lasting dispositions, and my habitus (along with the embodied sedimentations of the social structures which produced it), all informed perceptions (Bourdieu and Wacquant 1992). As such, these should be recognised, as my intellectual dispositions have undoubtedly restricted or biased in some way the fieldwork I have undertaken (Löwstedt 2015).

Me, the daughter

If I were to adhere to Bourdieu's theory (Bourdieu and Wacquant 1992) that there are mainly three types of biases that distort the social gaze – biological and social origin, my position in the academic field, and my intellectual bias - I would present myself as a middle-aged, Latino female, undertaking fieldwork for the first time in a setting that is both familiar and mysterious; a novice in the academic field, but a seasoned designer in the architectural realm. And while many researchers may approach a field of research from a strictly scholarly and intellectual perspective, without exposure to actual practice, my position was the inverse; I was approaching a field of practice that was familiar to me from a completely different academic perspective.

Like any other researcher, I have intellectual baggage that helped me make sense of that which I encountered; my own traditions, assumptions, forms of expression and personal expectations influencing this research work (Cunliffe 2010). Nonetheless, albeit undeniable influences and insights produced through intentional reflexivity, this work was never about my personal story. It was meant to investigate outside of myself, to learn about others. And while connected to the topic due to our family experience, it endeavored to maintain a degree of separation, thus allowing me to increase understanding of a social reality which I would not have been able to access solely through my reflections (Charlotte 2008). Yet, within the context of my experience, this work was undeniably personal.

Trying to grasp somebody else's point of view is not a novel pursuit, we do it every day in our lives (Van Maanen 2011). I would argue that my ethnographic journey on this topic started before my academic one did, as I tried to make sense of the way in which my mother was experiencing her world while living with dementia. This desire to understand her experience, my search towards an explanation of the 'how' and the 'why', and my attempt to build a bridge between these two questions (Katz, J. 2001) foreshadowed the method of research I adopted for this study. The ethnographic work I have undertaken suggests a natural progression in my desire to understand the human experience of an individual living with dementia, by studying not only the everyday life in a care home residence, but also immersing myself in the interactions, tensions, and relationships of this particular group of people (Cunliffe 2010). Furthermore, acknowledging the strong filial bond with my mother, a testament to our loving relationship and indoctrinated as part of my Latino culture, I favoured approaching this research topic from a relational and personal angle, trying to capture the complexity of the intense lived moments of life through the use of story (Bochner 1997). This reflected my belief that as social beings, we live storied lives and that personal stories are not only a way of disclosing information about someone's life, but conceding that they are the means by which identities may be constructed (Rosenwald and Ochberg 1992).

Me, the ethnographer

The decision to adopt an ethnographic approach resonated with my emotional and personal bias for this topic. In many ways, the stories that emerged resonated with my own experience. The pain and sorrow expressed by family members regarding the failing cognitive condition of their loved one was a familiar sentiment. The fear and concern of the unknown, of how the progression of dementia would affect their loved one, mirrored what I once felt. The depth of loss of a familiar way of life that had been forever disrupted by dementia echoed my own reality. Through this process, I was able to discover a generalizability of experience, where the stories that were shared seemed familiar, albeit coming from unfamiliar people. Nonetheless, through data collection and analysis, other less familiar stories emerged; tensions in the care home environment that were veiled were slowly revealed; groups of people, like staff, started to gain a more critical and influential role. As much as I had intuited that the essence of my work would be best conveyed through stories rather than theories, the connection of emerging topics to existing literature became glaringly obvious. Nevertheless, as much as I acknowledge the context of my personal experience, the work I undertook did not aim to be autoethnographic. My story was not the thread used for seeking validity. My personal experiences were not used to illustrate cultural experience, nor have I used my story to compare and contrast other people's narrative (Ellis et al. 2011). Yet every single point of collected data has prompted me to reflect upon my own experience, my values, my views; both personally and professionally.

Reflexivity has been of central importance in this study and has been used in every stage of the work, facilitating a connection with the research setting by enhancing sensitivity to the issues that were encountered. The process of self-reference also prompted a hyperawareness of my active role in the collection of data and of the potential effects my presence could have on the field of observation (Charlotte 2008). Furthermore, reflexivity aided me in seeking to increase understanding of the social reality being studied, in developing explanations of social forms and events by critically examining these by relying on existing literature to conceptualize and explain data. However, ethnography is not only about discovering what story to write or what truth to report; it is also about discovering who you are as an ethnographer (Cunliffe 2010). Personally, this process helped define my sociological lens, while prompting me to question deeply rooted values and preconceptions I had nourished throughout my architectural practice.

Me, the architect

My training as an architect has engrained in my psyche that design is a problem-solving endeavor. This academic preconception provided me with invaluable tools of inquiry: ability to identify a problem, proficiency in establishing design criteria, identifying challenges and opportunities in every situation, and a creative disposition to ably conceptualize and synthesize the many constraints into viable solutions. Above all, my training allowed me to develop an incredible attention to detail, prompting me to develop great observational skills. It has also sensitized me to a bias for beauty, for aesthetical compositions that are circumscribed into orderly solutions. Skills like attention to detail and great observation prowess were an asset during fieldwork. Having collaborated with the design team that worked on this care residence along with my deep interest in the physical environment, undoubtedly influenced my gaze, with my design skills and aesthetic bias unquestionably teasing my eye to gravitate to the immediate surrounds. And while existing literature had presaged that many critical assumptions that were once accepted as the bedrock of personal belief could potentially be ‘ripped out’ through fieldwork (Agar 2008), it was not until I was fully immersed in this work that I was able to attest to this. More than three decades of architectural training and practice were constantly shaken during my fieldwork experience. The culture shock of being immersed in the lifeway and physical environment of people living with dementia was tremendously impactful on my everyday practice as a designer of dementia care environments. This research has prompted reflection on my practice and on the effect design strategies and decisions have. It has allowed me to humanize the design problem, sensitizing me to the tensions decontextualized solutions create.

Ethnography has been theorized to be a 'liminal' discipline, straddling, or even serving as a threshold between two social worlds (Kleinman 1999). This ambivalent location of self where I was not truly a native of the world I studied, yet immersed enough for me to experience an internal 'tug', led to internal questioning (Kleinman 1999), resulting in continuous self-reflection about my architectural practice and about my values as a designer. In this regard, this work was a reflexive ethnography, as it was through reflexivity that I developed and adopted new ways of understanding the environmental experience of the dementia care setting.

Me, the neophyte scholar

My personal journey of coming to terms with my mother's dementia, my desire to better understand, my natural inclination to constantly ask 'why' or 'how', led me to a more formal discovery of knowledge. Constantly grappling with the inner tension of identifying myself as an architect that is discovering a whole new world of inquiry and critical thinking, I often felt that identifying myself as a scholar or an academic was arrogant. Nonetheless, as I approached fieldwork, mindful of being identified at the time as a leader within the organization, I was acutely aware of the need to carefully manage how I presented myself in the field, given the impact perceived status could have on participant's behavior, thus affecting data-gathering (Caruana 2015). Knowing of the potential effect my presence in the field could have on participants, measures to intentionally dispel any implications of abuse of status or power were taken. These included implementing an ethical and rigorous on-going consent process, effectively dismissing any insinuation that consent was being assumed based on my professional status (Homan 2001).

To further assert my role of scholar, I outwardly reflected my role by using subtle visual cues, like my attire, as well as adopting all visitor's protocols. Instead of wearing a corporate name tag, I followed the residence's sign-in procedures for external visitors, clearly displaying a visitor badge. A sign stating research was taking place was posted for all to see, providing everyone the opportunity to either join or avoid the field of study. Aside from adhering to committed ethical guidelines, my approach to this study was one of honesty, humility, respect to privacy, adherence to organizational policies; everything an 'outside' researcher would have been expected to do (Unluer 2012).

Conclusion

Ethnography is about understanding human experience. The knowledge mined through ethnography is a form of knowing from within; discovering how others live and how our own life in relation to others can create meaning (Cunliffe 2010). As such, the process of gaining knowledge is not a neutral action; it is profoundly tied to our own humanity. Therefore, the different lenses that have influenced my sociological gaze have been described acknowledging that who you are influences what you see and what you say (Van Maanen 2011). My intentional reflections, my willingness to ponder on how my 'insiderness' could potentially influence the quality of data and findings, enabled me to develop a capacity to accept and use criticism, to be self-critical (Norris 1997). This critical reflection helped mitigate any insider positionality by making field notes, keeping a journal, introspecting on where the 'self' and the 'other' began and ended (Chavez 2008). I remained acutely aware of not allowing knowledge of 'self' to become self-absorption, but having it instead be an instrument for gaining knowledge of others (Charlotte 2008). In addition to self-reflection, discussing concerns with my supervisors proved to be invaluable, as they effectively challenged me and helped me identify potential insider bias, prompting me to address issues with transparency and rigor.

Chapter VI

FINDINGS: THE CHALLENGES OF A HYBRID TYPOLOGY

Introduction

If the ethnographer is a miner of data (Gray 2014), then the data analysis process would be comparable to the sculpting of the rock from which a valuable gem is crafted. The quality of the 'gem', the insights and findings of the phenomena being studied, is dependent on the creativity and imagination applied when deciding how best to carve the facets that will ultimately determine the quality of light the gem casts (Mason 2011). Drawing from ethnography's concern of bringing light to the 'particular' and to the situatedness of social experience, and extending the gem analogy, the multi-faceted explanations offered in this chapter aim to propose meanings rather than measurement or causation (Mason 2006).

Acknowledging that the lived and social experience in the dementia care milieu was multi-dimensional, relational, and complex, the explanations of the 'how' and 'why', the findings, reflect a 'dialogic' and 'multi-nodal' approach (Mason 2006). Dialogic because of the way in which data was linked to theory, with explanations being constructions where more than one version was possible. And multi-nodal because the findings were drawn from a range of data types and user perspectives, providing insights into the tensions and plurality of experience in the dementia care milieu (Mason 2011). Each finding contributes to a more holistic understanding of this milieu, recognising that the social world the research aimed to explore was multidimensional and often existed in tension, rather than neatly integrated (Mason 2008).

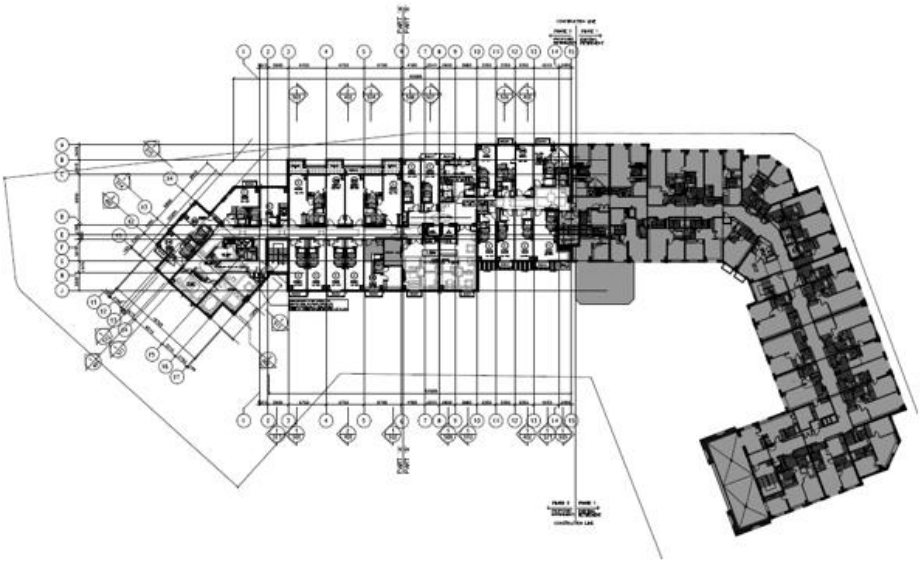
A Hybrid Typology

> *Among the various places that become meaningful for us, home is the single most significant one. Beyond meeting the need for a shelter, a true home is where we can be ourselves and be at home. (Chaudhury 2008, p. 7)*
>
> *A total institution may be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time,*

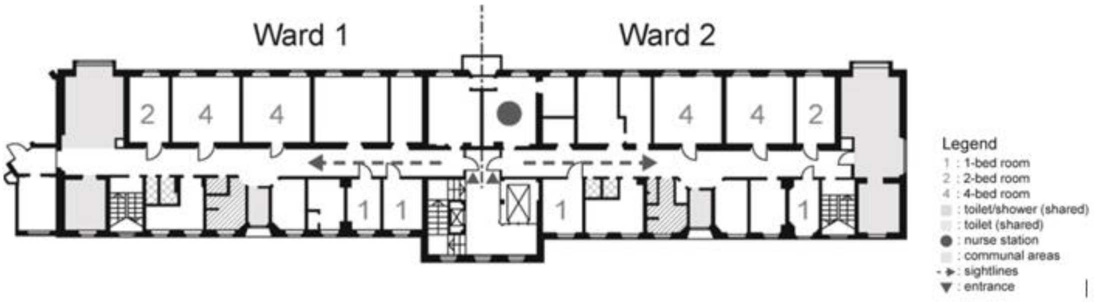
> *together lead an enclosed, formally administered round of life.*
> *(Goffman 1961, p. xiii)*

This research work focuses on a specific building typology, whether it is referred to as a retirement community, a care home, nursing home, a seniors building or as is the case of the host organization, a care residence. The ethos of the care residence is to provide bespoke care for older adults, depending on their assessed level of care needs, within a residential environment. Being a private pay business model, the host organization must continually ensure their 'product' (provision of care within a premium residential environment) is appealing, marketable, and profitable. These are critical factors that start presaging a deep schism or dual identity, for the offering and environmental experience must encompass and reconcile two different typologies with all that these represent: healthcare services and residential environments. This suggests that the elder person in need of care is reconstituted as a consumer who is both a resident and a patient, where the practices of healthcare are played out in hybridized sites of consumption (Martin et al. 2015); where the care home is neither a hospital or clinic, nor a private residence. The care residence is at the same time someone's 'home' and others' place of work. It is an arena where realms collide; the private and the public; the domestic and the institutional; the congregate and the personal. The experience within the residence is one of tensions; life at home, which is autonomous and regimented by one's individual preferences, and life within the care residence which is subjected to organizational policies and administrative regimes. Life at home surrounded by family, and congregate living where staff, caregivers and fellow residents are strangers (Dobbs et al. 2008). Consequently, this state of ambiguity affects the concrete, where architectural design cues must appear domestic to reinforce the residential aspect of the environment. And the intangible, where social cues must reconcile the institutional and residential aspects of life within the care home.

For the care residence to be successful, the overall offering must be appealing to the person who will live there and must also be attractive to the resident's family, specifically to their adult children who are typically the surrogate decision makers of where to institutionalize their parents (Buse et al. 2017). Therefore, the care residence emerges as a hybrid site where competing narratives and contested meanings must coexist (Peace and Holland 2001). Few physical spaces are infused with as many memories as our homes, hence establishing an extraordinary emotional bond with its typology. There is an amplified sensitivity and awareness of how a home should feel, conditioning our minds to assume how domestic space should be organized (Heathcote 2018). Nevertheless, the healthcare aspect of the care residence borrows from hospital spatial organization principles. With an emphasis on the single cell, or resident's suite, corridors emanate from a central hub where staff and residents gravitate to, reminiscent of a typical hospital ward where patient wings radiate from a central surveillance area (Prior 1988).



Care Residence Spatial Organization



Psychiatric Ward Layout (Ulrich et al. 2018)

Figure 12 - Floorplate Precedents

This borrowing from different archetypes - drawing from precedents that either prompt a familiar domestic cue, or respond to a health care functional requirement, or that aesthetically appeals to the eye from a hospitality perspective

- results in a hybrid typology that slides between the residential, hospitality and healthcare architectural models. Hospitality design features are intended to appeal to a wider audience in a marketing effort that dispels negative institutional association; residential cues are incorporated to echo domestic living; while the healthcare-related images become quiet evidence that care is provided within the same environment (Buse et al. 2017; Heathcote 2018; Martin et al. 2015).

Hospitality Cues

One of the principles borrowed from the hospitality industry is the focus on providing high level customer service within a beautiful setting that meets or exceeds safety and comfort. The décor, furnishings, furniture are intentionally displayed in a way that support the 'atmospherics' that can influence the decision to opt for the residence (Fottler et al. 2000). Showcased below, the amenities of the care residence - a pool, a cinema, the bistro, a hair salon, a spa - are designed to evoke a hospitality feel. These are used to project a welcoming environment that presents itself as aspirational; areas to read, to socialize, to watch a movie, with fine dining every day. With the emphasis on premium, the building presents a vision of later life that is very remote from the institutional models associated with care needs (Buse et al. 2017).

Figure 13 - Hospitality Cues. Marketing Collateral.

According to the data, the 'surrogate' decision makers are often the adult children of potential residents who typically tour different residences to compare offerings, thus ensuring the best care residence is ultimately selected. Observation notes showed that with spaces carefully staged and beautifully decorated, the reality of clinical care was disguised so as to provide a welcoming environment showcasing the many different spaces, activities and services available to the resident, family, and visitors. As confirmed through the interviews, families took pride in knowing that after exploring care home options, they settled for this care residence, perceived to be the best in class.

- Claudia: ... And when you started looking for a care home, was it you, was it the kids?
- Charles: Well my son and I went around to half a dozen care homes. And my son lives in Dundas with his family and his daughters are close by, and we looked at different places and we thought the location of this place is wonderful. And the facilities are looking good. And we looked at … half a dozen other different places… I wasn't worried about the money. This just seemed like the best choice.

Interview Transcript. September 12, 2019

Likewise, staff also expressed their pride of association in working in a beautiful environment, as captured below:

- Stella: Oh ya, I walk, and I park… You know I think … it's nice, very nice lobby when you walk in.

Interview Transcript. October 11, 2019

…………………………

- Claudia: And ah when you come to work overall do you think that the space helps you do your job? Are you happy you come to your office?...
- Lila: … I mean I think coming into the building, I think after working in the environment for a while you forget how lucky you are. That not everyone comes to work and this is what they come to…I think we all take that for granted…

Interview Transcript. October 25, 2019

Therefore, the aesthetics of the residence support one of the organization’s objectives which is to create a pride of association with the residence due to its quality architecture, location, design, and ambiance. This hospitality ambiance resonates with the substitute decision makers, usually the target audience for marketing campaigns and promises. Often a group decision made by the immediate family of the person living with dementia, or professionals tending to them, the adult children are actively involved in searching for a place for their parents. Research indicates that relatives involved in the decision of what care home to choose often interpret the quality of the physical environment as an indicator of the quality of care their loved one will receive, with the hospitality model proving very effective in distancing any institutional connotations associated with feared old age (Buse et al. 2017; Davies, S. and Nolan 2003).

Furthermore, acknowledging that typically, placement of a loved one in a dementia care place is an irreversible decision, it is one that can be guilt-ridden. Potentially interpreted as a sign of moral failure, of betraying the filial responsibility of caring for their parents, and fed by skepticism of institutional care (Groger 1995; Moody 1987), the surrogate decision makers tour different residences to ensure their loved one is placed in the best possible environment. Consequently, there is an organizational expectation to have the residence show ready, staged to reminisce a luxury hotel, thus supporting the brand promise of a quality, premium offering. Staging, a marketing strategy used to intentionally shape the experience and emotional response to the material environment to affect the reactions of prospects touring the residence (Bille et al. 2015), demanded the place be staged beautifully, with the interior decor creating an attractive ambiance, resulting in an appealing place that made visiting loved ones more alluring.

- Claudia: Do you like to come to the care floor to visit?
- Greg: Here?... Yes I do. I think this is the best. I’ve told people, I’ve said ‘ You should come to Memory care there is stuff going on there, there are people wandering around and you can talk to them believe it or not” You know. I say to them, the that Memory Care is not what you might think it is. It is a very, very nice atmosphere.

Interview Transcript. August 29, 2019

Domestic Cues

Kitwood’s seminal work on dementia care advocated for a person-centred care approach that acknowledges the persistence of the person living with dementia’s identity and personhood, despite cognitive impairment (Kitwood 1997). He argued that if a person-centric approach was used consistently in the care of the person living with dementia, the individual would develop a sense of well-being and personal security (Kitwood 1993). This insight was further theorized, arguing that people living with dementia should have a care experience within a setting that should reminisce their life at home (Simmons 2011), as home is argued to set the stage for our life experience; a psychological and emotional frame of reference from which all other places and life experiences relate to (Chaudhury 2008). It is argued that this theoretical background, the aspiration to deliver care within an environment that is a remembrance of past home life where the individual is still entitled to choice, self-worth, respect, self-determination, informs the environmental context of reproducing ‘homelike’ environments.

Figure 14 - Domestic Prompts

The above images, taken during fieldwork and from the organization’s marketing collateral, provide a sense of how the architectural design of the residence strived to emulate a residential scale that implied domesticity. From the exterior roof lines and materiality, the residence relies on evocative textures and palettes that are relatable to a domestic setting. The scale of the furniture is meant to feel cozy;

the way the dining area is laid out suggests a convivial and familiar atmosphere; the way serving of food is planned as an open kitchen, provided a family-style ambiance. The artwork, fireplace, and accessories, are all carefully selected and staged to suggest a 'homelike' environment, where the resident can feel at home; a place where frailty and decline are not obvious.

The Messiness of Care

The fear of ageing, of disease, of impairment, of frailty is a natural emotion that can contribute to the idea of advanced age being dreaded. Furthermore, being assigned to a group of people who are living with dementia, in a care environment that may well be their last abode, interpreted by some as a terminal place where there is nowhere to go other than death, can help explain why many people do not want to be associated, reminded, or come in close proximity to death, be it a social, personal, or biological death (Gilleard and Higgs 2011). The care needs related to the inevitable cognitive decline in the dementia journey are strong predictors for institutionalization (Falk et al. 2013), a decision that families living with dementia eventually often face. Data suggested that the decision to bring their loved one to the care residence was usually triggered by an event or a loss; be it the loss of independence, the loss of a loved one, of domestic life as known before, or care needs that could no longer be met at home, it was typically a difficult and challenging decision. The move to a dementia care environment therefore became a need-driven decision, where clinical care was required. Nontheless, it was an action that was full of uncertainties for both the family and the individual with dementia, as it represented a dramatic rupture of the 'normality' of feeling at home (Schillmeier and Heinlein 2009).

From the observational data it appeared that in order to appease the natural anxiety families experienced with this move, and in an effort to make this difficult decision more tolerable, the care environment was presented as residential and appealing as possible, with the raw images of clinical care tucked discreetly away. But dementia care cannot fully predict individual needs, behaviours, or reactions; it cannot orchestrate placement and movement; it cannot be neatly programmed to fit a rigid schedule, nor staged to look a certain way. The vestiges of care are messy, as photographs taken during fieldwork illustrate below.

Figure 15 - Images Signaling Care

These photos capture some reminders of the reality of dementia care. The wheelchair tucked away in the corner, away from the main common space of the care floor, reminds the observer of the mobility issues residents experience. The knot of vertical blinds stashed away from view, still seem to express the frustration and abruptness with which the resident with dementia, unable to operate the system to open the vertical blinds, had simply torn them down in order to be able to view the outdoors from their bedroom. The rolling bathing chair parked inside of the built-in shower highlighted the enhanced care the resident required to bathe, and that despite the shower unit having integrated grab bars, their individual care needs had to be met differently by staff. Electronic controls and number pads mounted near the exit doors, asking for secret codes in a specific sequence that even the sharpest of minds had difficulty remembering, was a silent reminder of the access controls people living with dementia are subjected to as a way to address the risk of them wandering away from the care floor. Medical charts, nurse's reminders and clinical gloves suddenly showed up, replacing the carefully curated artwork on the walls or the carefully selected accessories meant to emulate home. Gradually, once the initial layers of hospitality and residential cues were peeled back, the reality of care seemed to emerge unannounced; an undesired reminder of frailty, yet an unescapable dimension to the care environment.

The blend of architectural and design cues within the same environment resulted in a state of hybridness, with obvious contrasts between life at home - typically a personal domain – and the life within the care residence that, while it rejected the aesthetics of institutions, provided medical care. It was an environment charged with tensions arising from this amalgamation of different functional and experiential requirements, where caregivers shared how residential design strategies were not adequate for the delivery of care.

The concept of home embodies personal control and self-identity (Oldman, Quilgars 1999), yet the semi-public nature of the care residence and the ethos of the dementia care floor constituted a place that was a primary site of care provided by professionals (Falk et al. 2013). And although design strategies and architectural cues were integrated in the space to capture the physical, emotional, imaginative and symbolic cues meant to promote an experience and connection to home (Wiles et al. 2009), the meanings of home were expected to be drawn from a space that was ultimately an institutional setting, where the person living with dementia had to interact with strangers. Therefore, the resident living with dementia had to somehow reconcile their loss of space and possessions; expected to adapt to a different reality where preferences and daily life was regulated in an unfamiliar surrounding (Dobbs 2004). The ambiguity of meaning and experience resulting from this hybrid typology had a direct impact on the user experience, not only for the person living with dementia, but also for staff. Likewise, the architect, pressed by project economics and market demands, had been expected to fulfill the organization's brief of producing an environment that delivered on all projected finanical metrics; attractive and appealing to the surrogate decision makers, yet also expected to effectively function as a healthcare environment within the aesthetics of a domestic scale. These design and functional criteria at times collided, or diverged in meaning and intention. It is therefore argued that the disenfranchisement of the designer from the actual user of space generated architectural solutions rooted in an aesthetic narrative that was more an imagined conceptual model, than an effective solution to the functional reality of a dementia care environment. The following vignettes, extracted from the data, illustrate how this estrangement often resulted in misguided, presumed, or innocent assumptions which informed design solutions that were inadequate and erred practice judgements (Regnier 2003), arguably contributing to tensions in the user experience.

Tension in the User Experience

> *"A doctor can bury his mistakes but an architect can only advise his clients to plant vines." - Frank Lloyd Wright*

The permanent nature of buildings, the inherent difficulty of retrofitting architectural environments, and the limited flexibility of building systems - structure, mechanical, electrical, glazing, amongst others – poses a tremendous burden on the design team to ensure all functional, operational, and aesthetic criteria of the architectural programme are addressed successfully (Jensen and Maslesa 2015). As previously discussed, the overall design and development process is a complex network of relationships and decisions which involves a multi-disciplinary team of professionals with different stakeholders having parallel agendas. Development and construction of a building is an intricate endeavor that can take years to complete, thus adding a layer of complexity to the overall process due to this time lapse. Discontinuity of stakeholders, changing business models, evolving care strategies, volatile market conditions, shifting customer preferences, emerging trends, are some of the issues which lend fluidity to real estate development, and which must be absorbed as part of the design process. It is therefore argued that designers operate in a world of imagination unable to test solutions on a trial-and-error basis, making decisions based on incomplete information; anticipating, guessing, and intuiting consequences to design initiatives that can only be qualified once the building is fully operational (Horst Rittel 1971). Consequently, design misses or mistakes are often the result of not fully understanding the practical application of design initiatives, or of misjudging the effect of unforeseen side effects which can only be absorbed as testable insights for future designs (Lawton, Nahemow 1973). Therefore, the quality of a design, the functionality of the solution, and the efficacy of a spatial layout, can only be asserted in the indefinite future as different users interact with the designed space, and their experience with the space becomes evident.

As discussed, each building typology demands different design interventions, offering different contributions to the narrative and experience of the space. Nevertheless, through fieldwork, it became evident that the same physical environment had to meet demands, needs, and expectations from different user groups. Furthermore, within the commodified context of dementia care and given the accelerated pace of construction, to expedite the design process, while ensuring all residences adhered to brand aesthetics and operational requirements, the organization had developed proprietary design guidelines. These guidelines were a collection of design initiatives, informed by marketing and operational preferences, kept in a binder with relevant sections shared with the design team, arguably endorsing a prescriptive design approach that contributed to the disconnect of operator, designer, and the abstraction of the user. The following design misses, extracted from the data, illustrate the inherited challenges from misaligned and misinformed design initiatives, supporting the critique that adopting generic design guidelines can render decontextualized spaces and experience.

Design Misses

Design Initiative: Provide a 'bathing spa' that emulates a premium wellness spa, with a therapeutic tub, a television on the wall for residents to be entertained while they are bathed.

Most residents living with dementia need assistance with their daily activities, specifically with bathing and personal care (Ontario Long Term Care Association 2019). While some residents had their bathing assistance in their suite, others preferred baths. Anecdotally, it was shared that most residents would have lived in a post-war era, where water pressure was insufficient, thus preferring to have an immersion bath as part of their routine. As such, the residence was equipped with a spa that had a special tub which provided the flexibility to be used for a soak bath or for therapeutic uses. Following the organization's marketing desired image, the aesthetics of the room were well coordinated for ambiance and emulated a wellness spa, using a soft colour palette, introducing finishes like stone, large ceramic tile, and custom millwork.

Figure 16 - Bathing Spa

Notwithstanding design intentions, there was a clinical and austere feel to the room, arguably due to its institutional scale and furnishings, such as the Hoyer lift and the ample space in the middle of the room designed for wheelchair maneuvering. When I interviewed staff, this bathing spa was identified as an issue and a challenge:

- Vicky (Memory Care Coordinator): … and then like even if someone is not used to a shower we would try to accommodate a spa bath as best as we could. But a spa bath in memory care has been like the absolute worst. You know with the leaking, we've had floods because of it… and you can't fit a Hoyer lift underneath…
- Claudia: … exactly what issues you've had in the spa? … Talk to me about them as this is the first time you're explaining to someone why that bathing spa does not work.
- V: OK so it's very scary for the residents. Let me give you an example for Betty. We got her in the spa tub, she really wanted a tub, like a bath, she got in the tub, the door started to go up. She got scared initially because of the noise of the door. The TV in front has been ah a comment for a lot of them, for some reason. I think they think they're going like 'It's too close to the water' So they get very scared as the TV is too close to the water… they're not used to that right. So when Betty was in there you know we tried to turn on the TV. She didn't like that so we turned it off. The water started to come and then she got freaked out once it got to about her knees. You couldn't drain the tub or put the emergency break without breaking the

seal. So, she's trying to get up on the seat to escape and the seal is broken so now the tub is being released and the water's going everywhere. So safety for the staff, for the residents, you know she's trying to hop over the door because it's not draining fast enough, and then the only way to stop it is from breaking the seal and having the water go everywhere. So we have had a lot of issues even in the beginning with it leaking and not draining properly and you know the emergency button if you press it breaks the seal and the water goes everywhere rather than draining the water first… there has been quite a few incidences with the tub.

- C: So you don't use it at all right now?
- V: Ah no…

Interview Transcript. October 18, 2019

This detailed account of the user experience of both resident and staff, described a situation of chaos, fear, and anxiety. This experience is in sharp contrast to the soothing and calming spa-like experience that had been envisioned. As shared by Vicky during one of our interviews, this space was a great marketing tool, as family members were very enthusiastic in knowing their loved one would have access to this type of bathing assistance. As another staff member describes below, this was not an isolated incident.

- Claudia: … How often does that (the spa) get used?
- Stella: That, oh I'm not sure. I, maybe I have only twice but I, I find that the people that I've got once it, they get a little anxious so if the water, and the water won't stop until, you can't stop it like a bathtub… It has to fill up and if they're short and they're sitting in there it's going to fill up. You know a couple of times they've had to pull the emergency plug and have it come right out into the floor.
- C: So when you are doing the bathing assist do you prefer the bathing spa or their suites?
- S: Oh theirs. Oh I prefer theirs ya…It's kinda nice for people that are with a walker... ah I'm trying to think would a Hoyer lift go in there? Not sure. You couldn't get a chair in there... A what's really good is having a chair and a commode for everybody that needs it, you know that can't make it to there...

Interview Transcript. October 11, 2019

Stella’s account highlights other design misses. Not only does she confirm how anxious the person living with dementia feels when sitting in the tub, waiting for water to fill, she also points out the fact that the implemented design completely ignored the care reality of needing to use a Hoyer lift and did not consider the ergonomics of the intended user. The tub is a walk-in tub, not a typical residential immersion tub and the Hoyer lift is a device used to ease the transfer of a person with mobility issues, while reducing the physical strain on staff (see Figure 16).

Figure 17 - Hoyer Lift and Freedom Bath Tub.
(https:www.hoyerlift.com);(https://www.arjo.com)

Design Initiative: Provide quiet lounges at the end of the corridors for family visits, while also providing a walking loop on the care floor to encourage residents to exercise and safely wander.

The location of these lounges, away from the chaos and buzz that characterized the central dining area, was intentional. They were designed to provide a quiet common area to be used by families during their visits or for residents to socialize or watch television in a more intimate area. The three-season lounge was planned as a space where residents could enjoy the views of the garden and the sunlight coming through the generous glazing. Their placement at the end of the corridor was also meant to encourage residents to walk, allowing them to exercise and wander within the secured environment.

Figure 18 - Quiet Lounges

Furnished to provide a residential feel, echoing therapeutic design guidelines that assert that meaningful engagement will be facilitated by placing chairs at right angles to facilitate successful conversation (Calkins 1988), furniture was placed in a sociopetal arrangement to encourage socialization, conversation, and casual encounters (Mehrabian and Diamond 1971). In line with environmental evidence of colour theory and its effects on ambience (Brawley 2005; Marquardt et al. 2014), the sunroom used bright colours – lime green and bright blue – suggesting a fun and informal ambiance. The wood floors were introduced as a detail to evoke a residential porch; the stone texture on the walls, the floor to ceiling glazing, the faux beams all contributed to the suggested ambiance of an outdoor space. The other lounge had a more formal ambiance. With earth colours and a neutral palette as a field, this space was meant to replicate the domestic feel of one’s living room. The furniture was arranged more formally, yet still facing each other to facilitate conversation, with a more discreet range of colours, presenting a quieter space. With a carpeted floor and full drapery panels, framed art on the walls, and decorative light fixtures on the ceiling, the illusion of a living room was rendered for interpretation. Two beautifully appointed spaces, with carefully curated furnishings and clear design objectives, which data showed were seldom used. The following extract highlights how mobility challenges affected user experience and how residents preferred to remain in the central hub of the dining area, amongst the buzz of people, and the din of activity.

- Edith: Like we're trying to be polite for life enrichment while we have to get things set up or cleaned and they try and come down here, but when you try and bring people down here not a lot of them wanna do it. If you leave it in the kitchen a lot of them will sit there and participate in the activity. When they come down here they're grumpy cause they've had to walk all this way they don't want to go back so they just fall asleep…
- Claudia: … do you think it's the walking because there's, there's some residents that really like to walk.
- E: Yep there are some. But there are some that are just in too much pain.

Interview Transcript. November 9, 2019

The distance from the central hub to the end of the corridor would seem manageable to most people. Nonetheless, for someone living with dementia, this trek could seem unsurmountable. As shared by staff, some residents were visibly uncomfortable walking this distance, highlighting a dimension that would not have been assumed during the design process; physical pain, often undetected and untreated due to the individual's inability to verbalize their discomfort. This travel distance also triggered other symptoms associated with dementia such as agitation or withdrawal (Sampson et al. 2015), as reported by staff:

- Edith: … and by the time you bring them from the kitchen all the way down here they're mentally not with it anymore…and they're agitated and they're just over it…

Interview Transcript. November 9, 2019

This disregard for the physical limitations of someone living with dementia who is often dealing with other physical ailments in their old age, supports the criticism of architects conceiving the human body during the design process as an essentialised, abled-bodied user, disregarding the interaction between different body types and the environment, hence neglecting the corporealised nature of the physical space (Imrie 2003; Imrie 2004; Imrie and Luck 2014). In addition, disregarding the physical frailties of the person living with dementia contributed to the undermining of the relationship of the user experience, the individual's wellness and even their behavior, as related to the appropriateness of fit and the pressures and demands the environment posed on the individual (Lawton, M. P. and Nahemow 1973; Lawton, M. P. 1974; Zeisel et al. 2003). Furthermore, data showed that residents on this floor gravitated to where staff were, preferring the central dining hub as a space to visit, a use not anticipated in the original architectural brief. The following extract confirmed the need for architecture to interface with the everyday; recognizing the myriad of bodies and their particular mobilities (Jones 2014); demanding a production of space that is more attuned to the actual needs, preferences, and abilities of different users.

- Claudia: And ah we're sitting here at the end of the corridor in this very quiet lounge. And it is quiet because every time I seem to come by it's empty. Why do you think that is?
- Edith: Nobody ever comes down this way.
- C: Why do you think Edith.
- E: Cause it's too far. We always do the kitchen is more towards the other end. Everybody we always do activities in there. A lot of the people that like to do the activities their suites are closer to the kitchen. We've tried to start using the sunroom…But it's too far of a walk for people right now that we have…It's not do-able they don't like it.

Interview Transcript. November 9, 2019

Similarly, the location of these lounges, visually disconnected from the central hub where staff lingered, created additional stress because of having residents away from their visual field. Dementia is often associated with behavioural symptoms arguably rooted in unmet needs which can manifest as challenging behaviours, including frustration, fear, sadness, screaming, aggression or mood disturbance (Kitwood 1997; Kovach et al. 2005; Sampson et al. 2015). As such, staff felt more comfortable when they were able to visually supervise residents, knowing they were fully accountable for their safety and wellbeing. The intentional remote location did not account for this dementia care need. As shared by management, they were actually relieved these lounges were seldom used.

- Vicky (management team): Again it's very scary not knowing what's happening down there, if anybody is down there...we had … an incident with two residents that got physical and it was down there and no one saw

> it they would just hear someone yelling. You know so from a safety perspective, behavioral perspective a hundred percent open concept… I feel like it could be worse if residents actually went down there. We would have a lot more incidents but they don't… Sometimes the behaviors are happening in the sunroom, or in the lounge or down the hall I don't hear it, I don't see it…

Interview Transcript. October 18, 2019

These lounges were beautifully appointed with carefully selected furniture scaled to fit the space, ergonomically proportioned to mitigate physical discomfort and to encourage use. Nonetheless, given the realities of dementia care, where incontinence can be an issue for some residents (Ontario Long Term Care Association 2019), the stain-resistant fabrics were selected to ensure furniture was easily disinfected. Most of the furniture was single lounge chairs with arm support, meant to facilitate residents getting up from the chair. These design interventions were efforts to aesthetically address the care needs of the users, nonetheless data suggested that these design interventions had not achieved their objectives. Furniture was reported to be uncomfortable and not 'cozy'; the sterile beauty of the staged space had not properly captured the desired weathered comfort of furniture residents would have at home, as there was a recurring observation of how these lounges should have a comfortable sofa, as one would at home, which would have provided the option of sitting together.

Figure 19 - Lounge Furniture

She (Sara, the daughter of a resident living with dementia) feels the sunroom at the end is redundant and a waste of space. Nobody uses it, it is too far away. She says that when she takes her mother there, by the time they get there they are tired, and given the uncomfortable furniture, she doesn't feel compelled to stay. She mentioned:

- The room looks like a show case. It looks like something staged in IKEA. Nice to look at, but not practical…The furniture is very uncomfortable, it is firm and too hard. The vinyl fabric doesn't help.
- It does not feel like home. There is no couch or even a nice coffee table where people can put their feet up. Just think, when you go home, don't you just want to throw yourself on a comfortable couch and put your feet up?
- The room does not have a 'patina'… She prefers to take her mom to the conservatory on AL (Assisted Living), as the furniture looks more residential and feels more comfortable.
- The sunroom feels like an airport lounge; it feels like I am not supposed to be sitting there for a long time…It doesn't feel open nor inviting. Lights are never on.

I asked her why she wouldn't turn the lights on, she said it felt like she shouldn't touch anything. I said to her that this was her mom's home…that should she go to her mom's home before, would she had felt comfortable turning the lights on. She said yes, but not here…she doesn't even know where the switches are.

During this interaction, Kim (staff) was standing close by and she also offered her comments:

- Yeah, the furniture is very uncomfortable. But the vinyl is good, as just look at the dining room chairs, they stain so easily. The vinyl is easy to clean.
- Nobody likes that sunroom, nobody uses it unless they have dancing classes and Heather when she goes to work on her puzzles.

- Yes, when you use those chairs, they are so stiff it feels like your back will break.

Observation Notes. June 5th, 2019

The negative feedback was consistent; the lounges were seldom used and did not work well for residents. The furniture was uncomfortable, the location was too remote, exacerbating mobility issues. Staged to evoke a domestic living room, the space was compared to a showroom or airport lounge, suggesting an obvious disconnect of design initiatives with the actual spatial experience. This design miss was further confirmed through comments made during other interviews, as noted below.

- Vicky: It just doesn't work for the residents. The chairs are good. I like the colour of the chairs, and I like how firm they are so those are actually pretty good and they're wipeable so that was actually great, very good. I think it's just more so the tables, and the fact that it's all the way down the hall that nobody goes to… the tables are way too low. So if we were doing… so if we try to actually… set activities to be there and make people kinda come and have designated activities there; but at the same time you have to choose wisely what you pick. Because if it's anything with a snack or anything with drinks, things like that, we can't do it down there. Because the tables are way too low…

Interview Transcript. October 18, 2019

…………………………………….....

- Edith: But one thing I will say is that furniture in the sunroom should be a little cozier... that's firm furniture. I get it, it's plastic, it's easy to clean, wipe down. That is not comfortable for anybody to sit on for a long period of time. It's supposed to feel like your home. Nobody has that type of furniture. You go in all their rooms they've got those sunken couches. Or those pillow top couches type thing it's not very comfortable at all.

Interview Transcript. November 9, 2019

………………………………………..

- Stella: Well in there, there is a sofa for two. And I know like Heather and Daisy will be together on it. Or even whenever we'll get Adam in there with Joan, they would sit together on it.

Interview Transcript. October 11, 2019

While the design intent of providing individual lounge chairs was to enable resident's autonomy by making it easier to get out of the chairs unassisted, data indicated that the overall layout of the room was not functional, resulting in a beautifully staged space that was never used albeit being envisioned during design as a place of encounters. Furthermore, unlike residential use, institutional furniture is usually selected based on long-term durability, ease of maintenance, and value (Grantham 2010), often resulting in aesthetic and functional tensions as exemplified by the vinyl fabric that, while practical to clean, did not provide the soft tactile experience of a residential textile.

The dimensions of the furniture were carefully specified to address the ergonomics of the intended user. Nonetheless, they failed to incorporate the embodied domestic practice, the comfortable and familiar feeling of sinking into a well-used couch. Likewise, the chair placement was designed to facilitate group conversations, but had failed to acknowledge the sense of connection that comes from sitting close to a loved one; the human warmth of feeling companionship that comes from the embodied familiarity of touch, of someone sitting next to you. These findings would arguably suggest a link of how physical comfort and familiarity of experience enhance the sense of being 'at home', congruent with similar findings where 'home comfort' was associated with the cozy feeling of being 'at home' and 'comfy couches' were associated with the 'ideal' home (Ellsworth-Krebs et al. 2019).

Design Initiative: Design the dining area to resemble a residential dining room, avoiding institutional models where serveries are protected by sneeze guards, or gates. It should be open plan so residents and staff can interact and participate in the rituals of dining, as they would at home.

The space designated for dining was centrally located in the floorplate. With generous glazing and a view to the park, across from the administrative area, this central core had become the hub of activity for the care floor. Data revealed this space had evolved to its current use partly due to the convenience the open plan provided, allowing visual supervision of residents while staff completed their tasks.

- Claudia: … What about the common area where Vicky's office is?
- Edith: I find it useful when it's by the kitchen yes, because if we're doing our paperwork we can still hear. We're close enough to hear if anything's starting or if a resident's getting agitated, we're right there. We're not at say if we were to have it here at the end of the hall…that would be horrible because we can't hear anything. We're not close enough and by the time we get to it there's already an incident that's happened.

Interview Transcript. November 9, 2019

Figure 20 - Dining Area

Having the television always on was convenient for staff, residents, or visitors, to watch the news or a movie. With comfortable tables and chairs, soft seating in front of the fireplace, and generous views to the outside, this space had become the place where residents ate; where families visited; where staff congregated to chat about how their day was going. As shared by one of the resident's daughters during our interview, the social aspect of this space was what made it so inviting:

- the reason why residents all gravitate to the dining room is because the lights are on, there is activity, laughter, staff are there, 'there is love'.

Observation Notes. June 5, 2019

It was where people came to have a glass of water or a cup of tea; it was the first place to be checked when looking for someone – be it resident or staff. The familiar smells of fresh bread permeated the air, coffee brewing invited the senses to connect with home, and the din of ongoing conversations and the clatter of dishes was a welcomed companion when feeling lonely. The architectural space that was carefully designed to evoke a domestic kitchen area had been transformed in function by the users of the space, testament to the dialectic relationship of space where the user's creativity, often prompted by practical needs, adapts the architectural object to fit their need, while also being stimulated by the qualities the space provides (De Carlo 2005). Nevertheless, data showed that the main function of the space remained as dining services. Embedded in the design were domestic cues meant to remove any institutional cues of how food was served, evocative of therapeutic design guidelines that associate resident autonomy and interaction with the provision of domestic kitchen features, like appliances and the inclusion of a 'lowered open counter' facing the kitchen, to facilitate social engagement (Calkins 2018; Chaudhury et al. 2017) some of which, as data revealed, were design gestures often disconnected from the reality of dementia care.

Claudia: So the idea, from a design perspective, was to make it look like your home …

- Stella: And if you had your home and you were taking care of your own mother or father … who had Alzheimer's you would not allow them in the kitchen alone or near anything hot or where they could be hurt. They go into the fridge by themselves too. They don't remember what they're in there for and they might start taking things and drinking and put it back. You know we gotta watch…

Interview Transcript. October 11, 2019

The dominant feature of this space was the open-style food servery and the breakfast counter island anchoring the room meant to replicate a typical breakfast kitchen counter at home. This design initiative was meant to prompt the informal interaction of staff and residents during meal service. Initially designed with stools neatly arranged along the counter, a seating arrangement that has since been removed given resident's mobility and balance issues, and their inability to maneuver high stools.

As observed, the tables were elegantly set with tablecloths with utensils rolled in napkins, evoking a fine dining experience, yet the tableware was bright yellow, a striking dichotomy of fine dining. The china colour selection was explained as a wellness initiative and as a sensitive approach to help residents more easily handle tableware, acknowledging the impact environmental furnishings can have in providing therapeutic and enabling opportunities (Calkins 2018) to sustain autonomy, while addressing the eventual decline in visual abilities and contrast perception due to dementia (Neargarder et al. 2003). The back counter proudly displayed a series of shiny stainless-steel appliances, showcasing the level of service in the residence, yet for staff, these posed a potential safety risk to residents.

- Claudia: … I've seen so much of the work happens in the dining room… How do you feel about the design of how the island is and the equipment there? Do you think it's practical? Is there anything that you think … this could make my job easier, or this makes my job harder the way it is?
- Stella: Funny you should mention that … a lot of us believe that it should be made safer because of the cognition of the residents.
- C: … can you elaborate on that?
- S: … you know even if you had a type of a gate, even, like I'm thinking I had five kids I had to keep my kids away from the stove and out of the kitchen and you know when I was opening an oven and this kind of thing. We have people we can lock the knife drawer. We don't have any sharp knives up here, when the kitchen downstairs comes up they bring all their own… it's just sometimes we've had some people come back and you know try to put things in the toaster because they don't remember what the toaster is and you know we'll keep all the toasters unplugged but what if you didn't that day and somebody's sticking a telephone in the toaster and you're trying to you know... It's just it's a danger or the stove the heating bins get quite hot… We turn them on about an hour before the meal. Shut then off after the meal… but still we've got people behind us when we're serving and plating...

Interview Transcript. October 11, 2019

The open-ended breakfast counter was meant to invite residents to come behind the serving counter, as they would have done at home, encouraging them to reach out for whatever they needed, enabling them to interact with the kitchen space. Nonetheless, data suggested that the exposure to risk and safety of residents living with dementia were not fully considered or understood during design. As observed, these risks ranged from residents unknowingly touching hot surfaces and burning themselves, or diabetic residents being able to access sweets and dessert at any time, or infection control issues due to residents opening the refrigerator to drink from a bottle of milk as they would have one day done at home. The following excerpts narrate some of the issues resulting from this open design concept.

- Claudia: You would prefer if they couldn't access behind the counter.
- Stella: … all of us have said "Wouldn't it be nice to have even a baby gate" That's what we're all, we're all mothers, or something. You know, where they, they know that it's not a passageway with the walkers especially too. Like you got Jeffrey… and you've got the dishwasher open and he's just headed right there… You know I mean we're watching but there's one person in the dining room cleaning the whole of dining room and people still eating and then you go down to the dishwasher and it's very hot steam and you don't realize, he's fast. People are fast, even if they have their walkers.

Interview Transcript. October 11, 2019

Even though the centrality and openness of the space has made this central core the 'hearth' of the care floor, the transfer of domestic design principles applied to a dementia care environment created additional pressures for staff to manage. In particular, staff reported their apprehension in terms of resident safety. The effects of these safety concerns and perceptions of high risk by staff have been reported in similar studies, where the assessment of risk presented acute dilemmas in dementia care environments, becoming a stressor for staff and at times influencing care approach by overriding the individual's rights (Cantley and Bowes 2004). Therefore, congruent with findings from other studies (Gilmour et al. 2003), regulating risk, freedom of action, and autonomy was a problem that created tensions and constant negotiation. The frontline caregiver focused on the physical aspects of safety – residents getting burned with hot steam tables, cutting themselves with sharp objects, or getting ill from eating or drinking from the wrong source – while the person living with dementia and their family were arguably more focused on maintaining the individual's identity by enabling the person to freely interact with the environment and others.

Moreover, the image of marketed services had to be upheld, as this was an area that was fully on display for family and friends and was therefore closely regulated by the organization as conveyed by the Coordinator:

- Claudia: But your concern is, is safety again.
- Vicky: Yep. Ah residents can go in there. We only have a few that kinda go behind there, and they can touch that right and then there you go. Like there's a burn right there. You can't block it off because we're not allowed to.

This tension was aggravated by the pressure the management team felt to deliver the marketed 'fine dining experience' with inadequate staffing ratios, an issue that would not have been considered during design. The lofty goal of fine dining was often not achieved, adding to the sense of frustration of those who deal with the realities of care.

- Vicky: It's because, our biggest pain point … is the lack of dining support. We don't receive any support from the dining room, so the biggest struggle that we have, like one of my staff, one of my PSW's *(personal support worker)* who are certified to provide care, is in the dining room cleaning the dishes, setting the tables… you know, giving out snacks and things like that. That expense like is six hours a day in the dining room for our PSW… that's a lot of time. ….. everybody knows that that's a big pain point. But at the same time you know, you expect fine dining… So, there is no way you can expect fine dining in memory care neighbourhood with PSW's serving when they're getting pulled left right and centre. That's not possible right, and like you'll see. Like I don't know if you've observed a mealtime like the PS – like they're amazing and you know we have our show plates you know, things like that, like we have that but it just, it just doesn't work.

Interview Transcript. October 18, 2019

Data revealed that staff and management were acutely aware of the expectations associated with culinary services; provide well-balanced and nutritious food, catering to individual preferences, while ensuring resident safety. Furthermore, dining services had to deliver on the promise of a premium fine dining experience within hospitality-level standards, arguably contradictory to a homelike meal. As expressed by management and staff, their inability to meet all expectations of safely caring for residents within the expected service delivery model, while managing the pressures of a dementia care environment and the customer demands that come from families who pay a premium for this expectation, was a source of stress and tension.

- Vicky: … you know from a culinary perspective that's also one we struggle with. I think the idea and the model of having the RCP's *(resident care provider)* in memory care… serve the food, plate the food do the dishes right in the neighbourhood was because you know, and I think the thought process is good, the RCP's know these residents best. I think what maybe we're lacking though is that the RCPs also have a certain skill set right. And culinary's not their skill set. They're not servers … presentation of food … they're not as conscious as – ok that's been sitting, you know the heat's not gonna be there…I haven't had the steam table on long enough so my food's not gonna be as hot. They're not so worried about that…I think they are truly focused on the residents and getting the residents the food and you know be the same as me serving my family dinner right. I mean I'm not so worried. If I have company over I may take a little bit of extra time and plate it differently… their focus is just you know yes that people get the nutrition and get the food, not necessarily on you know that, that service aspect. Which is a challenge for us... we have used the resources that we have available and tried to shift…to have a culinary person, at least up there plating the food…. They're not serving, but someone's supporting the plating of the food and I think honestly for us to be able to move the bar to provide you know the service in what our residents and family members are expecting for what they're paying for…

Interview Transcript. October 18, 2019

Design Initiative: The dimensions of the suites are regulated by metrics that safeguard financial returns. Suites must be efficiently designed based on prescribed gross floor area ranges and efficiency ratios, where leasable floor area is compared to overall gross floor area. Furthermore, the width of the suites shall be determined by the most effective structural grid to maximize yield.

As previously discussed, the unit of design that prevailed on the floorplate was the individual cell or residential suites, a clear borrow from hospital design. The care floor had double-loaded corridors, suites on each side, flanked by common amenity spaces. The geometry of the building allowed for different suite types, ranging from studio or bachelorette units to one-bedroom suites. These suites were efficiently designed to provide a sleeping area which was typically tucked away from view should the door be propped open, a small closet, a private bathroom designed to facilitate care support, a generous window to the outside and in larger suite types, a separate living space and balcony.

Sample memory care one bedroom ~ 408 to 580 sq. ft.

Sample memory care studio ~ 318 to 504 sq. ft.

Figure 21 - Memory Care Suites

Similar to hotel rooms in size, yet with intentional residential details, these suites were finished in a neutral palette to ensure mass appeal; conceptualized as a blank canvas where residents could personalize their private environment. The basis for all financial metrics, the number of suites and the suite size was critical in deriving staffing ratios. They were the unit used in evaluating the design efficiency of the floorplate and a reference in establishing the critical mass needed to be able to provide the proposed level of care. These suites were designed with individual temperature control, with access to cable television and wireless internet. They met relevant code criteria: fire safety, smoke annunciation, were provided with a nurse call system, and met maneuverability standards. Above all, they had to appeal to both the resident and their family as a residential space meant to be their new 'home'. As evident from the comment below, albeit these design considerations, residents were keenly aware of how limited space was in comparison to their previous homes:

> Sally went into the wrong suite. I offered to help her find her suite and she said to me: You told me you were showing me to my place. This is my bedroom. Where is my living room? To which I was honestly taken aback. I said to her, this is your suite. Again she repeated: This is my bedroom….

Observation Notes. June 10th, 2019

The ambivalence of meaning derived from space designed to represent home, yet also expected to function as a place of care, was felt by the residents as well as care staff. The following excerpt highlights that while the suites adhered to residential aesthetics and design standards, the realities of care and the associated infrastructure required, were not fully incorporated into the design solution. This gap resulted in challenging and unfavourable conditions for staff to deal with, contributing to stress and tension in their work.

- Claudia: Tell me about…some of the things that are not working so well that maybe make your job a little bit more difficult.
- Edith: …one of the residents has a Hoyer lift… it's tight to bring her off the bed and try and bring her in the bathroom. Like you have to make sure all doors are closed … The bathroom door opens…if that was a sliding one that would be helpful … the doorways in the bathroom some of them should be bigger…for the wheelchairs, that are for bigger people

These comments, coming from those facing spatial challenges resulting from incomplete briefing of requirements, support the thesis of prompting a reflexive architecture that is sensitized to the multiplicity of corporeal schema of the body, and the need to further corporealize codes and standards (Imrie 2004). Different user needs must be acknowledged, as people's bodies are not the same size as conceptualized by codes and standards.

- Edith: … we're trying to accommodate everybody as best as we can but even when we have a gentleman that I'm telling you is seven feet tall, and his wheelchair is longer obviously, but with his bed being right to the wall we still hit his feet sometimes. Like it's just… the bedroom … make it all a bit bigger…

Interview Transcript. November 9, 2019

While the suite 'cell' was the modular unit for the layout of the care floor, data indicated that a one-size-fits-all approach to suite design was inadequate. Data also revealed the challenges staff faced from the gap between design intention, a residential 'home', and the clinical requirements, objects, and equipment needed for care delivery:

- Claudia: What do you think in the suite makes your job difficult or your job easy?...
- Stella: Well easy, is the space… sometimes there's lifts. Hoyer lifts that you have to store away in the bathroom bring it out…and the wheelchair at the same time beside the bed … the windows are really nice to have it's nice to be able to open the window and have them look out even if they're in the bed you know… maybe electrical outlets I don't know I'm jumping wires a lot…Outlets… I don't know, we jump wires beds …we have to do care on both sides and pull the bed out, so jumping over the wire, you know, like it's nowhere else to plug it in except at the bottom of the bed… it would be nice if there was one at the top…

Interview Transcript. October 11, 2019

This example illustrates how during the design phase, the suite would have been imagined to be furnished with a residential bed, not a medical one which would require electrical connections. Having omitted this requirement resulted in daily gymnastics from staff to clear the wires, posing not only a challenge to their duties, but also a tripping hazard. Moreover, the lack of understanding the sequence of movement demanded by care delivery, also created additional challenges for staff:

- Claudia: … when you say we need to do care on both sides can you elaborate on that?
- Stella: … if they're in a hospital bed… they need to have two-person transfer, two persons helping them with brief changes, bed baths… you pull the bed out somebody goes in between the wall and the bed…to assist. With the rolling of the bed pad, lifting them up this kind of thing…an alternate place to plug it in…
- C: But what would you plug in?
- S: like those hospital beds have air constantly pumped into them…So there's a lot of plugs… I'm not sure… haven't really looked around all I know is I'm jumpin' wires, especially in 2216. Am wondering if that could run to the head of the bed would that be any better. I could not, it maybe it's not the design it's maybe just the cords aren't long enough or the bed…is repositioned wrong but that makes it difficult. You don't wanna trip while you are doing care…

Interview Transcript. October 11, 2019

These comments by staff support the need to conceptualize the spatial design of suites with a deeper understanding of the functions of the healthcare being provided. The coveted residential ambiance cannot suppress the reality of function nor can the architectural end product be dissociated from use, as form that properly addresses function is one of the fundamental parameters of quality of space (De Carlo 2005). In the need to propose design solutions that are 'homelike', the reality of someone living with advanced dementia needing a hospital bed that continuously pumps air was never contemplated.

The tensions emerging from this hybrid typology of space and use were palpable to staff and residents alike. The care residence had to achieve a residential scale, where people could react to cues meant to prompt memory of 'home'. These residential design interventions were influenced by the organization's vision to create care environments that do not look institutional, that feel like home, and that show as a premium hotel. As conveyed in the following comment, the synchrony of objectives often resulted in confusion for the person living with dementia.

- Lila: It was interesting the resident that I was talking about where initially this was kind of put as this is a hotel and you know she would go on about 'Yes a lovely establishment but I just wanna call and go home'… or she wanted to go see the sights because she thought this was a hotel; she thought it was a city she had never seen…She wants to 'just go out and explore' and 'she'll be right back'… she actually got to the point where she pulled up a chair to the elevator and was just pushing the button continuously…and we would say 'Unfortunately the elevators you know… they're not in service…'

Interview Transcript. October 25, 2019

The care residence was an architectural hybrid that wanted to be too many things for different people. At times a cruise ship environment where you could choose activities; at times a premium hotel that enticed you to stay. A new home for residents coming for care, a healthcare environment for nurses trying to find efficient ways to manage tasks. During the design development of the residence, branding, marketing, and operations were heavily involved in critiquing the proposed finishes and overall aesthetics of the building. Furthermore, specific design criteria were provided to the design team to ensure the operationalization of these care concepts were viable, albeit it would seem, within a vacuum of insight to staff functional needs. The dominant design direction was to ensure the building did not read or show as institutional, but that through its design features it would feel like 'home', a direction that arguably disregarded the practicalities and pressures demanded from caring for people living with dementia. This misalignment resulted in additional pressures on staff who were compelled to deliver the care vision that was promised to the resident's families, while also wanting to meet the targets established by the organization. The following comments demonstrate how conflicted management felt when unable to perform to the highest levels, expressing disappointment at their inability to deliver what was expected.

- Vicky: We're advertising that we can do pretty much everything, they have specialized services, and like they do, and specialized activities and things like that. My staff are great at doing them. But when they don't have time who's doing them?

Interview Transcript. October 18, 2019

……………………………..

- Lila: … I think the family wants nothing but the best, is the reason that they've chosen us; is the reason that they, that they've decided to have their loved one stay with us… they want nothing but the best… but from our… you know, our sales and our marketing perspective… that's what we are, that's what we're selling. You know we do our best to upkeep that, but it does become challenging… I think we underestimate from a cognitive standpoint from a cueing and re-directing, I think we underestimate the amount of time that can take.

Interview Transcript. October 25, 2019

Conclusion

Residential care environments are complex, with intricate webs of interactions of people, the environment, and culture (Johnson and Barach 2008). Expected to function as a place where individuals can feel at home and at a clinical level, where healthcare is being delivered, while maintaining a marketable ambiance that emulates a hospitality environment. Findings highlighted the many tensions of the hybrid architectural typology of the care home. This is an area where future theoretical insights would be valuable. Critically evaluating how each typology affects the overall dementia care experience could help guide future design and operational strategies. Further research on this area could also help conceptualize an architectural typology that is more sensitive and responsive to the experiential issues related to dementia care practices.

The discussed design misses are examples of misaligned design initiatives, where the envisioned architectural space did not respond to the functional requirements of use, resulting in ongoing challenges, suggesting a lack of understanding of the everyday context and pressures of dementia care. These findings support the critique of applying design guidelines without contextualizing them to particular situations, reaffirming the need to widen the evidence-based theoretical lens to evolve current guidelines from environmental attributes of generic settings to guidelines that prompt reflection on particular contexts. This evolution would require building upon current knowledge which associate therapeutic goals to environmental attributes but arguably disregard embodiment; be it embodied knowledge of care practices (the basic knowledge that care is delivered from both sides of the bed, thus requiring more than one outlet for example) or embodied experience (the embodied familiarity of touch from someone sitting next to you versus assuming face to face seating prompts social engagement). I thus argue that design guidelines need to be corporealized to propose design parameters that acknowledge embodiment, that consider different levels of design intervention to best support the individual within their personal trajectory of dementia and of ageing, and their ability to consume space.

This evolution would also imply a different approach to design practice, demanding a more reflexive disposition, a more empathetic approach to design, and moving away from conceptual design shortcuts, often facilitated by essentialized checklists offering guidance for design decisions. I posit that a more insightful and qualitative dissemination of therapeutic and functional goals associated with environmental attributes would arguably encourage a more critical evaluation and application of prescribed standards. Designers would also benefit from a central repository of evidence, a platform providing insights on experiential evidence to be analyzed and considered for future designs. Lawton (1973) suggests that misapplied design solutions are often due to lack of knowledge. It is therefore critical that the design team be educated in the nuances of dementia care design. Furthermore, the architect must also be well versed in the organizational philosophy of care, as the physical setting must be congruent with organizational policies, care, and relational practices (Chaudhury et al. 2018).

Data also revealed that designing based on metrics, be it financial or design parameters, essentialized the individual by disregarding particular needs and plurality, supporting the need for a more insightful and inclusive design process (Imrie 2004). Organizational design policies could be established whereby the care operator endorses a closer collaboration during the early phases of design between the design team, staff, family members and above all, with people living with dementia, thus allowing for enhanced understanding of each user group’s pressures and needs, potentially resulting in a more appropriate and cohesive design brief. Ideally, the same collaborative approach could be encouraged to canvass insights and feedback after the environment has been in use. The organizational design policies could require post-occupancy working sessions which would allow the operator to maintain a ‘living’ document which evolves through evidence, dialogue, and time, to better direct future design commissions.

The evolution of experience and use in the building should also inspire the organization to incorporate true person and relationship centered care practices in their policies. Staffing ratios and roles need to be realistic and carefully evaluated to mitigate the reported tensions of trying to provide the envisioned care within allocated resources. Dementia care is a practice that demands time to understand the individual; staffing models should reflect this and not be based on formulaic time/task calculations. Likewise, small gestures and relaxation of organizational aesthetic control, like allowing residents to bring their own furniture to be placed in lounges and common areas (a familiar couch, a rocking chair, their own favourite dining chair), could enhance resident’s sense of belonging.

Chapter VII

FINDINGS: CARE AND PLACE

> *Mead explained that in the animal kingdom, if you break your leg, you die. You cannot run from danger, get to the river for a drink or hunt for food. You are meat for prowling beasts. No animal survives a broken leg long enough for the bone to heal. A broken femur that has healed is evidence that someone has taken time to stay with the one who fell, has bound up the wound, has carried the person to safety and has tended the person through recovery. Helping someone else through difficulty is where civilization starts. (Byok 2012, p. 254)*

Introduction

Care enriches our lives and strengthens our ability to function successfully and to thrive (Milligan and Wiles 2010). In more generic terms, care can be considered as the vested interest of one person in the well-being of another (Silk 2000). Advances in knowledge regarding care has challenged the view that care is a unilateral and unidirectional activity, suggesting that care actually involves a reciprocal dependence in which both the individual being cared for and the care-giver are involved in the co-production of care (Fine, M. and Glendinning 2005; Milligan 2005). Furthermore, there is a growing recognition in dementia care literature of the impact the physical environment has on personal wellbeing (Fleming and Purandare 2010; Marshall 1998; Steele et al. 2019), effectively relating care to place. This social and relational construct of care supports the stance that the care experience is interconnected to the place where it is being delivered (Milligan and Wiles 2010), with the environment influencing the care relationships that are established within this milieu.

It is therefore posited that the place where care is delivered matters (Milligan and Wiles 2010), where place is understood to be both materially and imaginatively constructed, concrete and abstract, and is charged with meaning, culture, and politics (Massey 1996; Massey 1999); a milieu, a place that encompasses both the physical and the social aspects of the environment. It affects how care delivery is structured and it impacts the social realm of the place. Hence, it is argued that care involves not just interpersonal relations, but also people-place relationships. Moreover, it is suggested that the setting where these social practices take place are both shaped by the care space where they occur, as much as they shape the place where they happen (Milligan and Wiles 2010); producing spaces, practices, and experiences that emerge through these relations of care (Conradson 2003). This chapter discusses this dynamic relationship of care and place, highlighting how place shaped these relationships and how the approach to care influenced the structuring of place, arguably resulting in reduced opportunities for the individual living with dementia.

Shaping the Care Experience

Through observation and discussions with different people involved in the care relationship construct, the multilayered ensemble of care and place became apparent, disclosing visible and invisible issues that shaped the relationships established. These layers of issues ranged from work-associated tasks and responsibilities, personal beliefs, risk tolerance, to the social, emotional, and physical aspects care delivery demanded (within the context of organizational directives), all helping sculpt and transform the physical space that contained these layers. Even the name of the place where these relations evolved, the care home, evoked a contradiction of images and meanings. Care speaks to the institutional; home relates to the domestic. Care is clinical; home is residential. Care homes are public places; while home relates to the most personal and intimate domain. The care home as a place then, emerged as a public place where individuals were emplaced to live their everyday private lives (McColgan 2005), separated and uprooted from their familiar places, while expecting them to now consider this place their home. As such, this place was unsurprisingly charged with tensions surging from different social realms colliding: the individual versus the collective aspects of everyday life taking place in the same space; the public and visible aspects of care and the most private and intimate dimensions of care; the paid care-worker and the filial responsibilities (McColgan 2005). This social arrangement of people within the same space, brought together by the practice of care, was experienced in different ways by those involved in the care relationship (Conradson 2003). It was a place influenced by the care organization’s vision of care, where everyday care-work included the management and negotiation of routines, schedules, and relationships (Milligan and Wiles 2010).

This often resulted in social control of residents, by promoting a culture where daily activities were structured around efficient management (McColgan 2005), evoking elements of Goffman's description of 'total institutions' (Goffman 1961). As captured in the following excerpt, schedules, and routines - meant to efficiently manage resources and organize tasks - had an impact on the resident's everyday experience.

- Lila: … I mean, we're working around set things like mealtimes… mealtimes are mealtimes we're gonna have to work around that…the kitchen has to know what time to prepare food … so we're serving it hot and things like that. But one thing we did do to try and kinda alleviate this … using the resources, being the staffing that we have, was we did adjust the mealtime, the lunch time up in memory care a half hour… because everyone in the building has meals at the same time. So there's always this chunk of time where it's down time for our life enrichment team… that you know they could be utilizing, so we did do that adjustment and I think it's helped… in terms of you know for the lunch time being able to have an activity up there prior to lunch. They're able to spend a little bit more time, it's not as rushed and it's given that bit of flexibility…

Interview Transcript. October 25, 2019

While this solution provided residents on memory care with thirty minutes of dedicated programming from Life Enrichment, it was a solution that did not take into consideration personal preference of mealtimes. The decision to shift the group mealtime to an earlier slot was viewed by management as demonstrating flexibility in resolving the issue. Nevertheless, assuming that everyone was fine eating earlier, or that everyone would simply adapt to the institutional schedules, ignored personal preferences, arguably contributing to a discounted view of the individual (Dobbs et al. 2008).

This extract also suggested an inequality of experience for those residents living with dementia, given there was an assumption that whether the individual was hungry or not, the person with dementia would adapt to an earlier lunch time to at least have access to a 30-minute activity session; a session they may not even have wanted to attend. There was also a tacit belief by culinary services that the dining experience expectations in Memory Care, be it presentation or food serving temperature, would not be as demanding as in the main dining room, a stance the General Manager was aware of and was trying to correct:

- Lila: if you're not gonna serve to someone in the main dining room why would you ever serve it up in memory care? And in terms of… obviously, the quality of food and the food prep… it's all coming from the same kitchen. But it's, it's more in you know… it gets transported and the delivery of it, and the temperature of it, … if someone was you know… complaining that food was cold in the main dining room what would we do?... we do the exact same in memory care... and that does get lost… I just think they're not seeing it. It's not as in their face from a culinary, from a cook perspective…

Interview Transcript. October 25, 2019

This finding is congruent with similar studies in which power relationships within the care place often result in people living with dementia experiencing services that are inadequately resourced and in which staff inadvertently develop discounted attitudes to their care (Cantley, Bowes 2004). Therefore, the way that care delivery was structured by the organization was embodied in the approach to care, contributing to the overall experience of those involved in the care relationship: the resident was forced to lunch earlier, management had no recourse but to exert their power to enforce schedules and change routines, and care staff were pressed to optimize their time. This finding supports the perspective that landscapes of care are social settings, configured by the interactions associated with the provision of care, where the power relationships manifested are influenced by broader conditions and underlying organizational structures (Milligan and Wiles 2010).

Structure of Place

Wiles et al. (2009) have argued that it is important to recognize the spatial ways care is structured and delivered, and how this structure is manifested in the relationship between place and well-being. Further to the previous discussion of the dichotomy of the care home as a place, one could argue that place, whether it be a care place or a domestic place, has an underlying structure that infuses the relationships and social encounters that occur. The home as a domestic setting is a place that is typically structured to enable privacy and intimacy, where visitors are vetted before they are allowed access to front hallways, living spaces, and more intimate areas like bedrooms and bathrooms (Twigg 1999). The relations of power in the home are manifested in the spaces one is allowed to enter, in the rendered aesthetics, where spaces are demarcated by controlling who may be encountered, what the expected range of activities are, and the appropriate modes of behavior within each space (Angus et al. 2005). The meaning and experience of home is related to privacy, security, identity and choice where, as a place, it embodies and shelters the self (Twigg 1999). Moving to a care home, especially for people living with dementia, is often against their will and under duress, with individuals often experiencing limited control over their plight (Steele et al. 2019). This move from their home to a care environment implies a biographic disruption, where their previous social positions – be it related to income, culture, profession, or civil status - dissipate as they enter a new social microcosm. Often, due to their dementia condition, they will experience diminishing autonomy; normatized to be treated in the same way, cared for by the same staff, and supported by the same infrastructure (Brossard 2016). The following exchange with one of the residents illustrates how difficult this change can be:

- Sally (resident): But I don't know people well enough to want to live with them. I don't know if I would want to live with anyone I see here…
- Claudia: But it looks like a fun group
- S: Who is?
- C: The people that live here
- S: Yes...but what are they here? Why do they live her? I couldn't live with 5 people more than a week. It's bad enough to live with a sister or a husband. So why would you put yourself through this? What do I do about it? I just try to get out of here? Can you think of a quick way to get out of here?

While we were having this interaction, Sally placed her cane on the countertop. Alexa (staff) told her…'Sally, cane on the floor' (as she looked at me and said…'I just cleaned the counter'). Sally looked a bit embarrassed, she put the cane down on the floor.

Observation Notes. June 19, 2019

This excerpt exemplifies the challenges of adapting to communal living, where rules and protocols limit the individual's ability to do as they please, as one would at home. The change in living arrangements from a private home to communal living, where remnants of their former lives were minimal (some clothing and some furnishings), implied a social repositioning as chronically ill and increasingly dependent consumers of care services (Angus et al. 2005).

Unlike other physical conditions, people living with dementia often become the condition, rendering part of their social identity to the affliction (Milne 2010). As dementia progresses, the individual experiences a constriction of roles where their identity is not linked to a valued social role – be it spouse, parent, professional, friend or other – and the only seeming remaining role is that of a person with cognitive impairment that requires care (Cantley and Bowes 2004). The individual identity of the person is overridden by subscribing them to a new category; a subset of older adults living with dementia (Link and Phelan 2001). Prompted by concerns that the individual will exhibit certain undesirable behaviors that are linked to stereotypes around dementia, the resulting stigma or bias is revealed in organizational approaches to care that at times may result in discriminatory actions (Dobbs et al. 2008), as Lila suggests:

- CS: … Do you think that…people living in memory care…get the same amount of attention in terms of life enrichment and activities?
- Lila: I think for us, that's an area that we struggle with… absolutely, I think in terms of if I look at each of the neighborhoods… you know everyone's paying hospitality…I think for memory care residents it is different. As much as we say, 'Well they have the opportunity to you know… go to other activities or come to entertainment.' If we have a big entertainment happening down say in the Great Hall, they have an opportunity to do that but they still need a team member to be with them and bring them off the neighbourhood and stay with them right…and it's not for everyone. If you have someone that will get up and wander you can't have one staff with five residents… so you're really selecting which ones you bring off the neighbourhood.

Interview Transcript. October 25, 2019

The selection process described above was based on organizational risk management and on assumed dementia-related behaviors that could potentially be found disturbing to the other residents. It manifested the power shift that resulted as the person living with dementia loses the ability they once had at home to exclude others as desired, only to now find themselves excluded from certain areas within the care home (Milligan 2005). The bias that was reflected in this conversation seemed to go unnoticed by the manager, supporting the argument that societal stigma associated with cognitive and functional decline is also evident in care residences (Dobbs et al. 2008). This finding was consistent with similar studies where tensions arising from the transition residents experience from living at home to residential care facilities were evident, as management's concerns around risk tolerance were balanced against residents' autonomy (Milligan 2005). It also showcased a commonly found tension in care environments, the perceived need for security and surveillance versus open access throughout the care environment (Curtis et al. 2007). This remains an unresolved design conundrum that has greatly influenced how space is structured through the physical design of care residences.

The research site provided multiple levels of care; independent living, assisted living, and memory care. The physical layout of the building reflected these levels of care. The frailest residents were on the lower floors, with the more independent residents enjoying the upper storeys, a reflection of life safety assumptions. The frailest of residents, or those with higher cognitive impairment, were assumed to have higher mobility issues, making their evacuation in case of a fire more challenging the higher they resided in the building. The memory care neighbourhood was designed on the second level as a secured environment, without direct access to outdoor space, with limited amenities, explicitly creating a physical segregation from the rest of the residence. This design approach of structuring space according to disability has been challenged from a human rights and disability perspective, arguing that the care home built environment segregates people living with dementia by assigning them specific spaces to live, often with unequal opportunities (Steele et al. 2019). It has been reported that by physically preventing residents living with dementia from interacting with the rest of residents, and by denying them access to communal public spaces and services, individuals are segregated and stigmatized, perpetuating stereotypes that are conducive to the normalization of practices that would be considered unacceptable for other abler or younger groups; a reflection of how deeply rooted ableism and ageism are in popular thought (Devandas-Aguilar 2019).

Place and Sociability

Studies show that the structuring and configuration of a care residence into different care wings (or care neighbourhoods as the host organization refers to them), deeply influences the residents' ability to socialize (Brossard 2016). Segregating residents based on their cognitive ability promotes the control of their movements throughout the care residence, with the visible signs of disability – such as exit controls and alarms – being a structuring principle or 'disability-based distinction' (Brossard 2016), reducing the person living with dementia's prospects of sociability. Basing the organization of physical space on care needs and cognitive ability was identified in fieldwork as a barrier for residents to fully experience the care residence as a social place, limiting their access to social activities and outdoor space. This finding is congruent with other studies where environmental restraints, such as locked doors, limited the person living with dementia to interact with a broader community, restricting their sociability and contributing to the social exclusion that has long been identified as a factor in the social withdrawal older people experience, effectively limiting their potential to live at the fullest of their ability (Dening et al. 2016).

The host care residence has staff dedicated to 'Life Enrichment'; a proprietary term used for the team responsible for the programming of daily activities. These activities include exercise classes, games, crafts, entertainment, outings, and all other activities offered for residents to enjoy. During fieldwork it became evident that residents on the memory care floor had unequal opportunities to access programmed activities in relation to the rest of the residents. Environmental design challenges partly contributed to this. As discussed below, one of the environmental factors contributing to the challenges of delivering appropriate daily activities on this floor, was how remote this floor was from the residence's Life Enrichment hub, located on the ground floor. Its location introduced mobility as an issue for consideration, as some residents were visibly fatigued and found it challenging to walk for long distances, with staff challenged to cover the range of distance within expected timeframes.

- Lila: … I think it's very difficult for a life enrichment or RCP's to kinda gather people in that far end… you know you get one or two people down there, you go to get someone else and then all of a sudden you get, you get back and they've dispersed cuz they're looking for activities. So unless you can get kind of three or four people all together and take them down to the area and then right away start the activity or have them engaged… I think that's been a challenge typically for life enrichment… when life enrichment is up there we're sending one person… and it's at a time that the RCP's are busy doing something else.

  So they don't always necessarily have the support from the RCP's to gather people. And I think that's a challenge from a life enrichment standpoint and something as a team that we've really tried to look at and ok how else can we, how else can we do this…?...I think truly and for the amount of time typically we're looking for programming from a you know forty-five minute, half hour… standpoint as kind of the attention span that we're looking to run something…by the time you go up there you gather people… it's very easy to kinda burn through your forty-five minutes…

Interview Transcript. October 25, 2019

This account captures the anxiety and tension management experienced in delivering the expected quality of care within the context of effective performance, mirroring evidence that suggests that care homes operate in a field where logics of cost and efficiency predominate (Angus et al. 2005). The spatial layout of the residence made it challenging for management to meet expected goals, as travel distance had a direct impact on movement and time efficiencies. To bridge the operational gap, the focus on schedule dominated. This finding was similar to findings from other studies, where care home routines were structured around efficiencies, resulting in the resident's day being structured around staff routines and not their individual preferences (McColgan 2005). Mobility, as related to spatial travel, was identified as an environmental factor that affected all users of the space. As shown on the floorplan below, the overall length of the corridor on memory care was less than fifty meters; a distance that from a design perspective would seem manageable:

Figure 22 - Memory Care Floor Plan

Nonetheless, as previously discussed and supportive of Lawton's environmental theories, environmental demands, such as distance, should acknowledge the different levels of physical limitations individuals may experience as significant determinants on their ability to function in that environment (Lawton, M. P. 1974). While space is often designed and organized by the architect to foster movement, social encounters, and interaction (Curtis et al. 2007), data confirmed that the concept of distance was relative to the user's ability and perception. The physiological effects of dementia affected resident's ability to reach remote spaces, suggesting that 'far' was a personal perception based on individual ability.

Figure 23 - Corridors

These photos, taken from the central hub of the floor looking down either end of the floor, without a place to rest, illustrate how long the corridor could appear to residents. The reported challenges (physical pain and issues resulting from short attention span) negatively affected the experience of the resident, often resulting in agitation and frustration, supporting evidence from similar studies where behavior was linked to environmental challenges and functional competence (Lawton, M. P. 2001; Lawton, M. P. and Nahemow 1973; Lawton, M. P. 1974; Zeisel et al. 2003); a very different outcome than the one envisioned by the architect.

Data also supported the argument that the way people use and regard space changes through time, as space becomes more responsive to people's needs (Bakhtin 2002; Jencks 2002). As reported by staff, the quiet lounges were not used. Through time, the dining area had become the hearth of the care floor; used to dine, for activities and to socialize, as described by Lila:

> Lila: … I think naturally in life people tend to gravitate towards you know the kitchen... I mean in my own home that's, the smallest area in my house is the kitchen, people are over it's always the kitchen that everyone's standing around… you know there's always a team member for safety reasons…the reason that the team member's there is because it is the hub but there also is somebody in that area…so people I think get, get used to that.
> … breakfast, lunch and dinner is served there as well as any snacks. So residents do tend to, I think, become very familiar also with that, that environment. I think it does become a place of comfort almost… often times if we're trying to redirect or if someone is agitated, they're upset, they're waiting for a loved one, we'll have them go to the country kitchen and maybe have them have a cup of tea, or a snack, or to try and distract them. So I think it, there almost becomes a bit of a comfort there too…
> I mean it's also a nice bright area… I think it is very inviting. There is you know with the small seating area too… the team does put on movies and different things, musicals there's always something happening. There's always something to kind of engage in…it's so popular, even for families is because it's natural to sit and have a cup of tea… or have a coffee with

> Mom. I mean you may not have a conversation but I also think family members enjoy interacting. Someone will always come over … and having that engagement with other people… is also very natural as well…

Interview Transcript. October 25, 2019

The evolution of how spaces on the care floor were occupied, from conception to habitation, reflected how use and experience of space responded to the needs of the individual users over time (Whyte 2006), facilitating embodied practices that felt comfortable. This adaptive use of space underlined the potential malleability of space, which is often undermined, and usually conceptualized as static, finished, and assigned with a predetermined function.

Barriers by Design

The intentional spatial separation of the dementia care floor from the rest of the residence meant that residents living with dementia were not able to independently access common amenities such as the home theatre, the crafts kitchen, the hobby area, the library, the bistro, the games room, the pool, greenhouse, or outdoor patios. This design approach reflected the tension resulting from risk avoidance and the presumed need for security and surveillance, against freedom of access; a tension also evident in other care environments (Curtis et al. 2007; Milligan and Wiles 2010). It is an approach to design reflective of engrained beliefs that people living with dementia need to be confined, yet it is one that disregards listening to people living with dementia on how they want to live (Cantley and Bowes 2004) and one that risks their social exclusion (Duggan et al. 2008). Fieldwork allowed the opportunity to interact with residents living with dementia that contest the often-held view that they are passive victims of their condition (Gilleard and Higgs 2000). Similar to findings from other studies (Duggan et al. 2008; Joseph Rowntree Foundation 2005), residents were are able to communicate their desire to interact with others and to keep active. Kate, a resident who struggled expressing herself due to her advanced condition, shared that her fellow residents needed entertainment and activities; yet they had to be escorted to be allowed out of the memory care floor:

- Kate: Well you need, you need to have something happening with them so that they will interest what they're planning to do so, because half of them are like down there, they really don't want to go without men.

- Claudia: They really don’t want to go…?
- K: Without taking men with them.
- C: Oh really.
- K: Ya, that’s what they told Roy and everybody else on the row.

Interview Transcript. October 11, 2019

Residents living with dementia had to be escorted by a care giver or family member to be allowed out of the care floor. As such, their participation in social activities easily available to other residents was limited. While this approach to leisure activities mitigated risk of elopement or wandering, it arguably resulted in unequal opportunities for residents living with dementia. Nevertheless, the observed logistics around supervision and surveillance of residents was consistent with the social construction of wandering as a high-risk activity, and how it is typically addressed; through containment and secured environments (Dreyfus et al. 2018; Wigg 2010). Initially devised as a response to privacy, autonomy and safety challenges, and as an attempt to contain and manage in one place the socially inappropriate and impulsive responses of some people with dementia, it is usual for care homes to implement routines where frailer residents are ushered to and from activities without agency (Steele et al. 2019). However, similar to other studies, this attempt to encourage socialization with other residents in different areas of the care home created other tensions, as the different levels of ability to participate in the social activity at times inhibited, rather than facilitated, social connectedness (Barbosa Neves et al. 2019). And while predicated on providing more appropriate care to these residents, this strategy also contributed to the labeling processes among residents, highlighting the resulting sociability boundaries within the care home due to the stigma associated with dementia (Brossard 2016).

During one of the observation sessions, a concert in the Great Hall had been planned for all residents to attend. That evening, a group of residents from the memory care floor were escorted to the main floor to attend the concert. I decided to join the group and attend the concert. As I was coming to the ground floor with the group, the challenges, logistics, emotions, and efforts, both from staff and residents, to navigate from one level to another crystalized.

> When we were coming downstairs we took the elevator, which has been designed to close doors slowly to allow residents maneuvering in/out. Unfortunately, 2 out of the 4 residents who came along were using walkers. What caught my attention was that one of the frailest residents (Geoff), in spite of his tremors, compromised gait, hunched over, was able to walk backwards to get out of the elevator. By the time he was out, and other residents and caregivers had stepped out, Joan was left coming out of the elevator with her walker. The elevator started to alarm and close the door, as the door had been open longer than expected. The door is heavy and kept closing in spite of me trying to put my hand in to stop it. Luckily, Joan's walker stopped the door from hitting her, but both she and the other residents were visibly alarmed. Thankfully, a colleague helped me hold the door back and slow the closure, preventing it from harming Joan. I was very worried, as I felt that if she had been stuck in the elevator, she would have panicked.
>
> As we stepped out on the ground floor, everyone was asking what way to go. We pointed the way and started walking down the corridor. It was interesting to see how those I thought would be elated to be outside the floor – Betty and Daisy – seemed insecure and hesitant of where to go. As I also escorted them to the Great Hall Betty was saying:
>
> - I will need to get back to my place. I don't know if I will be able to
> - Claudia: Don't worry, I will help you
> - B: But I don't know how to get back
> - C: That's ok…

Observation Notes. June 19, 2019

Having experienced with the group how challenging and emotionally-charged taking a short ride on the elevator had been, helped me understand how accessibility and mobility are intricately related. Distance was relative to the user; what for me would have been a quick elevator ride to the ground floor, moving as a group of people that have mobility and cognitive challenges became an arduous feat. This concert took place in the Great Hall, located at the far end of the ground floor. Planning this event and expecting residents from the memory care floor to join and enjoy, underestimated their challenges of mobility and access. Unable to enjoy a concert on their own care floor, they had been escorted to attend this social event, suggesting an unequal opportunity for them to socialize and enjoy an event that could be easier for them to access. This experience supports arguments that standardizing collective activities, rather than individualizing social opportunities, often inhibit rather than promote social encounters, given that for residents to socially thrive, there needs to be an adequate fit between the individual's need to socialize and the environment's ability to fulfill them (Bergland and Kirkevold 2008; Brossard 2016). Having attended this concert further illustrated how seemingly benign actions, like having people with dementia sit in a specific section, contributed to their distinction from the rest.

> Betty held my hand to walk to the Great Hall. In her frail touch and grasp, I could feel both frailty and fear. We came in, the concert had already started. As I was walking in, Cez (*staff*) instructed me to guide Betty towards the side chairs of the hall, 'towards the edge'. I guess they sit them in that section because it will be easier to escort in/out should they need to. Nonetheless, it seems that even in the general area, they are segregated from the rest of the residents. To exacerbate this, the area where they are sitting has different chairs than the rest of the hall, so it does feel like a special section.

Observation Notes. June 19, 2019

Walked in as a small group, holding hands, and escorted by uniformed staff, the stigma assigned to the residents coming down from the memory care neighbourhood became evident. They were being seated away from the central section, where visibility to the performer would have been better. The chairs in their section were different than the central seating area – different design, different fabric, different colour – thus reinforcing the sense of segregation:

Figure 24 - The Great Hall

As they were led to ‘their section’, the other residents who had independently attended the concert and who were already seated in the central section of the Great Hall, were visibly annoyed with the disturbance. The group of residents living with dementia were joining the concert late, with music already underway; a consequence of the logistics needed to address the challenges of physical distance, accessibility, and mobility to bring them down to the Great Hall. Oblivious to how difficult the trek from memory care to the Great Hall had been for these residents, other residents used their body language and their glare to express irritation. Their attitude was consistent with other studies which suggest that in care settings that provide different levels of care, as is the case of the host care residence, the ‘abler’ residents gauge themselves against those residents who appear to be frailer and in need of care, assigning them stigmatizing traits (Dobbs et al. 2008). Key to stigmatization is seeing the other person as different. As evident in this concert, we react and reject out of fear, either of the person we stigmatize, or out of fear of becoming like them (Hrybyk et al. 2012). What was observed also supported the argument that sociability in care homes is structured by the intertwining of “levels of disability” among residents, where signs of disability deeply influences the institutional sociability, becoming a distinctive characteristic that reinforces social boundaries (Brossard 2016; Dobbs et al. 2008). The physical segregation of assigning a dedicated section of the Great Hall to people living with dementia, in conjunction with the social segregation experienced by the reluctance of other residents to engage with them, suggested that stigma is both spatially and socially constructed (Kitchin 1998).

Risk Management and Resistance to Place

In recent years, a growing focus on risk governance has resulted in accepting confinement and surveillance of groups perceived to be vulnerable or dangerous to others, as a valid strategy to address safety concerns (Curtis et al. 2007). The design decision to provide a secured, segregated area for residents with dementia is in direct response to the desire to mitigate risk, which is often understood in terms of their interaction with the environment (Eckert et al. 2005). The focus on residents potentially wandering away from the care residence, is congruent with other studies that associate unsafe behavior and safety concerns with wandering and elopement (Aud 2002). Consistent with other findings (Milligan 2005), staff concerns about risk mitigation and potential legal liabilities, conveyed a tension in trying to negotiate the expressed needs of residents to have some autonomy, and their duty to ensure all residents were safe and closely supervised. The following passage captures a moment in which Adam, a decorated air force pilot, usually poised and dressed impeccably, and who challenged all stereotypes of what people living with dementia look and act like, was demanding to be allowed to go out for a walk after lunch:

> Adam came into the admin hub and in a very commanding voice said:
>
> ‘I want to go for a walk’
>
> Wait for a while, we’ll find someone who can come with you (staff)
>
> ‘I am an adult, I don’t need anyone to come walk with me’
>
> He was visibly frustrated. Ana finally took him out for a walk around the block; they were back after a short while. He wanted to go to the Legion on the bottom of 7th Street in New Toronto. This is very far.
>
> In this brief interaction, it was evident that Adam’s embodied identity of someone who is in control, used to giving orders, used to being obeyed and heard, was still very evident. This exchange happened around 2:00 p.m., just when… staff from the morning shift review their notes with the starting afternoon shift. Adam, over 6’ tall, standing straight, with a very firm voice, simply interrupted the meeting and basically commanded he be allowed to leave the floor. He had such a presence that without further ‘feeding him a line’, a staff member looked at him and quickly proceeded to put on her

> jacket to accompany him on his walk. Upon their return – Adam obviously discouraged he had not been allowed to go to the Legion – I asked Ana if he had conversed with her during their walk. She said he hadn't; he had actually walked ahead of her, as he was uncomfortable sensing he was being accompanied.

Observation Notes. June 10th, 2019

What was significant about this exchange - and consistent with similar studies - was that upon closer understanding of the individual, and with an open mind of how one views people living with dementia, their individuality and personal biographies became evident (Hughes 2001; Kontos 2012; Wilde 1999). The residents ably stated their preferences, capable of meaningful interactions, and still competent in creating survival techniques and strategies of resistance (Milligan 2005).

Despite his condition, Adam asserted his identity and personhood. He commanded attention and firmly reminded staff that he was an adult. His stance and reaffirmation of selfhood was supported by the theoretical construct that the sense of self and self-determination that Adam exhibited, was one that was developed through the different stages of life, and that far from ignoring it and dismissing it, it had to be preserved and not undermined (Cayton 2006). His voice, his delivery, his assertiveness moved staff to action. Furthermore, as glad as he may have been to go out for a walk, he refused to chat with the caregiver who was escorting him, choosing to walk ahead of her, resisting feeling supervised. With the undeletable image I had from his portrait in full military uniform that hangs outside his suite entry door (there as a memory prompt to help him identify his suite) it became evident that his personal identity and values as an individual had been shaped by his life experience; a personal history that was embodied in his being and that transcended cognitive memory.

The design solution of securing the memory care floor, was consistent with the framework of risk which sees people with dementia as less capable of undertaking risk assessments and of managing risks than other adults (Manthorpe 2004). The assessment of risk therefore, contributed to the tension of balancing risk, autonomy, and security (Aud 2002); of determining what was the right degree of supervision before it became surveillance, raising questions around the right balance of access versus restriction. This tension has been identified as an issue in dementia care (Aud 2002, Eckert et al. 2005, Manthorpe 2004), where these dilemmas have also been discussed within the context of civil rights and their rights to self-determination (Aud 2002). Too often, the perception of high-risk dominates care planning, with processes and policies often overriding the individual's rights (Manthorpe 2004), as care staff endeavors to address the operational challenges of managing a dedicated dementia care physical environment with the resources at hand.

Similar to other dementia care environments, containing and securing the floor was justified as a means to ensure the safety of residents, and as a way to address perceived or real risk to themselves and others (Steele et al. 2019). The design approach of segregation of place shaped the user experience of residents, who were aware of their inability to move feely around the building. They constantly asked why they were not allowed to leave the floor, continually trying to find a way to leave without being supervised; an insistence argued to be a resistance strategy. Evidence suggests that the most visible resistance strategies used by residents are through physical actions such as regular attempts to get out of the secure environment they find themselves in (McColgan 2005). The following passages illustrate how Betty, a resident living with dementia, was trying to resist being locked in, while asserting herself. She submitted her credentials, hoping to convince staff that she had the ability to leave the care floor; referencing her biographic identity of a teacher that would drive around heavy traffic in a busy city like Toronto.

- Claudia: Hi Betty, how are you?
- Betty (resident): 'I have been better. I just want to get out'. I don't know how to get off this floor. Seems like people are locked from the first floor up. It's like they are expecting that someone will come in and kidnap us. I wish some would come and kidnap me.
- Kim (staff): Understandable you are frustrated because you can't get out…
- B: No, you don't understand
- K: We just want you to be safe
- B: I lived and worked in Toronto for 37 years and never got lost
- Staff: You are a teacher right?

- B: ‘No, I was a teacher. I was doing remedial work so I went to 2 different schools in a day. I used to drive in Toronto…

Observation Notes. June 10th, 2019

Betty’s efforts to preserve her autonomy, her self-determination, her independence (Aud 2002) were constant. Most days during fieldwork, I noticed that Betty would wear her coat, with her purse and a set of keys in her hands:

> Betty approached me today to again ask me if I knew where the stairs where, as she had to go out and run some errands. She wanted to go shopping for her sister in-law, whose birthday is next week. She also asked me why the elevators weren’t working, did I know when they would be fixed? If they weren’t yet fixed, then how could she get out of here? Vicky came to my aid and told Betty that Ana (staff) would take her shopping.
>
> This helped, and Ana did put her jacket on and away they went. Just a few minutes later Betty came back and asked me if I knew where the stairs were and when would the elevator be working. She said she had gone for a short walk, but that it was just window shopping, as she hadn’t been able to buy anything. Vicky told her she would take her in about 20 minutes. She seemed Ok with this.
>
> All throughout this, she has been wearing her coat and purse, with keys in hand, ready to go. If I didn’t know better, I would have shown her the way out, as she seems so genuinely OK to go out.

Observation Notes. June 10th, 2019

This presentation of self can be explained, as others have theorized (Milligan 2005), as a tangible and visible expression of resistance; outwardly expressing she was ready to go out, and that she did not belong inside a confined place. Her inability to exercise her independence, albeit her assertion of credentials, support the argument that the chronic nature of dementia is also related to a loss of self. As previous biographies are interrupted, there is a transformation of self; from a prior, recognizable and valued self, into a less known, devalued, and impaired self (Estroff 1989). Betty would consistently ask to leave the floor, trying every door, asking for directions on how to exit; at times sheepishly asking for directions, at times visibly frustrated.

> Betty approaches me and says:
>
> - Betty: Hi, I guess the escalators are not working still? I just wanted to go downstairs and go shopping. My niece's birthday is coming up and I didn't think it would be a problem to go downstairs to buy something
> - Caregiver: Betty…just wait, I am coming back and we can then see if the lifts are working
> - B: OK…how long will you be?
> - Caregiver: I will be right back. Just sit down I will be right back
> - B: Ok
>
> As she wonders off. She then comes back into the office area and wants help with her sweater. I offer to take her to her room to leave it.
>
> - B: I just wanted to go downstairs to get something for my niece. Do you know if the escalator is working?
> - Claudia: No, I don't think so
> - B: This is ridiculous to have this closed. I just want to get out. Don't you think it is ridiculous?
> - C: Well, stores are closed on Saturday afternoon
> - B: All of them?... Well, I just wanted to look in the windows. Do they always close?

Observation Notes. July 13th, 2019

Other times, as noted below, alliances with other residents were established to figure a way to get out.

> First time I observed Betty trying to figure out the code on the number pad to try and open the door that leaves the floor. Daisy was with her and at least from a distance, they seemed to be conspiring together. Betty sort of caught a sight of me from the corner of her eye, even though she was about 20 meters or so away. The moment she saw me, she sort of whispered something to Daisy and walked away from the keypad.

Observation Notes. June 19th, 2019

As recorded in similar studies, resistance strategies are often collaborative, creating a sense of unity amongst residents (McColgan 2005) . This collusion to resist and leave the secured floor was observed on different occasions, as described below:

> Betty, Sally and Helen are now gathering by the foyer and they seem to be encouraging each other, as they all want to go out. Even Geoff speaks up and says:
>
> - Well, if you want to go you better jump in the wagon
>
> Sally approaches me and says:
>
> - I think they have a plan. I don't know what they are up to…
>
> Ross has taken Sally's chair and offers it back. She says:
>
> - Sally: I don't need a chair. I am going to start another inquiry.
> - Ross: Do you have family that you can call to come get you
> - Caregiver: Something is wrong?
> - Helen: I have never been in this place before
> - Caregiver: You have a room here
> - Helen: No I don't.
>
> Looking at Sally, Helen asks:
>
> - what are they gaining here? Why do they want to keep us in?

Observation Notes. July 13th, 2019

Helen, who was questioning why they were keeping her from leaving, was 104 years old; Sally was 92. Even at their advanced age, the longing for independence, to wander freely, persisted. The frustration of being spatially restricted was evident; their comments expressing a longing for autonomy. This environmental containment was a new experience for them, one which an older person living independently at home would have never experienced (Dobbs et al. 2008), and one which arguably affected their ability to experience the care residence as their home. This is further theorized by arguing that the interruption of the sedimented meaning of home as a place – their new living arrangements, their loss of independence and autonomy, the loss of familiar environmental cues like smells, sounds, and decor – prevented residents living with dementia to connect the care place to feeling 'at home' (Angus et al. 2005). As reported in other studies, the physical environment, the social aspect of everyday life, and the emotional ties to home, are essential elements attached to the concept of the home as a place, making it difficult for the care home to replicate it given its institutional vestiges (Milligan 2005), as affirmed by Sally in the following exchange:

> I overhear the following conversation:
>
> - Sally: ... I was just brought in here. There's nothing I can do. I have tried everything. Just wasting time
>
> I join them and say:
>
> - Claudia: Hi Helen
> - Helen: Who are you?
> - C: Claudia. We have met before
> - Helen: Yes, we have. Do you know if we are ever going to leave this place?
>
> Sally also joins the conversation and says:
>
> - Sally: Why are we here?
> - C: Well… This is home
> - Sally: No it is not.

Observation Notes. July 13th, 2019

Having kept a personal diary of insights, I share the journal entry from that day, as I left the care residence with an overwhelming feeling of sadness and impotence, feeling there was not much I could do to improve these people's lives. Yet guiltily feeling relieved from having the freedom to leave the care residence and drive away:

> The one thing that I believe was the most upsetting was to observe that during the afternoon, residents do seem to have a heightened desire to go out. Betty kept insisting she had to go shopping to get her sister in-law a present for her birthday and Sally kept commenting on how something was just not right, as people were not allowed to go anywhere. Even though Betty, Daisy, Nina and Sally had earlier interactions that were not so friendly – Sally had decided to follow Daisy; Betty kept complaining about Sally – they did seem to come together in their desire to leave the 'neighbourhood'…

Journal Entry. July 13th, 2019

That day I left the building 'feeling' the gap of design intent versus design implementation and resident experience. Until then, I had not quite understood the deeply-rooted desire of residents to wander freely; to have access to the outdoors, to maintain their independence. For the first time I was 'feeling' the design criteria of this type of care environment, versus 'knowing' the spatial requirements of the architectural programme. I was also feeling the relief of being able to leave 'their' world. As I reflect upon these insights, I argue that one of the critical dilemmas in this tension is that by preventing residents with dementia to wander freely, by constantly redirecting their questions of why they are in a secured environment, the premise of a common shared world is challenged. Often resorting to lying in an effort to assuage their frustration of being contained, while assuming they can no longer understand they are being lied to, undermines the individual and their personhood. Gradually, the unequal opportunities residents living with dementia accumulate, risking and compromising our belief that we are standing as persons amongst equals (Hughes 2001); leading to a categorization of a distinct group of people as "them" versus "us" (Dobbs et al. 2008).

Reduced Opportunities

As previously discussed, the spatial segregation of the memory care floor, and the resulting cues associated to the physical configuration of the care home, contributed to stigma and social exclusion. Although the rationale of containing and separating residents living with dementia from the rest of the population behind locked doors was a risk mitigation strategy, studies done in mental healthcare environments have reported that environmental restraints – locked doors, alarms, security cameras, electronic key fobs, and key pads amongst other technological systems – designed to prevent the individual from harm, may have the opposite effect (Manthorpe 2004). Indeed, McSherry (2014) argues that segregation often results in social exclusion and depression, suggesting that environmental barriers may impede individuals from the opportunity to participate and socialize on an equal basis with others. The following exchange with Sally supports this, where despite her cognitive impairment, she shared how confinement affected her:

- Claudia: If you joined more things you would be less bored
- Sally: But I don't want to do anything. It's not that I don't want to be bore, I just want out.

- C: But maybe if you joined in you would have a better time… Why do you want to get out?
- S: I hate to be confined at any time (firmly said) …and because everyone walks like that. I may be too old but I am not stupid. I am glad I am old so I don't have to put up with this long. Unless I have a long life ahead…

Observation Notes. July 13, 2019

During my interactions with Sally, it became apparent how desperate she was to leave the residence. And while she was often reminded by staff that her placement in the care home was for her own good, she was quick to share her frustration of not being able to be independent. Like Sally, Helen, and Betty, most of the residents were very vocal in complaining about their imposed confinement. Similar complaints have been reported in other studies, suggesting that care homes typically promote a culture that is rooted in routine and surveillance as a way to mitigate perceived risk, and as a way to efficiently manage the care home (McColgan 2005; Peace and Holland 2001; Tirado et al. 2009). Therefore, the effects of physical segregation cannot be fully decoupled from the tensions related to the financial pressures of the commoditization of care; previously discussed as a tension that affects user experience, as shared by the General Manager:

- Lila: …in terms of the neighbourhood itself… some of the challenges with life enrichment is typically when we program. You know you allow, you give kinda a time period or a time slot to an activity and you say OK from this time to this time, this team member is gonna be up on memory care doing this activity'. But if it takes longer because maybe there is other things you know just based on people's…what kinda day they're having, the mood the feeling on the neighbourhood…If it takes longer if someone's struggling with a particular activity, if it's baking and it's taking longer than what it usually would take…I don't know that we have enough flexibility to have that person 'Oh well they were up there for an extra fourty-five minutes, no big deal'. We structure our staff in such a way that yes they have, you know… breaks and things like that but I mean… there's other commitments within the building.

Interview Transcript. October 25, 2019

The constant juggling of resources, within the pressures of financial results, to best reconcile actual versus projected care needs of residents, was palpable. The tension arising from continually trying to bridge the gap between needs, demands, and available resources prompted staff to creatively implement solutions, making decisions that impacted the daily user experience of the resident:

- Vicky: You know if Life Enrichment is only up for an hour in one day – some days zero, like how does that… support people with dementia for them to be up for two times for a half an hour how beneficial is that really? you know what I mean …. I can't say that and expect an AL *(Assisted Living)* or an LEC *(Life Enrichment Coordinator)* just for memory care to be there all day… So that way it's very different right. Like they have all those services to help support the PSW's (*Personal Support Workers).* Whereas here *(Memory Care)* you have half an hour and half an hour. And then some days if there's big events they're not even up there…

Interview Transcript. October 18, 2019

The constraint on resources meant that residents in memory care had reduced opportunities to access quality daily leisure activities. The limited offering of activities often resulted in subjecting the individual with dementia to a regimen that, either by exclusion or forced inclusion of group activities, contributed to stigma rather than to social inclusion. Their exclusion from accessing dedicated, quality programming, the restricted offerings for meaningful occupational leisure activities, arguably resulted in limited social engagement. These limitations contributed to their social isolation, directly impacting the self by disempowering them and by limiting their autonomy (Cantley, Bowes 2004).

Consistent with findings in similar studies, it was observed that prompting residents living with dementia to interact with other residents in the care home was construed as integration. Nevertheless, often and unintentionally, the uniform approach to activities resulted in increased agitation for residents with cognitive impairment, exposing them to further stigmatization (Brossard 2016; Calkins 2003), as evident during an activity class held in the Assisted Living floor, where memory care residents had been escorted to participate:

> Physical Activity starts – people follow the movements in general. Dorys is just napping through the exercise class. The same lady resident (Heather)

> that sits at the corner and just lingers, she is trying to pay attention, to follow the class, but she does struggle to follow some of the exercise sequence.

Observation Notes. June 5th, 2019

Escorting residents living with dementia as a group to programmed activities elsewhere in the building, could arguably be interpreted as cues to their cognitive impairment, preserving the notion that people living with dementia are less able and more limited than other residents, reaffirming disability-related distinctions as a structuring principle of sociability (Brossard 2016; Dening et al. 2016; Duggan et al. 2008). By expecting them to fully assimilate into activities that have been planned for all other residents, expecting them to integrate to the group classes at the same pace and rhythm than others do, can pose a negative burden on the individual living with dementia, as it did on Heather who was visibly anxious trying to follow the class. Even if the intention was to have individuals participate in the scheduled group activities, research indicates that social exclusion emerges when a group of people, in this case residents living with dementia, is unable to achieve what is viewed as 'normal' levels of social acceptance and participation (Burden and Hamm 2000). The resulting distinction or exclusion, impacts the individual and promotes feelings of embarrassment and stigma, negatively affecting self-esteem, contributing to a sense of loss of dignity that can potentially cause distress (Cantley and Bowes 2004).

The following excerpt highlight how difficult it was for some residents living with dementia to follow prompts, how the cadence of instructions was too fast for them to react, and how other residents were visibly annoyed and disturbed by their interjections.

> In the background, there is instrumental music being played, "Oklahoma Medley". One of the residents spontaneously starts singing 'Oh what a beautiful day" ….
>
> Nina just walked into the activity room, a bit disturbed that the room was full. She was reassured they would find a spot for her, which they eventually did…The activity coordinator was telling me that the room is nice and bright... Today is trivia…Brain Exercise for a few minutes

- Question from the coordinator – what holds the oyster together? A muscle? Response in the room…yes!
- Nina – why does it do that?

She was told they didn't know why. She said they should find out.

- Question from the coordinator - how can you tell if it is a male or female oyster?
- Nina – I would just look at her private parts…and she smiled mischievously...

Observation Notes. June 5th, 2019

During this group class, it was evident that residents who considered themselves more physically and cognitively able, seemed uncomfortable with those residents that lived with dementia, perceiving them as less capable and less competent; an attitude consistent with findings from other studies (Dobbs et al. 2008). This attitude could be attributed to ignorance around dementia, or as reported in other research, may be informed by the inherent fear that lies behind people's concerns that dementia may be their own possible future (Manthorpe 2004). Considering these residents as service users that can be shuffled around to different areas of the care residence so they can participate in daily programmed activities, contributed to stigmatization, negatively affecting their user experience, and could imply a reductive view of the individual, undermining their personhood (Hughes 2001). By limiting their opportunities to fully participate in leisure activities that were bespoke to individual preferences and abilities, they were also denied the opportunity to be full participants in the construction of daily, ordinary social life (Cantley and Bowes 2004).

The barriers to participation were found to extend beyond the formal restrictions (gates, alarms, or fences) they included everyday events like locked cabinets where art or other supplies were stored. These limitations reduced the opportunity to independently undertake leisure activities of their choice, limiting the individual's potential to reconstruct their past, to maintain autonomy, and assert their identity (McColgan 2005).

Enabling Embodied Selfhood

Something so trivial as a locked cabinet, where art supplies are stored away from easy reach to prevent residents from 'making a mess', can be a missed opportunity to enable the individual's personhood. As discussed in Chapter II, embodied selfhood is a theory that asserts that bodily movement and behavior reveals aspects of the individual's biography and identity (Kontos 2004; Kontos 2005). The following vignette illustrates the potential of how facilitating opportunities around the individual's biography can support personal identity (Dobbs et al. 2008).

> Joan was sitting by the foyer, looking upset. Vicky approached her and asked her what was wrong. I came over to say Hi. Vicky offered to 'set her up' in the paint station, I encouraged her saying that her work last time was beautiful. She said:
>
> - 'Well. My fingers are ready. I guess it is one of the few things that still work in my body'.
>
> - No Joan, I said, everything works; just works a bit differently.
>
> Enthusiastically she said: 'let's go then. I think I am ready'.
>
> As we were walking down to the table I once again complimented her on her last work. She told me she could not remember at all. That she was at a blank, that she did not recall. I reassured her it was OK, that once she got going, she would remember.
>
> I was fascinated by the fact that Joan can associate her painting with the performance of her fingers. I believe this is what embodiment is; there is a memory in every cell, in this case in her fingers. This allowed her to be confident and enthusiastic that she can paint.

Observation Notes. June 10th, 2019

These photos capture the moment when Joan started her coloring and show one of her completed art works. Impressed with Joan's ability to combine colours and to create such a beautiful composition, mindful of balance and symmetry, I was informed that she used to be an art teacher.

Figure 25 - Joan's Art

As Joan was colouring, in the most natural way, she started reminiscing, as captured in my field notes:

> Joan shared with me a story about one of her students, Freddie. She said he was: ‘this high’ (showing table height) and he would come up and always politely say something. His mother would always make sure he did the right thing. He was just adorable. He must now be in his activities now. (I wonder if she was trying to say he would now be grown up).

Observation Notes. June 10th, 2019

The activity of colouring, the familiarity of holding colouring pencils, having someone to chat with about her artwork, had reconstructed her identity of an art teacher. Evident from her smile and demeanor, her mood had been lifted and it was apparent she was just feeling great. This encounter with Joan, the observed actions – her bodily composure, gestures, expression - and the exchange we had, confirmed that enabling leisure opportunities around personal identity supported the individual’s personhood. Moreover, this experience would also support the construct that a person’s life story and identity are also inscribed in their body, outliving any cognitive decline (Jongsma and Schweda 2018). Enabling and encouraging Joan to colour and work on her art had prompted Joan’s embodied memory. Acknowledging the conceptualization of embodied selfhood as a ‘sedimentation’ of an individual’s lived experiences that speak to the individual’s personality, identity and preferences (Jongsma and Schweda 2018), allowed this spontaneous activity to connect with Joan; to enter her world, to uphold her personhood and identity and to truly enrich her life in that moment.

As enriching as this experience had resulted for Joan, this was a leisure activity she would not have been able to access independently. As shown below, the worktable where she liked to paint was at the end of the corridor, close to her suite. Although walking down the corridor with her walker was a stretch for Joan, she was able to independently access this workspace. Nonetheless, Joan’s art supplies were locked in a cabinet for fear of residents taking these and ‘making a mess’, meaning Joan had to wait for staff to come unlock the art supplies, effectively limiting her autonomy.

Figure 26 - Joan's Worktable

It is therefore argued that the social exclusion people with dementia faced went beyond the physical segregation of the environment, or the access restrictions to the rest of the residence's common spaces they were subjected to. The limited opportunities for them to independently access leisure activities that they would find enjoyable, that could enable artistic expression, enjoyment of the arts, or the continuation of a past hobby, all contributed to their social isolation (Cantley, Bowes 2004).

Conclusion

The organization's vision of care – its metrics, its staffing ratios, its marketing image – reflected the way the residence was structured. Housed as a subset of the overall population due to their cognitive impairment, with surveillance systems integrated into architecture to mitigate risk, are design strategies that reflected the spatiality of stigma, and which arguably contributed to residents living in the memory care floor being most vulnerable to the negative effects of stigmatization. Physically separated from others, the stigma these residents experienced from other 'more abled' residents - and the organizational regime which they were under - suggested reduced opportunities within the care residence for autonomy and for asserting their individual preferences.

Structuring the care residence based on levels of care, versus integrating care delivery, is a care strategy that should be re-evaluated from all perspectives. Theoretically, more research validating this approach to care and living accommodations is needed. The effects of physical and social segregation should be studied within the tensions of risk mitigation, operational efficiencies, financial pressures, and their effects on the care experience. The effects of containment on the individual's ability to connect the care place to feeling 'at home', and on their ability to feel emplaced in a common shared world, should be further considered.

From a design perspective, architects should develop novel design strategies to address risk management, promote efficiencies and stimulate place-making. Architects would benefit from a more immersive and reflective approach to dementia care design and from a deeper understanding of how design decisions influence the care experience. Designers are also encouraged to consider new conceptualizations of space that move away from assuming space as static and finished, assigned with a predetermined function, to a construct of a more adaptive and organic consumption of space, emphasizing the malleability of space and its potential of becoming place. This mind shift could inspire novel spatial layouts of care environments by testing floor plates that better address established goals in more natural and intuitive ways, relying less on environmental restraints (like locked doors and alarms), giving more preponderance to the possibility of flexible, unfinished space enabling spontaneous social interactions.

These findings also suggest there is an opportunity for the organization to evaluate their policies. Policies should reflect appropriate programming of leisure activities, ensuring assumed staffing ratios support the delivery of personalized care. The current approach is predicated by efficiencies (time movement efficiencies, staffing resource allocation, efficiency in the physical areas dedicated for programming, etc.) versus a focus on the individual's wellbeing. The negative burden posed on residents living with dementia to assimilate activities planned for the general resident population can induce stigma and unequal opportunities for the individual. The provision of adequate leisure opportunities that support the individual's autonomy and identity would enhance their social connectedness and care experience. In particular, facilitating opportunities around the individual's biography, encouraging residents to independently undertake leisure activities of their choice, would arguably enable the individual's potential to reconstruct their past, to maintain autonomy, and assert their identity (Dobbs et al. 2008; McColgan 2005).

The physical configuration of the care residence reflected the structuring of care. The limitations and environmental barriers posed on residents were multi-layered: access control, locked cabinets, regimented schedules, overruling of individual preferences, imposed routines, limitations on the number of personal belongings. The focus on efficiency and risk management often disregarded the embodied biography of the individual, undermining their embodied selfhood. I argue that one of the most critical opportunities to improve the lived experience of dementia care is repositioning the individual living with dementia as a sentient being, whose identity remains intact, who still is capable of resistance strategies, of conveying preferences and needs. Ignoring this risks rendering their social identity to their journey with dementia, challenging the belief that we are standing as persons amongst equals (Hughes 2001).

Chapter VIII

FINDINGS: THERE IS NO PLACE LIKE HOME

Oh! Give me my lowly thatch'd cottage again!
The birds singing gaily that came at my call,
Give me them with the peace of mind, dearer than all:
Home! Home! Sweet, sweet Home!
There's no place like Home!
There's no place like Home!

(Bishop 1856)

Introduction

The popular idiom of 'There is no place like Home' has been engrained in popular culture through song, literature, television, and film (Chapman 2001; Wikipedia contributors 2022). Used at times as an exultation, at times a lament, or at times as a nostalgic longing, this phrase has captured the idealization of home as a place beyond compare, where all is fine. The concept of home has been thoroughly dissected, as it represents a symphony of sentiments that are intangible, yet associated with space and location (Chaudhury 2008; Heathcote 2012; Örulv 2010). Its meaning is complex, as it is constructed through abstractions that reside in the embodied memory of the self and yet it has an inescapable reference to the materiality of place. As an abstraction, home embodies ideals of safety, autonomy, comfort, agency, relationships; as a concrete place, it references materiality, space, objects, environment (Dobbs 2004; Groger 1995; Khan et al. 2013). Given the location of this research work, a care home residence, and the constant allusion to 'home' that the data provided, the concept of home becomes critical to discuss and locate within the context of the emotional, social and spatial experience of the person living with dementia. This chapter discusses how the care home aesthetics attempt to re-create a homelike environment, presenting case studies which illustrate how different individuals experience and adopt space as place.

Seeking to Re-create Home

As outlined in Chapter II, one of the design and marketing objectives of the approach to care within the residence was to provide 'homelike' environments that echoed domestic aesthetics and scale (Verbeek et al. 2010). This hybrid approach to the care home typology was similar to the design strategies that have been adopted in other healthcare environments, such as the modern hospital, where the migration of architectural cues from one typology to another is used to reduce the negative associations of institutionalization (Milligan 2005; Peace and Holland 2001; Peace et al. 2006). Thus, the care home environment tried to deliver on many fronts; borrowing cues from hospitality design, from residential forms, from healthcare design, and even from the retail amenity offerings (Martin et al. 2015). This anti-institutional aesthetic was a strategic decision to create domestic settings within the care home, rejecting negative associations of institutional life (Peace and Holland 2001). The 'residential' approach to aesthetics, as interpreted by the designers, romanticized the concept of home as a familiar place and sought to confer a material source of identity by prompting memories through the use of residential finishes and furnishings, striving to enable the self (Oldman and Quilgars 1999) while pleasing the market. The following images reflect how the care residence was staged as a domestic or hospitality setting, where everything was designed to align with every detail in the space carefully curated to reinforce a residential and premium ambiance.

Figure 27 - Satellite Lounge

In the lounge, the Audubon bird art collection had matching frames, with the dominant colours on the image echoing the red/rust of the throw pillows. The delicate burgundy stripes of the chair fabric picked up these tones, while the dark stain of the chair wood frames provided a contrast. The coffee table in the center of the composition was oval, therefore facilitating circulation around it; yet it was clear and empty, without any traces of use. The taupe of the carpet was selected to provide a neutral anchoring of the space, intentionally contrasting the beige walls, intended to help define surface planes. The window coverings had a residential feel to them, with blinds to modulate light and glare. The different layers of light fixtures provided uniform light and allowed for the modulation of brightness. Everything was in its place; even the games and puzzles, there for the use of residents, were neatly stowed away.

Figure 28 - The Library

The library was another example of how the different spaces within the residence were elegantly and neatly appointed. The coffers in the ceiling conveyed luxury, the marine theme was carried through the space with the aid of art and related knick-knacks; the sailboat on the mantel and the boat-like coffee table reinforced the theme. The use of neutral tones and discreet patterns all contributed to the ambiance of what the design team interpreted the space should feel like given its intended function; a calming environment, quiet in its aesthetic. The design intention was to use the objects in the space to help evoke the intentional serenity of the space. Even the books were carefully lined up, using its own system of classification; by size. The throw pillows seemed casually tossed, yet intentionally cornered against the arm of the sofa. The fireplace evoked the coziness of the hearth. Everything showed well, nothing was in disarray; the hospitality and residential ambiance had successfully delivered a non-institutional aesthetic, reminiscent of a domestic setting. Nonetheless, upon careful observation, the whispers of the structural aspects of an institution sifted through the administrative regimen of the single authority (Dobbs 2004; Dobbs et al. 2008), responsible to ensure these areas were maintained show-ready, neatly arranged.

As discussed in Chapter VI, transferring the typology of the home into an institutional care setting resulted in tensions (Martin et al. 2015). The residential design initiatives that aspired to make the care home feel ‘home-like’ often failed by disregarding the architectural specificities of functional and spatial needs demanded by each building typology; be it residential or health care. It also undermined how diverse the concept of home is for each person, especially for a person living with dementia.

Traditionally, Western thought has associated home as a closed space, circumscribed by walls that keep us safe inside; a refuge from the outside (Schillmeier and Domenech 2009). More recent conceptions tie home to the refuge of the familiar, a refuge from the chaos, a safe place for what is seen as vulnerable; all feelings and concepts usually disrupted by dementia (Tirado et al. 2009). It has been argued that the social conceptualization of home comprises both the abstract and the concrete; the abstract relates to the social relations, the domestic roles, experiences, autonomy, symbols, independence, comfort. While the concrete relates to the physical living arrangements, the aesthetics, and materiality (Dobbs 2004). This dissonance of the meaning of home becomes evident in these photos, given that the aesthetic appearance of home was present through the intentional use of residential design cues, yet the abstract meanings of home, which can only be socially constructed by the self, were missing (Dobbs 2004).

Therefore, assuming this concept of home as a place that is socially constructed, it is argued that the experience of the person living with dementia within the care home environment will be influenced by two aspects; the abstract and the concrete (Dobbs 2004). If the abstract relates to the social and emotional aspects of space – relationships, memories of family life, of past routines and social roles – one could argue that the abstract recollection of home is tied to experiential memories of mind. Furthermore, if the concrete construct of home relates to the physical realm, the physical attributes and materiality of the space – architectural scale, legible design cues, the symbolic meanings derived from décor and aesthetics, the arrangements of furnishings – one could argue that the concrete aspects of 'home' heavily relies on the body perceiving material conditions through the human senses (Heylighen and Strickfaden 2012). Hence, the physical space becomes legible and comprehensible due to the domestic cues embodied in the space (Imrie 2004), but also due to the experiential and embodied knowledge of the individual (Imrie and Luck 2014), recognizing the body as active and intentional in its agential role of manifesting selfhood (Kontos 2005). Therefore, the concept of home as a place where the abstract and the concrete converge, supports the holistic approach of the person living with dementia as a user of space where the individual will constitute meaning through both body and mind; giving the body as a whole a deliberate socio-cultural significance that supports selfhood (Kontos 2004) by valuing scattered memorial styles, where cognitive memory is not the guarantor of personhood (Katz, S. 2012). This embodied understanding of the user experience, which relies on both the abstract and concrete; the body and the mind, must account for the multiple meanings of space that will depend on the individual's experiences, as much as their particular impairment and bodily differences (Imrie 2004). These arguments are further substantiated later in this chapter by the case studies of Sally and Nina, who interpreted the concrete aspect of their new 'home' within the context of their lived experience and embodied selfhood.

This argument foretells that what is actually remembered in memory, however recollections come to mind and whatever body changes are happening to the person living with dementia, will affect their individual experience of the environment (Katz, S. 2012). The individual has different embodied experiences which personalize their connection with their surroundings, interpreting the objective, or material shapes and objects, through their human embodied knowledge (Latour and Yaneva 2008); inseparable from subjectivity, but in unity with past experiences with those of the present (Merleau-Ponty, M. 1962). The person's embodied biographies construct meaning drawing on familiar cues, influenced by their affective biographies (Buse et al. 2017), thus recognizing the full sensorial potential of the body of not only seeing the environment, but actually experiencing it (Pallasmaa 2005). The following images capture how a resident, responding to the environmental cues and social practices associated with setting the dining room, or as Bourdieu theorizes, the encounter between habitus and field (1977), spontaneously joined a caregiver in folding napkins.

Figure 29 - Staff Folding Napkin

Figure 30 - Resident Folding Napkin

The first images show the resident curiously stopping to see what the caregiver was doing. After staring for a moment, the resident walks towards a dining table and with incredible dexterity, starts to perfectly fold napkins. The sequence of folding the napkin was very complex, arguably suggesting that recreating this domestic practice relied on an embodied memory that was beyond cognition. It exemplified how habitus functions and how context can prompt habitus, where deeply embodied, inculcated corporeal dispositions, are converted to bodily automatisms which materialize in gestures and movement, expressed within the context of a particular social setting (Angus et al. 2005).

This example supports the argument that individuals living with dementia are capable of collaborative interactions, with sensorial memories that relate to personal biographies (McColgan 2005) arguably influencing how space and objects are experienced. Furthermore, it supports the construct that environmental cues can prompt habitus and that the body and its performative dispositions and practices is a fundamental source of selfhood that does not rely on a cognitive form of knowledge (Kontos 2005). Therefore, acknowledging that the dementia journey is different for everyone, that each person upholds an identity that is shaped by their own past experiences, it is argued that objects and moments of discovery in the care home had different meanings to people. In some cases, recollections came through the body, remembering through the senses, while other individuals retained the cognitive ability to recreate an almost photographic recollection. The following case studies illustrate how embodied experiences and identity influenced how space was consumed, how place was experienced, and the different ways in which these personal experiences were manifested; in how Sally resisted her new living arrangements, how Nina appropriated and claimed her personal space, how the environment accentuated Charles's mobility challenges, and how Greg used the physical setting of the care residence to bridge his past biography to his present plight, each rendering a personal account and experience of the care home.

Resisting Attachment to Place: Sally

Sally was in her 90s, a former teacher living in the memory care floor due to her dementia condition. I had the opportunity to connect with Sally, despite her apparent negative and gruff attitude and demeanor, through different types of encounters. I visited her in her suite, I did a walk-along interview with her, I spent time with her during my observation sessions, and informally chatted with her during all my visits to the residence. From these different touchpoints, I was able to understand that Sally was not happy living in the residence, and that her unhappiness was manifested by her refusal to consider her new environment home, not wanting to form attachment to the place. This explanation is supported by other research that has focused on the strategies used by residents to create a sense of home and to form attachment to space when relocated to an institutionalized environment, like participating in activities, personalizing space, and making friends (Falk et al. 2013). Findings from similar studies (Örulv 2010) have concluded that when the individual still felt that home was somewhere else, that their stay at the residence was assumed as temporary, or that the absence of familiar domestic cues was such that the individual was unable to feel in place, settling in was unnecessary or perhaps impossible. Data generated from this study suggested that residents who were observed as being 'unhappy', resistant to the care being offered, or frustrated from being unable to 'go home' reflected their discontent by refraining from personalizing their private room, by refusing to participate in planned activities, or by refusing to make new friends, as their home was someplace else. The following narrative describe Sally's experience of her current environment, and her overt refusal to consider and experience the care home as her 'home'.

> As I walked into the suite, it struck me how empty the walls are. They are all blank, off-white walls; dover white – the colour we have chosen for all

> resident suites in an effort to provide a neutral palette for residents to personalize… The suite suddenly seemed a bit too neutral; off-white walls, white furnishings in the bathroom, with off-white cabinetry and white light fixtures. She does not have any pictures on the wall, except for a letter-size calendar on the wall.

Journal Entry. August 19, 2019

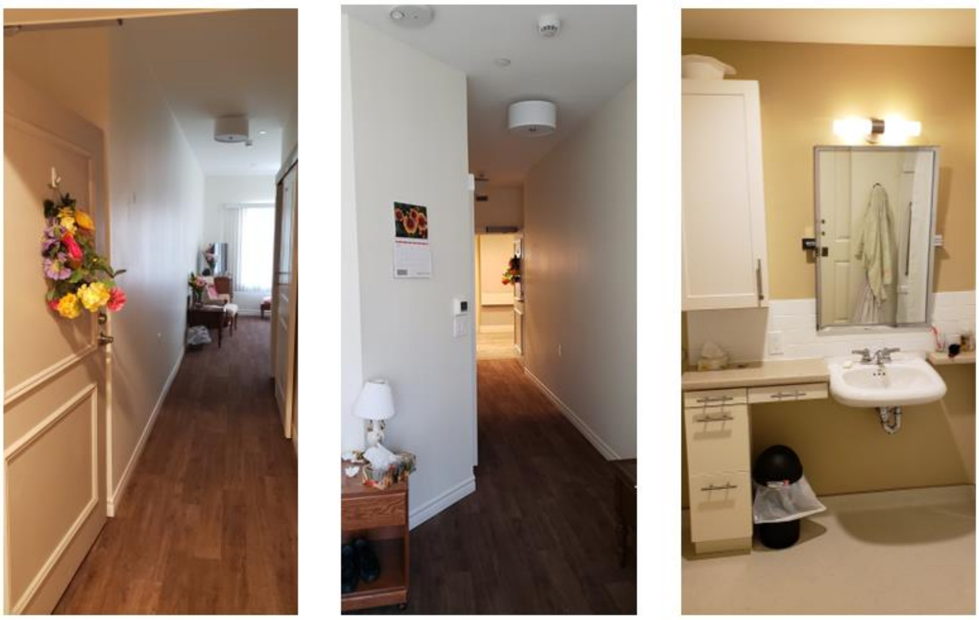


Figure 31 - Sally's Suite

Her suite was so stark that it felt more like a hospital room. The sterile environment had an effect on me, on how I was experiencing the space, making me uncomfortable, as my notes at the time reflect.

> In the back of my mind I tried to follow a certain visual path for queues in our chat; the seating arrangement, the décor on walls, the bathroom, closet and overall sense of the suite. It was so uncomfortable that I didn’t know how to refer to her suite. I called it a suite, a room, a bedroom, an apartment, her home. Incredible for an architect; I simply did not know what to call her living space.

Journal Entry. August 19, 2019

Once I started to interview Sally, it became evident that her sense of lack of control and independence, key constructs she associated with home, were preventing her from feeling she was home, a feeling consistent with the construct of home as embodying personal control and self-identity (Oldman and Quilgars 1999). For Sally this loss of control was a disruption to her understanding of home:

- Claudia: … So, I am hoping that you are going to be able to help me understand… For example… do you like living here?
- Sally: No, it's not my choice. I was shoved here so obviously I don't have much liking for it. No, I don't know if I would have picked it if I had a choice. So I don't know what you are going to get from that.
- C: So you feel you were shoved.
- S: Yes, I certainly do… not shoved, just given no choice.

…………………….

- Claudia: So is there anything in particular that you miss from your other house?
- Sally: Just being the house and being on its own… I like to be on my own in control of the whole thing. This I can't.

Interview Transcript. August 19, 2019

These excerpts supported the stance that territorial control is a source of identity which helps differentiate hearth and abode, from a place to stay (Groger 1995). Unable to control her fate and sensing she had lost territorial control over her surroundings, Sally was able to express her frustration. For example, by resisting the rigidity of mealtimes:

- Staff: Sally…it is time for supper (4:02 p.m.)
- Sally: I don't want food. I don't want any supper. I was put in here without my knowledge, without my information, without any foretelling moves. You are a slice of banana that you can move at any time. If I get really riled up I make it bad…noisy and words.

Field Notes of August 29, 2019

Nonetheless, Sally had intuited that she had more control of her private suite. She was able to control how her suite was appointed, or in her case, not appointed. Arguably, her refusal to personalize her space was a defense strategy used to assert her will:

- Claudia: And what about the artwork in the corridors? Do you like that artwork?
- Sally: The artwork in the where?
- C: In the hallways. Like if we walk outside of your room and we go to the main drag you know. They have all these paintings on the wall.
- S: On my wall?
- C: No on the walls in the corridors.
- S: Oh, Oh yea they are ok.
- C: They're ok
- S: I don't have a lot in here
- C: No you don't, no you don't. You prefer it that way?
- S: I've got a couple that I would have put up. I've only been here, what 2 months?
- C: Ya more or less. So you will get around to that
- S: One of these days I'll go through a trunk and pick out something like, "Oh here's a picture, oh I better put that one up". It might be 2 months from now or two years… they are not that important

………………………………..

- Claudia: … and what about your room. This is a very, very, lovely room. Did you decorate it yourself?
- Sally: There's no decorations here.

Interview Transcript. August 19, 2019

Sally's efforts to assert herself support the argument that individuals living with dementia are competent in creating strategies of resistance to manifest their preferences (McColgan 2005). Aside from resisting to personalize her space, Sally also resisted participating in the daily activities planned by Life Enrichment, albeit having the ability to follow the activity:

…She (Sally) then mocks the PSW that is doing the trivia. She mocks her tone of voice and says…

- Sally: Idiocy! Do you know how long I am going to be held here? Do you know why I am being held?
- Claudia: Maybe they fear you will get lost
- S: Lost! That is nonsense…

…The incredible thing is that Sally was listening to the questions and answering them…

- C: Sally…you know all the answers. Why don’t you want to let them know how sharp you are?
- S: Because it’s my business

Observation Notes. July 13, 2019

Sally’s actions and beliefs can be better understood by acknowledging that emotions only make sense within the context of particular places, and that place must be felt to make sense (Davidson, J. and Milligan 2004). There are essential elements associated with the concept of domestic ‘home’ and the ability ‘to feel at home’ which are difficult to replicate in institutional settings like the care home: the physical space, the social interactions that ensue, and the emotional dimensions associated with feelings of safety, identity, and meaning (Milligan 2003; Milligan 2005). The absence of these material and subjective cues directly impacted Sally’s ability to feel attachment to her new ‘home’. I argue that Sally’s resistance to the physical space, to abstain from meaningful interaction, her derisive attitude to the proposed opportunity for social engagement, her reluctance to interact with the wider group, could be interpreted as a resistance to her new ‘home’, rooted in her inability to make sense of the place and to feel like she belonged.

For Sally, a sense of autonomy and independence were directly related to her construct of home; her desire to regain her sense of control was constantly expressed. This supports the argument that traditionally, home means autonomy and independence in all spheres of life (Dobbs 2004). Nonetheless, it must also be considered that the gap between the individual’s current point of their dementia journey, alongside the different fragilities associated with ageing and their past lifestyle (Falk et al. 2013), influence how the environment and social encounters are experienced by the person. In the following passage Sally curtly rejected drawing, and consequently had a negative encounter with Joan; to the point of insulting those around. This could be understood as a strong positionality of not wanting to participate in a group activity. Nonetheless, Sally quietly acknowledged her visual impairment. Her low vision was not only preventing her from drawing, but also contributing to her social isolation.

Art supplies are under lock, so Vicky had to come open and get a sheet. This was not even 2 minutes after. She said to her (Sally):

- Vicky: Here is your drawing, I will give you a butterfly to paint.
- Sally: Why would I want that?
- Claudia: I said…you said you wanted one
- S: No, I didn't.

Vicky said, well I will leave this on the table in case you change your mind. She (Sally) whispered to Vicky, I don't see. I don't want to draw. These two are asses (Joan and I)

- Joan then said: Well, if she doesn't want to draw, I guess she will have to go elsewhere.
- Sally looked at me and said: This is my house; I don't have to leave the room if I don't want to.

Observation Notes. June 10, 2019

As previously discussed, the care home residence as a hybrid typology wanted to present itself as an inviting space, much like an upscale hotel. Yet the space was domesticated through different design features to emulate a residential scale. However, as evident in the following excerpts, the tension of typology was evident. The dining room layout was more reminiscent of a restaurant than a family dining room. The common amenity areas - meant to evoke a living room - were shared spaces that were not under personal control. The residential ambiance did not hide the institutional structure of the environment.

- Claudia: Do you miss cooking or no?
- Sally: Oh I don't miss it, no
- C: So that is a treat living here that they serve you your food no?
- S: I don't say they make my food here… this to me is a restaurant. It is not a make my food place.
- C: … So why do you feel it's a restaurant?
- S: Because I choose what I'm eating and for them to make sales

Interview Transcript. August 19, 2019

……………………………………

…. The RCP asked me if the concert was done. Sally asked:

- Sally: what concert?
- Alexa (caregiver): You were asked if you wanted to go and you said no
- Claudia: I came over and said, if you want, I can take you downstairs to the concert
- S: No, I don't want to go. I want to get out of here
- C: Why?
- S: Because I don't like it here
- C: Why?
- S: I will tell you one word; FRIEND (as she stared at my eyes)
- Alexa: I am your friend. You can make friends here
- S: Yes, but I don't want to live with my friends
- C: Where do you want to live?
- S: At home. I have a family and a husband *(Sally was a widower)*
- A: This is your home. It is like a slumber party
- S: I don't like it
- A: But it's beautiful. It's your home
- S: this...this is an establishment. Not a home. Otherwise, why would you charge money to stay here

Observation Notes. June 19, 2019

These conversations clearly show how Sally, despite living with dementia, had a clear concept of what home meant to her and of the social practices associated with it. She was resisting forming relationships as a way to convey her unhappiness; not wanting to join others in activities was her way to assert her control. The tensions that emerged between the private and public use of space, between what was expected from a domestic environment versus an 'establishment', were reflected in Sally's statements. Nonetheless, beyond her resistance to belong, she longed for the comfort, the physical qualities and relationships that meant home to her.

Sally's embodied memory of home lingered in her. She ably conveyed her ideals of home, expressing how living in a multi-storey building, in community with strangers, was not her preference. Linked to her autonomy, she expressed and associated home to a ground floor, single dwelling unit, where she would have been able to open the door and go out:

- Sally: I don’t like being on the third floor.
- Claudia: Why?
- S: Because I want to be on the base. I want to be on ground level.
- C: And why would that be?
- S: So I can go out at night by myself or do anything on the spur without deciding well I might need a sweater coat or blah blah blah
- C: OK, so you think that if you were living on the ground floor you would have more freedom to come and go?
- S: Well it wouldn’t be freedom it would be comfort.

Sally was able to ascribe function to space and frame her social life within the environment. She ably associated the spatialities of home to the social practices and relations she experienced, like chatting about recipes in the kitchen:

- Claudia: When you have visitors… where do *(they)* come to sit and visit? Here in your room or in the lounge…
- Sally: It all depends on who it is
- C: … So who comes to visit?
- S: If we came to visit we would be in the kitchen, or somewhere around, and we would talk recipes and things. We’d be in the sewing room if we were talking fashion or something. We would be in the library if we were talking books.

She also provided some insight into her former ability to decide what visitors were allowed to different areas of her home. This was very different from her current living arrangements, where communal living implied losing control over who used and visited the shared amenity spaces of the care home, making it very challenging for her to accept this new setting as her home. The memory of home was sedimented in her, perduring and prompted in the meaning she ascribed to special objects that had emotional significance to her:

- Claudia: Your bed looks super comfy, super cozy.
- Sally: This was our extra bed. Our single bed when we were married. Yep it’s handy
- C: So if there was one thing that you could change about this place where you now live. What would it be?

- S: Well that Al would still be here…

Interview Transcript. August 19, 2019

Sally was able to associate her single bed to her former home, ably communicating the longing for the home life that included Al, her husband. Despite her dementia, Sally conveyed her preferences, disclosed her biography, and asserted her identity. Her rebellious stance was arguably a reaction to the institutional structure of the care home, albeit its domestic aesthetics; it didn't feel like home to her. It was a tension that could be symbolized by her desire to have a cup of coffee like she used to have at home:

Sally asks for coffee. She asks me if I know what it is in her cup, I say yes…coffee.

- Sally: how do you know?
- Claudia: Looks and smells like coffee
- S: Well, it tastes like discolored water

Michelle *(staff)* comes over and says: used the special coffee your family brought because they want it to be like the one you had at home…

- S: Well, at home my cups were different. I had small cups, not like this one.

I turn to Michelle and interpret Sally's complaint as the coffee being too weak. I asked Michelle to put in more coffee. I say to Sally:

- C: She will put more coffee in to make it stronger
- S: She doesn't know the meaning of strong
- C: Yes, she does, wait and see, you will like it better

She tastes her new coffee and still complains, telling Michelle she should put 6 teaspoons of coffee in. There is an obvious recollection of her small wares at home and of taste.

Observation Notes. June 5, 2019

As previously argued, the construction of home includes embodied memories that have been registered by the senses and that are prompted by present sensations. Sally was used to strong, probably espresso coffee, which would explain her comments about the weak taste of the coffee and the size of the cup. The fact that her family brought to the residence her special coffee was an attempt of her loved ones to help her establish continuity through experiences, in this case taste, that would be familiar to her. However, this incident illustrated the tensions between the domestic realms and the realities of institutional living. The disconnect of personal choice echoed what Goffman (1961) refers to as ‘total institution’ or ‘batch living’. Meals were scheduled around efficiencies and not preferences; coffee was brewed by staff as a scheduled task, not around personal choice. The selection of tableware, a bright yellow china that was used on this floor only, illustrated the tension between domesticity and institutional living. The bright colour was a gesture intended to facilitate visual contrast, a healthcare initiative, yet it looked and felt very different from the china residents would have used at home:

Figure 32 - Yellow Tableware

Contrary to the envisioned potential healthcare benefits these wares represented, it appeared to be yet another visual cue that categorized residents living with dementia as different. Unable to make sense of her current milieu, Sally resisted. Her sense of being and feeling at home was disrupted by dementia and her need to be cared for. It had challenged her personhood and identity so dramatically that she constantly talked about not only leaving the residence, but actually killing herself. When I first heard her express her desire to kill herself, following established protocols, I escalated and documented my concerns. Both the Coordinator and staff in general were aware of Sally's constant threats around self-harm. I was reassured there was nothing to worry about, as they had a good handle on the situation. Nevertheless, the following extracts capture the depth of her discontent:

> As I was walking back to the main area, Sally was sitting. I said hello and mentioned her hair looked nice. She didn't agree. She said to me that I was the only person that had chatted with her and that again she was thinking about suicide….
>
> - Sally: I can break a window
> - Claudia: Why would you do that?
> - S: So I can jump and fall and break my neck. But this is only the second floor. With my luck my neck would not break
> - Vicky: Are you hungry?
> - S: No…I am never hungry for food, or drinks…

Observation Notes. August 29, 2019

For Sally, home was where she was in command, where her loved ones lived, where she was free. Her experience as a user in this regard was one of mourning over losses of capability and independence attributed to her previous self-identity (Falk et al. 2013). It was arguably such a deeply felt loss, that led her to constantly express her desire to die, rather than living in the care home.

Sally struggled to contextualize where she had ended up living; there was little that allowed for self-identity or that enabled continuity with her past history. This same issue has been reported in other studies as one of the most critical issues of care (Örulv 2010). The care home was a home-space that offered no connections or memories, a fragmentation from her past, causing her to feel ‘out of place’ (Calkins 2001; Milligan 2003). A disconnection so severe to place, that it left her wanting to die.

> Sally just walked in and there is a chair on the other side of my table:
>
> - Sally: Is anyone occupying this? Would I be interrupting your work?
> - Claudia: Of course not
> - S: do you know what I would like to do?
> - C: What’s that?
> - S: Commit suicide.
> - C: Oh come on…
> - S: I was trying to think of the methods
> - C: Why would you…life is a gift
> - S: Uh hu… But not all are welcome. Some things happen and some skip and don’t happen… keep it to yourself…
>
> Sally starts to leave and I ask if she is upset with me. She stares out the window and without looking at me she says:
>
> - No…I didn’t want to inflict on you whatever I am.

As she walks away.

Observation Notes. July 13, 2019

Sally’s close association of home with autonomy and individual preference, combined with an overt disregard for her objective surroundings, were expressed by rejecting her new living arrangements as her home. A rejection so deep that it had left her feeling displaced to a point that it affected her identity, as she did not even recognize ‘whatever’ she had become, supporting the construct that place is linked to wellbeing and quality of life, stressing the importance of the environment in the care experience (Garre-Olmo et al. 2012; White-Chu et al. 2009). This finding is also congruent with similar studies where individuals rejected their new environment as a potential new home based on their sensed loss of health and independence (Groger 1995), and that unsure of where they are, or unable to understand the place they are in, leaves the individual uncertain of how to conduct themselves or feel in place (Örulv 2010). In Sally’s case, the experience of her current environment was one that was significantly influenced by thinking of home as a metaphor of competence and independence (O'Bryant 1983). The lack of cues to support and enable these dimensions of home for Sally, the lack of continuity in her biography, resulted in her inability to relate her surrounds to an embodied experience (Örulv 2010). This thesis therefore posits that each resident had subjective experiences and values that they associated with home and as such, each individual contextualized their experience based on their embodied memories and meanings of home.

Making the Best of Things: Nina

It has been reported that those individuals open to accepting frailty, and acknowledging the residential care home as a place of protection and care, tended to downplay the negative aspects of institutional living (Falk et al. 2013). Deciding to 'make the best of things' has been reported in other studies as being an adaptation strategy by which residents in care home environments successfully navigate the dualities of the care home as an institution and as home (Falk et al. 2013; Kahn 1999). These findings are congruent with the findings of this research and are exemplified in Nina.

I became acquainted with Nina during my initial observation sessions. Even before knowing her name, she had called my attention, as she always sat at the same table during meals. Furthermore, her table was the only table in the dining room that had only one chair. This evident territoriality resonated with literature that suggests that an individual's self-expression in an environment, and their ability to make the space meaningful to them, is in part dependent on the user's perceived feeling of control and ownership of space (Chaudhury 2008). The theoretical frame of Nina's claim of the spatiality of the table made sense and could be explained, yet I struggled to understand why this would be her preferred seating arrangement; so different from the one that had been envisioned and scripted during the design process. The table with a single chair was unexpected, as the initial furniture layout had been designed with specific intentional seating arrangements, meant to prompt socialization.

Figure 33 - Nina's Table

Furthermore, when planning the arrangement of the dining tables, there had been an intentional care to place the tables in front of windows. The dining room faced a park, so it was rationalized that residents seating in front of windows would enjoy the outdoor views. The following plan illustrates the careful placement of the dining tables in relation to the windows; a design intervention meant to please residents by maximizing the views.

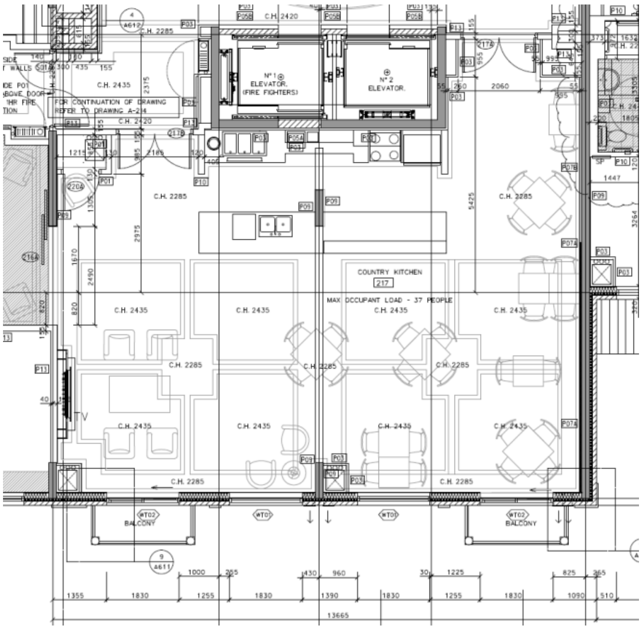


Figure 34 - Dining Room Layout

Nevertheless, Nina was happy to sit by herself, eating alone in silence. Her table, pulled against the wall and moved away from the windows, seemed counterintuitive to what the designers had planned. I therefore interpreted her desire to eat alone as someone who wanted privacy. From the first observation sessions, Nina seemed to me as someone who tried to keep her distance; aloof, very guarded:

> The TV is on, very low volume. The same resident is drinking coffee and sitting, watching amidst the noise of dishes.
>
> Nina sits in her same spot… even though she could sit next to a view, she sits at her same table, next to a column, so no view. She does look up to see the clock that is on the column. She occasionally looks towards where I am seating; she has a very harsh glare, intimidating almost. I feel she looks at me with some curiosity and in a way, lack of trust.

Observation Notes. June 5th, 2019

I was seated in the Serenity Room which opens to the dining room. I had decided to leave the lighting level as low as possible, enough to allow me to write down my notes, yet dark enough to go unnoticed by both residents and staff; trying to be the least disruptive as possible. Yet even through the space that separated us, and even though I was trying to be very quiet and discreet, I could feel Nina's gaze. I would later have the opportunity, during our interview, to learn that gazing was one of Nina's ways to communicate, and that she was actually very aware of her facial expressions as the following passages reveal:

On the topic of what she would do if someone else took her table:

- Nina: Maybe I'll be late one day and see if there is anybody else there and then I'll give them the eye (laughing)… or the face, as my sons used to say," You'd better watch out, because if you don't do it proper you'll get the face". And I never did find out what the face was.
- Claudia: Yes, I can relate to that. My mother was the same way and all she had to do was turn around, and you could see
- N: Oh boy.
- C: Either leave the room or shut up.
- Nina: Put up or shut up.

…………………………….

- Claudia: … And do you think staff here are flexible and adaptable to your needs?
- Nina: Oh… they seem to do what I would like them to do anyway… because, I think if they didn't they'd hear about it. My son would tell them "Don't do this or this or this cuz Mum will give you the face". That's Ian, and I never ever did find out what the face was. But apparently, as far as the kids were concerned, it was quite a deterrent. They never wanted to get the face…

Nina's gaze and facial expression had a harshness that was very particular. My initial judgement of her being a very cold and aloof person was dispelled once I got to know her better and once I was able to interact with her. Yet the fact that, albeit her cognitive impairment, she was so aware of her facial expression and of the effect it had on others was very insightful. When I was chatting with her about making friends in the care residence, her comments demonstrated how self-aware she was:

- Nina: … oh no I usually go where there's somebody. I usually like to find, I don't usually sit and wait for people to come to me, because that doesn't always happen. Because there is something about me, that people feel, maybe I don't always feel??? or show that I'm welcoming, I look like I have too great expectations or something. There is something about me that isn't always friendly………It's just how you are. Well you see I just go above that. Tough titty if you want to be intimidating go somewhere else.

Interview Transcript. September 12, 2019

As I got to know Nina better, I started to understand how her gaze was a way to assert control. As it has been argued, behind the gazing eye, is the thinking and affecting mind, where engagements are found, creating relationships and meaningful interactions, even in the absence of direct and practical action (Carrier 2003). Therefore, it could be argued that in her silence, in her distance and through her gaze and face, Nina was in relationship with her environment; she was actually setting boundaries by being in control and in possession of her immediate space. Studies have concluded that individuals who succeeded in creating attachment to place in their new environment had two distinctive characteristics: being in charge and nesting (Falk et al. 2013). Through her strong personality, her intentional gaze and use of facial expressions, by claiming her territory, by deciding when and how to befriend others, Nina was exerting control of her circumstance.

Her desire to eat by herself could be explained as a way to control her new social environment. By quietly protesting to group dining, by refusing to eat with ‘strangers’, she exerted her individuality by not having to comply with rules (Schillmeier and Heinlein 2009). For Nina, home embodied personal control (Oldman and Quilgars 1999); it was related to preserving territorial control and privacy (Groger 1995). This became ever more obvious after having the opportunity to visit her in her suite for our interview. In the intimacy of her space, Nina transformed into the most enjoyable and charming lady one could imagine.

Nina, a widower, was from Australia and had three sons; all doctors. Her husband used to be in the health sciences. During the initial consent phase, one of her sons had requested, as condition to providing consent, to chat with me before initiating any observation work or interviews with Nina. After reaching out to him via email, we agreed to have a telephone conversation to get better acquainted. He wanted to know more about the fieldwork that would take place. He asked about the association of this research with the University of Stirling and was very curious as to what areas my observation sessions would be covering. After a long conversation, he gave expressed verbal consent which was complementary to the written consent he had already signed. His interest in knowing more about the research work provided me with a glimpse of how involved he was in the everyday care of his mother.

> When I asked Nina where she would like to sit down and chat for the interview, she invited me to her suite. As soon as I came in to her suite, I could tell she was happy to host me. I was taken by surprise to see how lived-in her suite showed. Lunch had just finished, Nina sat comfortably in the couch; she had already changed her clothes to a house robe. I could tell she was proud to have me visit and her jovial facial expression visibly showed how comfortable she felt and how much she was enjoying her surrounds. I was very surprised to see her so relaxed, sitting on the couch; she came across so differently than what I was used to seeing. Her living area, was an explosion of colour, of texture, of things. It was at once all the mess one would associate with the most private areas of home. The neutral

palette of the suite had indeed been used as a canvas to personalize and decorate the suite.

I came in, unsure of where to sit and uncertain of what to focus on; the flower arrangement with a card saying how much she is loved, the beautiful straw hats peppered all over the area, the myriad of magazines and books, the playful toys, the small stuffed animals, or the family photos. The warmth and playfulness of the space, and the warmth of her expression, were completely unexpected.

Observation Notes. September 12, 2019

Figure 35 - Nina's Suite

The explosion of colour and things I encountered was a stark contrast to the organized and sanitized environment just outside her suite door, or the severity I had come to associate Nina with. It was as if the space outside her suite was a soft and quiet harmonious melody, while her living room was an improvised jazz session. Just like when the ivy crawls up and engulfs the materiality of stone, to a point were all you see are the soft green leaves and the wall is no longer legible, things had been piled and placed in a way that they had engulfed and covered objects to a point of dissolving their functionality. There were so many things on the ottoman, which was also used as a coffee table, that it was no longer possible to sit on it. The television console was so crowded with knick-knacks that, anyone trying to watch the portion of the screen that was not blocked by the flower arrangement, would have a hard time watching it. And as regimented and severe as Nina may have appeared, she seemed perfectly at ease amid her things, and not at all bothered by the way things were placed.

- Claudia: … I see you have a whole bunch of books and "Hello" magazines, so do you like to keep up with the Royals?
- Nina: Yes, I like to keep up with whatever's happening. I like to be on top of the news. I like to know what's going on.
- C: Do you watch TV every day?
- N: ... I do watch TV but I don't watch it a lot. I'm not a big TV, oh I mean, look at the flowers they hardly ever get moved

This unexpected informality and ease that Nina exhibited exuded comfort. She felt comfortable and was very aware of how this comfort was associated with the intimacy of her space and her things, as evident by the following dialogue:

- Claudia: You know you are very close to this end lounge and the three-season space here, which is quite lovely, it has a fireplace and a sitting lounge. Do you ever go…?
- Nina: Only if I've got somebody that's not comfortable to be here. I don't use it a lot… but it's nice that it's there. It's not that I don't want it… It's just as comfortable to sit here like I'm talking to you.
- C: In your suite.
- N: Yes. I'm comfortable and I can put my feet up if I want to. Or you know, this is nice and comfy.

- C: To slouch.
- N: Yeah…
- C: It's a very comfortable sofa.
- N: It is comfy isn't it?

Interview Transcript. September 12, 2019

In the privacy of her suite, Nina felt relaxed and in control. Her preference to visit in her suite and not use the common area lounges and her desire to spend time in her living space, was congruent with the two dimensions that have been identified as helpful in creating attachment to place; nesting and being in charge (Falk et al. 2013). Nina had personalized her environment, an action associated with nesting, filling it with personal belongings and mementos. Her furniture and objects had transformed the anonymous pale coloured suite into a place of recognition and familiarity. These objects and things spoke of her self-identity; a distillation and collection of a lifetime of memories, with experiences and meanings attached to these objects. Nina's suite felt like her place, filled with objects that were representations of things dear to her, not just material stuff, but representations of self (Martin et al. 2015). These objects, ranging from hats she had decorated; to a tiny hat she last wore for St. Patrick's Day, provided symbolic cues of Nina's identity and personal history. Sitting on the comfortable and familiar sofa, wearing her house robe, keeping herself entertained with puzzles and games, just basking in the privacy of her space, surrounded by her things, provided such different possibilities of understanding Nina.

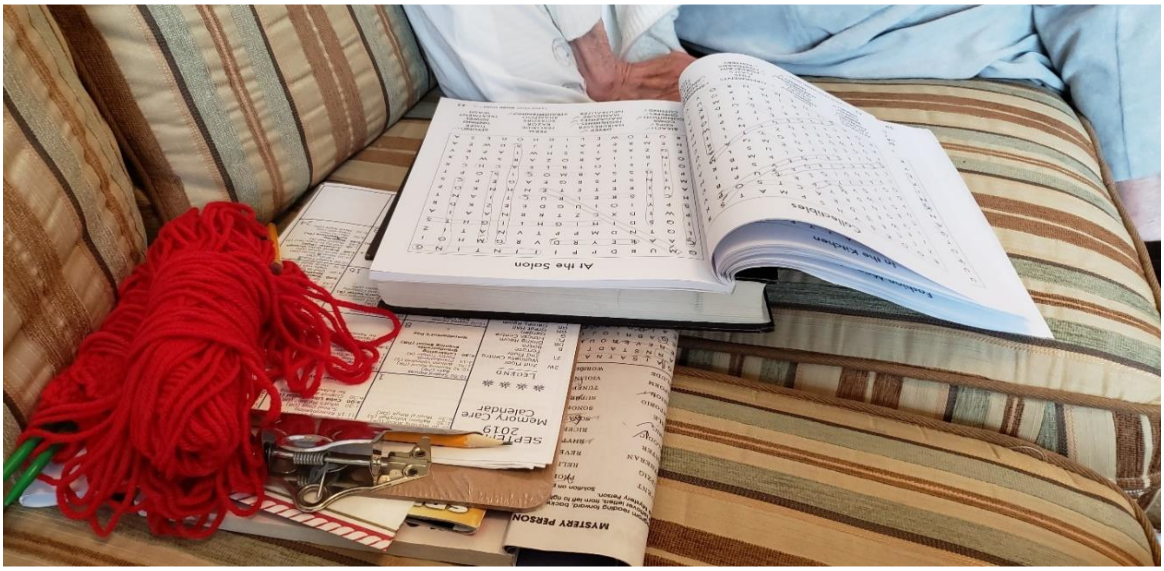


Figure 36 - Nina's Sofa

Unlike my experience with Sally, where I was at a loss for words when I first started interviewing her, feeling uncomfortable and so unsure of how to even refer to her personal space, I was completely at ease in Nina's place. From the moment I came into her suite, I felt as a welcomed guest, where Nina was unequivocally my host. The start of our interview was much more fluid and relaxed, and as the following excerpt shows, I was drawn in to her place from the start:

- CS: ... I love your suite. It's beautiful… it's so warm and so full of really beautiful things like these hats…

There was no ambiguity of place. Everything, albeit in some disarray and under traditional design criteria, messy, contributed to the legibility of the environment. From the moment I sat down, I right away started to refer to Nina's place as her suite; during the interview I interchangeably used different terms: suite, apartment, home. It was such an unexpected experience for me. The multi-sensorial experience of the environment was informing my understanding of her place. I took it all in, Nina wearing her light blue house coat, with a thin white sweater and slippers on, her relaxed posture; the comfort of the couch, the softness of used textile, the brilliant colours of all her things, the pile and smell of magazines and newspapers, the cup of coffee steaming on the corner of the ottoman. I had for a moment become the subject of my own research, for it hit me all at once, how real my experience as the user of this space was. How it was being informed by my own past experiences and associations of the material to meaning; my embodied memory was understanding and, in a way, decoding the space. The aroma of coffee, a very familiar scent in my home, made me feel at-ease. The way I was sinking into the well-used sofa reminded me of my favourite seating place where I watch television in the basement of my home. The coloured chaos of things all over the place echoed the aesthetics of my own art studio. Nina's place was at once festive, messy, welcoming; it was homelike. In particular, I was stunned by the number of beautiful hats that were placed randomly around her suite; some in the living room, some in the closet, others hanging on the wall.

Figure 37 - Nina's Hats

- Claudia: Did you make these?
- Nina: Well I made all of that.
- C: That's beautiful.
- N: You buy the hat and then you buy the things to put on it. See that's the hat that you bought………
- C: I'm going to go buy myself one of these hats and bring you flowers for you to do for me
- N: (laughs)
- CS: Is it something you've always done?
- N: Oh, I just pick things up and do them. I'm handy.

Interview Transcript. September 12, 2019

This dialogue captures the ease with which both Nina and I were able to chat. The same person I had first described as harsh, intimidating, and distrustful was welcoming me into her place, willing to share with me her most personal space and things. Nina's hats were so colorful and loud, so extravagant and so many, that they were impossible to miss; thus, our opening topic was the hats. These hats were obviously dear to her, with meaning assigned to them and as such, they provided her with a sense of comfort and continuity of identity. The relationship with objects has been studied and has been constructed as a materialistic lens in experiencing space, where understanding the person-object relationship of certain things, can provide insight on the meaning individuals assign to special objects. This approach to observation can enhance understanding of identity construction by focusing on the individual's relationship with the object (Chapman 2006). Through her hats, Nina was revealing part of her biography, congruent with the stance that meaning of home is partially created through displayed objects used to convey identity, becoming more significant in later life (Lovatt 2021). However, it was through our interaction that these hats actually conveyed the meaning Nina had ascribed to them (Lovatt 2018). She shared that she liked to decorate these hats and that she 'is handy'. She *is* handy; not in the past, not part of what she used to do or be. She asserted her identity as a handy woman, a quality that remained intact despite her cognitive impairment.

Nina's disposition and posture, the way she presented herself amid her things, all contributed to making me feel welcomed and to make her place feel homelike. In her suite, through the display of things, Nina had injected her personality to the space. The atmosphere she had created, the ambiance of her suite, were defining the quality and character of the space. This is congruent with the construct of 'atmosphere', or 'personality' of a setting, as two interacting and codependent dimensions; the physical environment and people's doing and way of being in the environment (Falk et al. 2013). The atmosphere in Nina's suite was that of a lived-in space, of a safe place that felt like her home. Furthermore, my conversation with Nina also supported evidence that suggests that how we experience space, how we create place, and how we construct home is informed by our lived experiences; it is what has been that becomes the indisputable foundation of who we are now (Chaudhury 2008). Both the imaginary and mental landscapes of our lived experiences shape and define identity and as such, become deeply rooted in memory, where these cues to memories of important life experiences become a way to maintain the self (Chaudhury 2008). The materiality and physicality of things in Nina's suite were a dimension that complemented Nina's way of being, of presenting herself. One could argue she was 'in place' or emplaced; she seemed to belong in the space and the space obviously belonged to her. In tandem, the atmosphere or the feel of place created was infused with meaning, divulging her identity, providing a continuation to her biography.

Nina's husband had been a medical researcher, associated with a prestigious Canadian University, whose work took him around the world. As such, the family had relocated on several occasions. This experience provided Nina with a very personal and practical meaning of home, making her appreciate change as a positive thing, stretching her capacity to adapt to new circumstances:

- Nina: … we had so many houses we just moved around and because I was in research, medical research with my husband… and so we just went wherever… and so, everywhere that I went didn't always feel like a home. I just made it homely, and it was a place to live. It was where I had to be for the moment… And then the University would send us somewhere else and we'd have to up everything and move somewhere else. And make new friends or meet different people, and always have to adapt to a different situation…… every home was different. Every place was different.

………………………………………

- Claudia: … what is a typical day for you here?
- Nina: To tell you the truth I don't know. I just do whatever comes up. And I'm more inclined to go with the flow and … I quite like change. I like things to be a little bit different. I like a challenge, and I like to have to rise to the occasion and then feel good that I can do things. So, truly I don't have a typical day. I just do whatever comes around… I'm quite content here and I think… I think wherever you go you'll always find something that you could possibly change a little bit or have a little bit differently, but it's nothing over the top that I, I'm quite adaptable and everything. There's nothing that's not to my liking.

Nina's lived experience had made her adaptable, comfortable with moving around and settling in different countries, adapting to new environments. Her strategy to make each place feel like home by making it 'homely' was serving her well in her current circumstance. She was using the same proven strategy to make her suite feel like home. This could be explained as part of an overarching approach to circumstances, a practical approach to making the best of things, as evident in her reply when asked what 'homely' meant for her:

- Claudia: What did you do to make it homely?
- Nina: I can't remember. I took whatever was there and made the best of it.

This particular attitude of 'making the best of it' was similar to other studies where participants who have successfully adapted to their new environment downplayed the negative aspects of institutional living and decided to make the best of things by looking to the positive side of life (Falk et al. 2013). Evidence also shows that this positive outlook on life in a care home is partly associated with the individual sensing they have no other option than to live in the residential care facility, but to accept their plight. While the care home arguably symbolized losses, it also became acceptable when understood as a place of shelter and respite as their health declined (Kahn 1999). During our interview, Nina explained many times how she was 'making the best of it', with her comments echoing findings from the above referenced studies:

- Nina: The thing is I'm not gonna be very good for you, because I, quite frankly you just make the best what you've got and what you've got is what you make the best of otherwise you're unhappy so what's the point.
- Claudia: (chuckles) So overall you have a very optimistic nature? You try to see the good…
- N: Ya because it's a waste of time otherwise you get unhappy and what's the point in being unhappy? It doesn't make sense to me… so you make the best of everything. That's what you do.

………………………….

- Claudia:… I'm trying to understand… how does it feel to live here…
- Nina: I think that pretty much depends on the person. And I think that some people choose to be unhappy with their lot in life, and so they will be unhappy whatever you give them. And some people like myself, figures

> that if this is what you've got make yourself happy cuz what's the point in being otherwise… so I truly don't believe in making yourself unhappy. And so I'm inclined to be content wherever I am and if anything is too objectionable then I do what I can… to change that …

Acknowledging that Nina's perspective was arguably shared from a standpoint of privilege, her optimism cannot be dismissed. She recognized her frailty, yet she did not mourn the loss of autonomy as Sally did. Supporting evidence from other research (Kahn 1999), Nina approached the loss of past domestic duties in a very practical manner. She, recognized her physical decline and acknowledged the concerns around her personal safety given her experience with dementia:

- Claudia: You miss your cooking?
- Nina: … I used to like it when I did it, but I can't say that I miss it now, because it's hard on your back. You have to stand up a lot, an… my back is getting a bit achy. And to tell you the truth, I like things are done for me now. I like not having to do things.
- C: … good so that's an improvement. Is that something you like better now?
- N: Well, I like it as much as, I don't say that I like it better, maybe I would like to go out doing things more, but if I can't I can't, so this is what you've got.

……………………………

- Nina: I look up every now and again to see what's going on.
- CS: Do you go out for walks?
- Nina: um I do, but I don't care for it very much on my own anymore, because I don't want to go wandering around and possibly lose my way like forget where I am or something. So unless I've got somebody – I don't go on my own… I don't think that's a good idea.

Despite Nina's cognitive impairment, she exhibited incredible self-awareness. One could argue that this is yet another way in which Nina was asserting her will and selfhood; she was not a passive recipient of care, she was actively constructing her happiness and taking control of her situation. As reported in other findings, the significance of 'making the best of it' was intricately related to its predicate, ‘making’; a creative act, an act of volition or will (Kahn 1999). Nina’s determination to be happy and feel content revealed her hope, actively involved in a process that required effort on her part.

- Nina: And so I find that life goes very smoothly. I’m quite content, but then I believe in being content with what you’ve got because I can’t see any point in being unhappy… to me that doesn’t make sense.

…………………………………….

- Claudia: … if there is one thing that you could change about the building, what would it be?
- Nina: First of all, I’ve honestly never thought about it because I don’t believe in wasting my time thinking about things I can’t change. So you accept things and you make the best of it. And that’s how I am in life I think… you just make the best of what you’ve got.

Nina’s past strategies to adapt and make a home for her family as they moved around, proved essential to her current view of her living conditions. She was aware of her limitations; aware she was not fully in control of being in the care home. Nonetheless, unlike Sally who associated home with autonomy and freedom, I would argue Nina associated home with meaningful relationships. Her love of her sons and their love for her provided a continuity to her past that proved essential to her present. This came across during our interview, when we were discussing how she came to live here in the care residence, and in the joy she exuded when her family came to visit her:

- Claudia: So who chose? ...who made the choice?
- Nina: I think my kids did. I think they looked around and found the best possible place for me. And I have faith in them and I trust them.
- C: And you trust them.
- N: And I know they love me, they have a feeling for what I would like and not like, and I think they would get the best for me so I never question it… Plus, if they took the time and trouble to do it, why should I make life more difficult for them. And that’s why I think, in a way, it’s just the way I am, but I think it’s serving me well, because I think that anything they do is because they want to do it, not because I’m a demanding selfish person.

> And they'd do it unwillingly. And everything they do, they do out of love and because they want to. They want me to be happy and content. So, I'm very fortunate with my sons…

Interview Transcript. September 12, 2019

During my June 19th observation session, the night of the concert, I had noticed Nina wanting to sit by herself.

> Nina just joined, of course she is walking with a brisk pace and confidently stretched her index finger to point to the RCP where she wants to sit. In the second row, with both chairs next to her empty…

Observation Notes. June 19, 2019

At first, I thought Nina's desire to sit in a specific chair, with two empty chairs next to her, was another version of her desire to be left alone. Nonetheless, a few minutes after the concert had started, I was proved wrong. Nina had been saving the chairs next to her for her son and grandson, whom she had been expecting to visit. Her transformation once they arrived and sat next to her was visible; she sat proud in the memory care section, singing along, happy her family had joined. Their presence infused her with autonomy and control, choosing where to sit and commanding the space around her; she was enjoying a night of entertainment with her family in her new home.

As previously discussed, the sense of home, the ability to form attachment to place, is informed by both concrete and abstract elements of the environment (Groger 1995). Nina's things, her hats, photos, furniture, all provided her with a continuity of the concrete elements she associated with past homes. Likewise, her ability to continue a meaningful relationship with her family provided her with a continuity of the abstract; her ability to continue important social relationships had proven critical to her biographical and emotional continuity, helping her establish affect to her new place. For Nina, her definition of home was intricately tied to her social relationships, as illustrated below when asked how she made her different places of residence homelike:

- Nina: … no one particular thing
- Claudia: Not one thing?

- N: Because every home was different. Every place was different… I think it was not so much friends - things, but I always had the need to go out and talk to people to make friends. And I've gotten - I was very, very lucky because people were very willing to be friendly.
- C: So that's really, that's another really good comment when you say that it's a, it wasn't about things. It was about the people
- N: The people, always the people.

The fact that Nina's construct of home was more tied to the abstract and not to the concreteness of a particular place had helped her form attachment to her new milieu. Her embodied knowledge that her sons loved her, and were there for her, provided her with assurance. Furthermore, it has been theorized that individuals who had weak symbolic ties to previous environments proved to be more successful in making the transition from their home setting to institutionalized care (Gubrium 1993). Nina's past life experiences of having to relocate and make a home for herself and her family in each location, provided her with valuable tools to adapt to her new place:

- Claudia: Flexible and adaptable. It seems that that's very important for you.
- Nina: Yes, because I think that if you are going to be at all content, I was gonna say happy, but I think even content in life, you have to be adaptable and you have to be flexible. And you have to listen to the other person, and you have to understand that you can't always have things your way. That your way is not always the right way…
- C: … is it fair to say you've always been like this, flexible and adaptable?
- N: I think so I think that's my nature.
- C: And do you think that that has helped you, be content in your new home?
- N: I think so, and I'm very grateful, yes… just be content with what you've got. I think you can strive for better. I think you can strive to prove yourself and to do better, but if you can't do it well that's it. Don't, don't let it get the better of you. If something is not possible well then ok it's not possible. That's it. Do something else...

Nina defied the image of a person living with dementia. She was strong-willed, she was in control, she was in charge as she had always been. Her personhood, identity and temperament were intact; her biography continued. Furthermore, her autobiographical insideness, enriched by the places she has lived in, and by the life experiences and strategies that became part of her, provided her with a sense of permanence within the context of the new physical setting of the care home (Rowles 2000). It helped her adapt to change, assisting the internal process in which Nina projected a sense of her identity by transfusing her 'self' with the physical environment, transforming her suite to a place of significance, creating a place that reminded her of her identity (Chaudhury 2008). Surrounded by things that were important to her, Nina succeeded in carving a place for herself. Suddenly, her desire to dine alone could be understood from a different perspective, as an almost accidental event:

- Claudia: I noticed something and… out of curiosity, because you just finished lunch and I knew exactly where you would be, you always sit at the same table?
- Nina: Oh, people tend to do that do they not?
- C: They do?
- N: That's human nature.
- C: ... and why that table in particular?
- N: I think that's because that's where they put me so that's where I stayed. I don't think I chose it for any specific reason. I think they took me here so I said "Thank you" and I sat down and then went back to that table.

Unlike Sally, who usually wandered the corridors and common spaces, Nina had found haven in her suite; the place she could control. Dining in the common area was just a need and a function; a convenience. She was quite content with eating by herself, comfortably trusting staff would know what to bring her.

- Claudia: And I've noticed… You don't like to eat with other people is that a preference…?
- Nina: Oh I can, but I tend if, I like to enjoy my food… and I'm not one for inane conversation…
- C: Do you think the food here, in the building is nutritious?
- N: Well I can't say for everybody because I know that they give me what I originally ordered and what I care for and they don't bring me what I

> don't care for anymore. So, I don't have to say anything because I know they are only going to bring me what I want to eat.

Nina had a clear strategy of feeling emplaced in an environment meant to support her, but that also restricted her. Her attitude supports Kahn's argument (1999) that residents who successfully adapt to their new 'home', engaged in an active process of making the best of their plight as they realized they were unable to control physical and social elements of their new milieu. While individuals acknowledged their inability to change the reality of their situation, they attempted to reconstruct both cognitive and emotional aspects of their identity, by placing importance and significance to symbolic elements of the environment and by making the best of their situation. This intentional and creative process, which provided individuals with a sense of control, was observed in Nina's attitude:

- Nina: I think a lot depends on the person's disposition. I think it depends on how you always accepted life or dealt with life. Deal with what comes along and make the best of it… I think that's been my bit of, unconsciously, my philosophy just make the best of it. I think that's what I've always done just make the best of it. And if you can't change something accept it and make the best of it. And if you can change it for the better then do so…all it just takes is a bit of effort, not to be lazy and sit on your duff and let other people do things for you…

To be is to exist somewhere, which means to be some place; to be emplaced (Chaudhury 2008). To belong, to be comfortable, to be in control, to be surrounded by personally significant objects which are integrated with one's personal history that help sustain identity (Wiles et al. 2009), are all attributes associated with home. Nina was actively building her happiness by making the best of things, granted she had the means, not only the disposition, to do it. She was quite comfortable to be alone, and quite happy in her suite. The continuity in biography that her relationship with her sons and family provided was a bridge to her new reality; helping her connect her life experiences from before and after her encounter with dementia. Her triumph can be summarized in the following excerpt:

- Claudia: Would you consider, Nina, this your home?
- Nina: Yes, I do. Well it may not have been what I might have chosen, but this is where I am and so I make the best of it.

Interview Transcript. September 12, 2019

Nina felt loved, connected to her loved ones. Her overt self-expression in her suite had provided her with a feeling of control and ownership; making the space meaningful to her, allowing her to assert her identity and to feel at home.

Environmental Implications of Dementia Care on Couples

Both Sally and Nina were widowers, their journey with dementia started after their spouses had passed. The following two case studies depict Charles and Greg's experience, both of whose spouses had been diagnosed with dementia and who had moved to the care residence while still being married. Similar to what other couples have expressed, through time, they constructed a shared sense of identity within their social context (Robinson, L. et al. 2005), with dementia disrupting their experiences of couplehood or 'we-ness', their shared identity and purpose (McGovern 2011), profoundly affecting the couple dyad (Holdsworth, McCabe 2018), supporting the argument that dementia is not experienced by individuals in isolation (Robinson, L. et al. 2005). It is a condition that plays out in the context of relationships that are stressed and at times broken as the cognitive and functional abilities of the individual affected by dementia decline. Nevertheless, caregiving activities, albeit often with highly gendered expectations attached, were understood by both Charles and Greg as extensions of their marital relationship (Perry and O'Connor 2002), arguably grounded in their marital vows of "in sickness and in health" (O'Connor 1999; Perry and O'Connor 2002).

Both couples had a home which had been the center of warm social relationships and personal identity; a place for family interactions, for personal seclusion, and intimate behavior, free from public scrutiny or control (Imrie 2004). It was the combination of the abstract and the tangible; the meaningful relationships, the physical space, and their personal possessions, which constituted the meaning of home for the couples (Gubrium 1993). Nevertheless, dementia had disrupted the life they had built, leaving behind a deep sense of loss. As Davies et al. (2010)

posit, it is a loss of relationship rituals; of a confidante, of a best friend, of a previous lifestyle, of future dreams, of a way of socializing, of a lover, a parent, a homemaker. The resulting in an ambiguous relationship often referred as 'quasi-widowhood' (Dempsey and Baago 1998), given the spouses find themselves still married, yet alone. The physical absence of the spouse in the couple's home presents a major attachment bond that is severed and irrevocable, prompting a re-positioning of the individual in relation to their spouse living with dementia, along with the implications to their relationship as a couple (O'Shaughnessy et al. 2010). This sense of ambiguity, uncertainty, and loss were evident in Charles and Greg's narrative; both facing similar situations, trying to cope with a new couplehood reality, yet each having a different approach and experience to their wife's journey with dementia.

Close yet Far: Charles

> "…she's not capable of rational thought. And she's not capable of thinking things through…she doesn't think in comparative terms… she's forgotten the old house. She doesn't remember the old house at all. She doesn't remember any of our old friends. And… this (*referring to the care home)* is all she knows…" (Charles talking about Kate)

Charles and Kate have been married for more than fifty-five years. A couple with means and resources, who led a very comfortable life in a beautiful home, as described by Charles:

- Charles: I still have it… there's five bedrooms. It's right downtown and quite conveniently located just a block and a half from St. Joseph's Hospital… and it's a lovely house… I'm really torn about what to do because I really don't have the energy anymore to be responsible for such a big operation… I had a lovely garden… a nice garden, and had a car and easy parking and I had a lot of bedrooms and I had a very nice house….

That is, until Kate's diagnosis. At the beginning of Kate's journey with dementia, the family decided to bring care to the home; they could afford it and had agreed it was the best way to support Kate. Nonetheless, the pressure of bringing nursing staff into their family home prompted Charles to look for other options, as the privacy they previously enjoyed had been compromised, and the level of care Kate needed had become unsustainable at home:

- Claudia: … was there any specific limitation at home… that prompted the decision to say "Ya know what it's not the right environment… this is just not helping her"?
- Charles: Oh, I would say that it was probably my reaction. I felt that I couldn't cope and I hated those nurses in the house all the time… and she was not doing well and we thought, talking to the children, two kids, talking to them and what we should do. My wife is a nurse…And my daughter's a nurse, and talking about and doing a little bit of reading… we thought it would be, everyone thought it would better to be looked after here.

Interview Transcript. September 12, 2019

Charles's experience resonated with findings from other studies which argue that often, the motivation of bringing care provision to the home, is an effort to maintain continuity of family life and preserve the sentiments of 'feeling at home' (Grenier et al. 2016). Nonetheless, evidence also indicates that the transposition of healthcare practices on a domestic environment disrupts the experiences and practices of home life (Angus et al. 2005). The spaces of the home are planned to enable privacy and intimacy, amongst other things (Twigg 1999). Having nurses come into the house, arguably entangled the logics of home for Charles, disrupting the embodied meaning of home. Charles also expressed his desire to regain quality of life and feel independent:

- Claudia: So… more than environmental space limitation in your home, what prompted you to look for dementia care unit was privacy? Or you didn't want the nurses to come in or…?
- Charles: No… I wanted to have some independence in my life…Ok and I guess I could say I wanted somebody else to look after Kate… although, I'm doing my bit but … I'm not a nurse.

Charles's attitude was found congruent with reported findings on caregiver's burden, where the changes to their everyday life arrangement socially repositioned the individual to a new role anchored in a chronic condition (Angus et al. 2005). Spouses in particular, reported a heavy burden of care in the early stages of dementia (Adams 2006), reluctantly acknowledging looking forward to placing their loved one in a specialized care home as a relief from excessive burdens of care (Meuser and Marwit 2001). The decision to bring Kate to the care residence was made by Charles, with the support of their children. Charles provided insights into their marriage; they enjoyed a trusting and strong relationship, viewing himself as having authority to be the decision maker. Kate was informed she was moving to the care home, a decision she accepted:

- Claudia: When you toured these six homes was it just you and the kids? Or did Kate come along?
- Charles: No, no me and the kids. You see we never talked to Kate about going into a home. She wouldn't accept it. She wouldn't accept, wouldn't talk about it. You see we just happened… "Ok Kate you're moving". And that was it. Then I think part of that is, as her husband I have a certain amount of authority.
- C: Of course...
- Charles: And we have a very good relationship as a married couple and I think that… that, she probably tends to go along with me.

Interview Transcript. September 12, 2019

Charles's narrative of why he decided to bring Kate to the care residence, and his honest acknowledgement of wanting to maintain his independence, was consistent with findings that discuss the tension between meeting own needs and meeting the needs of the spouse living with dementia (O'Shaughnessy et al. 2010). As Charles stated, they had a very good relationship as a married couple, so Charles's desire to maintain his autonomy, his sense of self, and not having his identity be subsumed by the role of caregiver, had nothing to do with his feelings for Kate. On the contrary, from the first time I met Charles, it was apparent how vested he was in Kate's care. He was the first person to arrive at the information session that was held; he was the last one to leave, staying behind asking questions. Once fieldwork started, Kate was someone that was hard to miss; her wit, her presence, her energetic strides up and down the corridor were simply impossible to ignore. I soon took a special liking to Kate, getting to know her better. In discovering part of her biography, I soon understood why her daily and tireless wandering and walking down the corridors seemed so intentional:

- Charles: ... She was a head nurse
- Claudia: A head nurse?
- C: Well, she was running a retirement home, she was a head nurse of a major ward, biggest ward in a long term care hospital. So she'd run the hospital, a big institution, and she was the head nurse there.

Interview Transcript. September 12, 2019

I had the opportunity to interview Kate on two occasions; one in her suite and the second time doing a walking interview with her, barely able to keep up with her pace as she wandered the corridors. It was during this shared walk that I understood that Kate's memory of her past professional life was embodied in her actions. During her 'wandering', she was very methodical in closing doors that were left ajar, turning lights off when rooms were empty, being critical of staff leaving food out, and gently touching fellow residents that seemed sad; she was still caring for people. Kate's actions made total sense within the context of her past biography of being a head nurse at a care hospital, supporting Kitwood's advocacy to consider dementia care as a process of meeting between persons, where communication of personhood can also be conveyed non-verbally (Kitwood 1993; Kitwood 1997). The following excerpts of my interactions with Kate illustrate how her embodied memory was informing her actions and how in her spirited nature, she was trying to communicate her challenges, providing a glimpse of what her prior professional and personal routines would have been like:

> Kate is pacing and walking the corridor. She tells me that she has a lot of things going on because 'new ones' have come in. she says:

- Kate: A lot of them are all over…
- Caregiver: Would you like some wine?
- K: Yes! Sometimes I feel that wine is all that is left

  The RCP goes into a locked closet, brings a bottle of wine out, pours Kate a glass explaining how it helps her relax. Kate takes a seat with us and starts drinking her wine.

Observation Notes. June 19, 2019

…………………………………..

Kate comes into Vicky's office to provide an update. She has been busy. She is asking if she is OK about 'it'. Kate is busy walking up and down the corridor and her demeanor has purpose. I said 'hi' to her and she said she was just busy, that she had lots of things…

A PSW *(Personal Support Worker)* asks Kate if she wants to join. In a very professional way she says:

- Kate: No dear, it is too much in here, just so much

I believe she senses the overall agitation. She walks into Vicky and says in an accomplice way…

- Kate: Jesus Christ!
- Vicky: Yes, Jesus Christ!

It is as they connect and share the burden of care.

Observation Notes. July 13, 2019

In many ways, Kate's routine of wandering, her comments, her desire to have a glass of wine at the end of the day were easy to understand and relate to. A busy professional woman, after a long day of work, at times frustrated by staff and at times overwhelmed by work, relaxing with a glass of red wine, sharing her day. Arguably, Kate's identity and memory of her past professional routines were articulated by her body, supporting the theoretical framework of embodiment, in which memory is contextualized, experienced, symbolized and embodied by the individual in ways that transcend cognitive dexterity or verbal expression (Katz, S. 2012; Kontos 2005).

After many such encounters with Kate, I remember running into Charles one afternoon and very spontaneously sharing with him that I thought Kate was great and fascinating. Charles responded in a very quiet and somber way, a serious expression on his face, simply saying "me too". It was evident just how strong their bond as a couple was. This made it difficult for me to understand why then, they were living apart, as I knew Charles had also moved into the care residence and Kate's suite was a large and comfortable one-bedroom unit. Eventually, Charles provided more insights about their living arrangements. Kate's family had made the decision to move her into a memory care suite. They had selected a large, apartment-type suite and had even hired an interior decorator to set it up.

It was important to the family for Kate to have the best possible living environment as attested by Charles:

- Charles: Well first of all there was the scale, we wanted them to be big enough. And secondly… she has a very nice room.
- Claudia: Yes, she does
- Charles: And we, we got an interior decorator to move the furniture for her, and set her room up for her. And that, that was very important.
- C: Why do you think that was very important?...
- Charles: Well it's big. Lots of space… and a separate bedroom. A lot of them just have rooms… and she has a separate bedroom, and a separate bathroom. That's good. A big living area, and… she liked it. That was important.

Interview Transcript. September 12, 2019

The process and criteria for selecting Kate's suite was reflective of the family's financial status and dynamics. Charles's approach to solving Kate's care needs, searching for a good place for her, and firmly deciding moving her to the residence, was congruent with studies that report on the approach husbands have towards caregiving: a practical, problem-solving attitude, and less of a 'hands on' approach (Baikie 2002). Nonetheless, the physical separation forced by Kate's increasing care needs, disrupted their relationship as a couple. As reported in other studies, among the stresses dementia poses on a couple are the loss of their family life as a couple, along with conflicting emotions like anger, guilt, depression and grief (Dempsey and Baago 1998); all emotional tolls compounded by a sense of losing 'couplehood' (Holdsworth and McCabe 2018). Consequently, wanting to be closer to Kate, and due to an unexpected fall, Charles decided to move into the care home as well:

- Charles: … she came in first for the first year. I was not here. And then I had a fall… and then I bashed my head. And then my kids, as usual, my kids ordered me to come in here… So I came in here on respite, and then I decided to come for a longer period of time because of me and Kate and that worked out well…

Similar to evidence from other studies that report how adult children make care-related decisions for their parents (Meuser and Marwit 2001), Charles was ‘ordered’ to move in to the residence. As per policy, he underwent a health assessment to determine the most appropriate care environment; matching his abilities and desired lifestyle with the physical environment that was thought would best support him. Assessed to need lower levels of care, Charles moved into a one-bedroom suite on Independent Living. Through the years in which I influenced design strategies and guidelines for the organization, I had never questioned this admissions protocol; until I listened to Charles’s perspective on how separated, isolated, and frustrated he felt living on a different care floor, albeit within the same residence than Kate:

- Claudia: … overall, are you happy with the residence?
- Charles: No I am not.
- C: No?
- Charles: I don’t like living like this… this is a nice set up. I have an office and I still do a lot of business... do a lot of charitable work. I like the staff. I think the staff works, are good people, and are kind, and they look after Kate properly which is good… I just don’t like living alone so … I really think it’s true that old people should not live in segregated environments. I think old people should live with the other people, and live in a mixed environment. And I really don’t think that… it’s the right way to live. And I think it’s terrible.

The design and categorization of space, the structuring of place, deciding on living arrangements and location based on physical and cognitive needs, suddenly seemed to be restrictive and selective. In a way, design and architecture seemed to be reinforcing a biomedical model that easily normalized the user based on perceived physical abilities, suggesting that there is certain validity to the harsh statement that through adherence to conventional design practices, designers reproduce disabling environments (Imrie, Luck 2014).

Charles’s intention of moving into the residence was to be closer to Kate. It was an effort to extend their identity as a couple. The physical separation of living on different floors had proven to be challenging, having tremendous impact on their ability to spontaneously meet and share both time and space as a couple. The environment was structured to favour operational efficiencies, at the same time assuming that the baseline abilities that defined an Independent Living resident would be devoid of individual frailties, such as mobility issues. Reaffirming Imrie’s criticism of architectural design being dismissive of the corporealised nature of the built environment (Imrie 2003), the design process would not have considered Charles's mobility challenges. The ability to freely move around the residence would have been assumed, and any impact of his mobility challenges on his ability to socialize would not have been a design criterion. Therefore, Charles's account of how difficult it was for him to see his wife was unexpected:

- Charles: Oh I'll see Kate almost four days out of the seven.
- Claudia: … does she always recognize you?
- Charles: She does, yes. She certainly does. And she knows me and she knows my name. And she is very affectionate towards me. She calls me her husband.
- C: … does she ever come down here to visit?
- Charles: She has been here… but not often.
- C: … And when you go and visit do you stay for a while. What do you like to do when you visit?
- Charles: The trouble is, that first of all it's hard for me to get there because I have trouble walking with this walker. I can't go that distance. It's hard for me.

…………………………….

- Claudia: … what do you think overall of the building?
- Charles: The building is fine. The building is, first of all it's too big, because I can't get to the facilities, for example the main entertainment room is away at the other end of the building… and I can't get with my walker. I can but it's very strenuous. It's too big but the building is fine….

The architect would have ensured that the hard layer of regulatory requirements for mobility – width of corridors, maximum length of corridors, grab bar locations, width of entry ways, etc. - were incorporated into the building. Nonetheless, the less apparent softer layer of actual criteria – such as physical strain, frailty, limited mobility - would not have been captured as a design requirement, echoing the critique of how design conceptions and space allocation of functions do not conceive of impairment as part of domestic being (Heylighen 2013; Imrie 2004). The envisioned user, a mental image of a healthy and abled male user as the design unit, falls short when measured to real individuals with unique needs (Buse et al. 2017; Crilly, Maier et al. 2008; Imrie 2004). In Charles's case, his physical limitations were further compounded by organizational policies that made his displacement around the residence even more difficult:

- Charles: And unfortunately, they won't let me have a motor scooter. With a motor scooter I could get back and forth a lot easier.
- Claudia: Who doesn't let you?
- Charles: They don't. It's against their policy.
- C: Really?
- Charles: … You should check into that... cuz that's nonsense, because I have two scooters downstairs.
- C: … they don't let you bring it to memory care?
- Charles: They don't let me bring it into my own place.
- C: Inside of the building?
- Charles: Inside the building. So I have two scooters. I have a very small one, which is no bigger than a wheelchair, and I have a bigger one, a more powerful one which I, which I had first but it scares me because it's so jumpy. And I have to drive it on the sidewalk…
- C: … if you had more mobility, if they let you use your scooter you could see Kate more often?
- Charles: I would see Kate more often, yes.

Charles was bound to his suite, on his floor, without being able to freely move about the residence to go visit Kate, or to independently enjoy the many amenities the residence had to offer. Consequently, the different meanings of home were in tension with life in the care home and its regulations (Örulv 2010; Peace and Holland 2001), arguably becoming obstacles for social relations (Schillmeier 2017), and compromising his ability to comprehend their new living environment as their home (Aud 2002; Davidson, J. and Milligan 2004; Milligan 2005; Peace and Holland 2001). Charles was not allowed to use the motorized scooter inside the building, a regulation that limited his autonomous mobility, leaving him no option but to pay to be assisted to go visit Kate:

- Charles: … the pricing here is outrageous… totally absolutely outrageous. And I happen to be well off so I can afford it, but … between my wife and I, I'm paying for over 15 thousand dollars a month.
- Claudia: … that's a lot of money!

- Charles: And as she needs more services it's going to start eating up more and more reserves. For example, to get somebody to take you down to the dining room in a wheelchair, they charge you 30 dollars… That's a horrifying thought.

Charles and Kate lived in the same building, yet on different floors due to their specific care needs. The cost, both in terms of time and money, associated with meeting Kate, had resulted in meeting only twice a week for lunch. This finding exemplified how organizational policies negatively impacted everyday experience by failing to promote residents' autonomy (Dobbs et al. 2008), and the consequences of commoditising care. It also highlighted distance as a design criterion that merits further understanding, as data disclosed that it is a relative metric, linked to the user's ability to navigate the environment:

- Claudia: … I'm trying to understand the experience of living here. Why do you find it more comfortable to visit with Kate, say in the lounge and not in your suite?
- Charles: Well it's a question of distance.
- C: Of distance?
- Charles: First of all, if she gets her here, and that's not so easy, and then if Rita brings her to the lounge it's sort of half way between us. So I can get down to the lounge and then I meet her in the lounge I can go for lunch.

Interview Transcript. September 12, 2019

Embedded in the architectural design, marketing strategies, operational aspirations and staff training was the goal to make the care residence look and feel like the resident's home. However, there was an evident tension between the expectations of what home should be or feel like, and the organizational policies that were in direct contradiction of the freedom and independence one would associate with being at home. Charles's loss of his role as Kate's husband, his lack of autonomy, his inability to control his immediate environment, arguably made it difficult for him to feel at home, adding strain to the challenges of adapting from life at home, a beautiful home he was proud of and which reflected his status, to moving to congregate living.

The experience of moving into a care residence has been described as a traumatic experience, as it signals the incapacity to maintain independence; it is an experience often emotionally charged with disappointment of being unable to fulfill filial responsibility, where the individual is forced to downsize and leave behind many of their material possessions and social relations (Groger 1995). Adding to this emotional experience was the rigid institutional policies which further constrained Charles from moving about the interior of the residence, echoing Goffman’s description of a total institution as being a place of residence where like-situated individuals lead an enclosed and formally administered life (Goffman 1961). Therefore, the ability to feel at home was hampered by these tensions: life at home being defined in one own’ s terms, as opposed to life in an institution where an administrative regime was imposed; between the desire for enabling care and support, versus the provision of what felt more like custodial care (Gubrium 1991).

The possibility of designing for a couple, with different care needs, to come live in the Memory Care neighbourhood was not a criterion that factored into the design strategy of the organization. It was evident that the potential impact of this approach on a couple had been underestimated, partly because typically, residents on the Memory Care neighbourhood are women living alone, due to the overall shorter lifespan of men – although this is gradually changing - and the fact that males with dementia will usually be cared for by their wives at home (Baikie 2002). The space was therefore designed imaging the user as a single occupant, who would most likely be a woman; a fact that Charles casually confirmed. His description of how he saw the typical resident conveyed an inevitability to their plight and of surrendering control:

- Charles: … but you have to understand what you are dealing with in terms of the clientele. You are dealing with a group of people who are technically very old and mostly infirm. They have sold their houses… their husbands are dead and they, they have very limited possibility of life. They don’t have the energy to move, they can’t go into an apartment. They’ve got no choice, nothing they can do so they, they, they live with it.

Charles was very lucid and insightful, despite having some physical ailments. His social isolation, combined with the new reality of his living conditions, made it very difficult for him to feel at home. All that was familiar to him was gone. He mourned the losses he had experienced deeply, to the point of questioning the purpose of his existence:

- Charles: Well, it's about the condition of being in this condition, right. I am not well. I need a bloody walker… I had a fall. I had a couple of falls and… I have injuries of different kinds, … and all kinds of health problems and so on and I'm just an old man. And I look on this and I say a lot of what's happening to me is because I'm an old man… That's all. I'm an old man and… you know you tend to wake up in the morning and think why am I still here? And there is a lot of people who think like that. A lot of people… I can't drive, I can't walk, my eyesight's gone, my kidneys are gone…and you know, these are the things that are the reality of things.

The sense of loss reported by Charles echoed the reported losses associated with living with dementia in similar studies (Angus et al. 2005; Dobbs 2004); where daily life is regulated and the meaning of feeling at home becomes compromised or displaced (Milligan 2005; Örulv 2010), prompting Charles to curse when thinking this is now his home:

- Claudia: Would you consider this to be your home now?
- Charles: No…No, I think Kate is reaching the state where she considers it her home. Rita *(their personal caregiver for Kate)* thinks the same thing… She says "I'm going home". And I say "I'm going home" and then I curse….

Kate and Charles clearly deviate from the envisioned user of space, highlighting a gap in the design approach. Unable to accommodate their different care needs on the same floor, they were living apart, both physically and socially, making the changes in their relationship as a couple even more accentuated, reinforcing the necessity to understand the individual requirements of different users. Their situation also illustrated the need to consider approaching space planning from a sociological perspective, where the relationship of social practice, in this case a couple, and physical design are more congruent (Prior 1988). Implementing socially decontextualized design solutions, where the user is established to be single, able, and without marital ties, only added to the challenges that a couple with different cognitive needs seeking care were already facing. The pain of acknowledging the reality of Kate's inevitable cognitive decline, and accepting their current separation, came through in Charles's words:

- Claudia: And when you go up to see her, do you stay there all morning? Do you visit in her apartment? Do you go to the lounge? what do you do?
- Charles: Well technically, I go for lunch… I go about a half an hour before lunch and 15 minutes after lunch… and I don't stay very long. It's hard for me because… I can't really sustain any kind of conversation with her… You know she's become, a lot of what she says is, just doesn't make a lot of sense. And I find that I lie all the time. I think I'm a professional liar…

Interview Transcript. September 12, 2019

Happily married, their beautiful and comfortable life was interrupted by dementia. A couple now living in the same building but separated to accommodate their individual capacities; close yet distant. Unable to visit Kate on a regular basis, resenting his submission to stringent organizational policies, mourning the loss of much of what they enjoyed as a couple, Charles expressed the depth of his loss:

- Charles: I never imagined that anything like this would ever happen to me.
- Claudia: … it's a nasty condition for sure…
- Charles: …for fifty-five years and we've lived all over the world. And ... we did a lot of interesting things in our life. And we had a really good finish…

Interview Transcript. September 12, 2019

For Charles and Kate, the environmental experience of the care home was influenced by a spatial form generated from the division and structuring of the residence into three distinct levels of care. A design that was informed by an operational attempt to control and provide predictability to the complex patterns of movement and use, derived by the presumed social activities of the intended user of each space (Hillier, Hanson et al. 1984), resulting in a spatial ordering that could only be understood as a means to control. Consequently, Charles's experience of the care environment lacked both the concrete and abstract associations of home, impeding his ability to feel in place.

Using the Environment to Bridge Biographies: Greg

> "…with her knitting… you should see her. She's just not lost anything. It's the same with her dancing. She still dances beautifully…even if she can't remember tomorrow what she did today, when she's doing it she is enjoying it which is important… I've noticed this, she is a much nicer person than she's ever been. Really…she is always even-keeled. She will sometimes say "I'm frightened". But why wouldn't she?" (Greg talking about Ella)

I first noticed Greg visiting Memory Care, jovially greeting everyone. The ease with which he found his way about the neighbourhood was very telling. He was obviously comfortable in the environment and very familiar with staff and with some of the other residents. With admirable punctuality, Greg came to the floor every single day, at two o'clock in the afternoon. He came to visit Ella, his wife, who was diagnosed with dementia and who lived on the dedicated Memory Care floor. Their routine did not differ, they visited in the residence for a while and then together, they went out for the remainder of the day, coming back to the residence around nine o'clock at night, just in time for Ella to go to bed. Greg and Ella had been married sixty-four years, and their current routine was Greg's attempt to be close to his wife, albeit the disruption dementia had been to their lives.

- Greg: … there was no space limitation at home… in fact, when she got sick, my family and I got together and they said "Dad, you've got to downsize". Because I had a fairly large house. They said unfortunately it doesn't look like Mum is going to be coming home again. So this was hard to accept… But I did and I'm now living in a condominium, across the road. So that decision was actually a family decision. My daughter being the leader.

Greg was in his early 90s; he was very healthy, active, optimistic, good-natured and full of life. Originally from England, a former RAF pilot, and a successful executive for one of the top petroleum companies in the world, he met Ella while she was finishing her training as a nurse in the same Canadian air force base where he was finishing his training as a pilot. They settled in Canada and in his own words, Greg described the beautiful life he built with Ella:

- Greg: … so I came to Canada with the kids in tow and my degree was you know… a good degree … what we did was plan the future of the company. That's what our job… and that meant taking in the environment around you and the world, and Canada and politics as well as economics. It was a very interesting job. … we were looking at places and my daughter said "Why don't you come and live out here. You'd love it here" So we said right, so we got a house built up there, and that was the start of a lovely relationship…. I retired at the age of 50…But a friend of mine … he called me up when this happened and he said," I got a job for you come and see me. I want you to do this job because nobody else can do it" … I was 50 and stayed with them until I was 65 so that's when I retired. But I had a wonderful life because that consulting job was only about eight months of the year… Yes, so it was a life to dream of. My sons often say "Dad you had a dream life" and I say 'Yes, I know" … Oh yes. Ella and I went wow… we went… talk about travel…yes… God isn't it wonderful. Wonderful remembrance of what we did.

Interviewing Greg was truly a pleasure. The warmth of his expression, the kindness in his eyes, his eagerness to share his experience made our conversation very easy. I had seen him on several occasions on the floor and had exchanged informal greetings, we were meeting in one of the quiet lounges at the end of the corridor, making our encounter comfortable. As we chatted, there were certain similarities to Charles's narrative, also consistent with findings from other studies, as Greg expressed feelings of sadness due to the emotional losses and the displaced sense of 'couplehood'; of frustration, and helplessness; acknowledging the significant impact and toll on the couple and family relationships dementia had taken (Baikie 2002; Davies, H. D. et al. 2010; Dempsey and Baago 1998; Holdsworth and McCabe 2018). In the following excerpt, Greg beautifully describes scenes from their past shared life as a couple while also confirming what has been previously documented in studies of spouses caring for their loved one with dementia; the feeling of an increasing sense of separateness from their partner when realizing how many of their shared activities have been lost, expressing a sense of uncertainty of how and when Ella's dementia would manifest, and the grief of losing companionship (Holdsworth and McCabe 2018; O'Shaughnessy et al. 2010):

- Claudia: What… do you miss the most from when your wife was living at home?
- Greg: The obvious one, the obvious one is you don't like being alone… That is my number one thing. I don't like being alone and I don't think anybody likes being alone. I think we got into a routine particularly after we retired… we didn't plan every day. And don't get me wrong but we were always going to be doing something small… I would say… "Ella, I'm going to go out and do some gardening today what about you?" And she'd say "No, I'll read… or I'll come out and sit" whatever. And so, there was that. And then we had I think, the social life is something which I really miss. Now I can take her out to dinner and that sort of thing but it's not the same because… you know we used to go out with friends. I belonged to the golf club, and to other places; going dancing and dinner and… stuff like that. And while I've… we've been out with my daughter and she has been perfectly well behaved I just get slightly on edge and I wonder if somebody makes a loud noise or something, what's her reaction going to be? So no… I'm going around in circles here; I miss the social part of our existence… Definitely… you know… it's, not the same … I mean… we often watch TV together. That's a lot of our evening stuff. So yes… what has changed is as I say, is the fact that we did a lot of things together really…

Supporting the comment that dementia is a condition that is not experienced by the individual in isolation (Robinson, L. et al. 2005), but that it is one that affects the entire family, Greg provided glimpses of how their family was affected by Ella's condition. Family gatherings were now marked with painful memories, family routines interrupted by the sometimes-violent episodes of dementia:

- Greg: … they sent her home to me with PSWs *(Personal Support Workers)*. And that was tough. Initially, it was fine but come the early spring March time she started deteriorating badly. To such a degree that she would kick, scratch, bite I'd have to hold her arms in. You know her arms are so thin now that when I was doing that would bruise like mad. And I'm thinking Oh

> God they are thinking I’m mistreating her you know and all I was doing was holding her because they get terribly tremendously strong. You can’t believe it. No, incredibly strong. So then we were out to my son’s I think it was a birthday Easter celebration in 2018 at the end of March. As we were going out the door she ducked, she ducked down behind the car and said “You’re not going to shoot me are you?” and I said ‘Of course not’ so I said come on into the car but she was all… we got her into the car, she opened the door and I locked the doors. We got her home with my son, my daughter Verna and my son-in-law were staying with us. We couldn’t get her to settle down she was all over the place and grabbing things and us so I said you know we’ve got to put her in the hospital again. So again called 911 and, she fought them pretty well I must say. She was in hospital then two months.

The detail in which Greg was able to recount these episodes suggested these were vivid and painful memories that had been etched in his mind. His story is similar to findings from other studies, where changes to everyday life, relationships and practices were reported during the initial stages of dementia, marking a transition period in which the immediate family began to experience the impact of the cognitive changes, yet delayed seeking help in caring for a loved one until a crisis forced them to take action (Adams 2006). As Ella’s memory loss advanced, her relationship with her sons and daughter was also affected. Having to call emergency personnel to control your loved one would be painful, but not as painful as having your mother forget your name, or forget who you are, and what you are supposed to mean to her.

- Greg: Names, she’s not good at names. Even, I think my daughter Verna, is the only one, and me of course. She always knows that I’m Greg, and she knows Verna is Verna, but our two sons she can’t remember their names. Soon as you say it, she will say “Well of course”.

Ella’s difficulty in remembering her children’s name, or to recognize them, is an emotional burden and grief that adult children of people living with dementia have reported in other studies (Adams 2006; Meichsner et al. 2019; Meuser and Marwit 2001). This reported grief is associated to the gradual change of family roles, where reciprocal and enduring family relationships and parent–child roles become reversed (Meuser and Marwit 2001), changing the relationship dynamic to one of caregiver and care recipient (Meichsner et al. 2019). In these passages, I could sense Greg's nostalgia in recounting the events that led them to their current living situation. But through his narrative, Greg's optimism would surface, his pride and excitement most evident when recounting how Ella, who had been a master knitter, had suddenly begun to knit again.

- Claudia: … I think it's wonderful what you just shared with me about Ella, that she is knitting, how she was a master knitter, and suddenly, did it just start today?
- Greg: Yesterday
- C: …Yesterday, prompted or…
- G: Prompted. Kim who looks after her most mornings, said to me when I came in, "I've got something to show you." She said "Come with me." I went in and there was Ella, sat quietly and I said, "I don't believe I am seeing this"
- Claudia: How long had it been since?
- Greg: Two years… when she was in the hospital they tried... took all the stuff out. Still no go. Every so often I would say 'Yes Ella I think you should try to knit - No I don't want to knit. I have no interest in the thing.' But Kim said yesterday "that I got angry with her and I said Ella, you are going to knit" and she said it sort of took her back.

Interview Transcript. August 29, 2019

The enthusiasm Greg expressed about Ella's knitting goes beyond being happy she had rediscovered her past hobby. His delight can be explained as Greg trying to sustain the 'we-ness' of their couple identity, with him as the intact partner of the dyad becoming the custodian of Ella's self; reminding others of who Ella was in her prime (Graham and Bassett 2006; McGovern 2011). Ella's embodied knitting skills support the argument that the body is a fundamental agent of selfhood; an active and intentional vehicle by which the person living with dementia is able to constitute and communicate their identity and selfhood (Kontos 2005). The intricate way in which Ella maneuvered the needles to create a certain stitch, the elaborate assembly of patterns, the beautiful compositions she created, were testament that the body remembered. Ella's memory lived beyond a cognitive form of knowledge; it was a natural and fluid embodied process. It was an expression of selfhood that had been prompted by Kim, a caregiver that knew her past biographic details, challenging the Lockean construct that cognitive memory is the sole guarantor of rational personhood and that personal identity resides only in the consciousness and intellectual memory (Locke 2000). Ella's memory and biography could not be reduced to one organ – the brain – it lived and was expressed through her entire body. Her knitting, in the privacy of her suite, had provided a link to her past identity. And for the moment when we were in Ella's suite with Greg showcasing her knitting, it was evident that they both felt at home in the residence; albeit living in different locations.

Figure 38 - Ella's Knitting

Greg's daily visits and his vested interest in Ella's care had helped him established great rapport with staff. In an effort to bridge their past biography to their present condition he had creatively appropriated the environment. One of their shared hobbies had been ballroom dancing. Consequently, he had creatively organized ballroom dancing Tuesday afternoons as an activity on the memory care floor, in the seldom-used lounge at the end. Despite needing a walker as a mobility device to help keep her balance, Ella was still able to dance, further attesting to how the body remembers and how it is agential in expressing selfhood:

- Greg: You should see her. She's just not lost anything
- Claudia: Incredible….
- G: It's the same with her dancing. She still dances beautifully.
- C: You guys were ballroom dancers?
- G: Yes, yet she needs a walker to walk. Well she can walk without it but it's safety.
- C: …I've always seen her with a walker
- G: Yes
- C: Yet she can dance
- G: Yes (chuckles)

Interview Transcript. August 29, 2019

Ballroom dancing was a shared activity they had enjoyed for many years. Through Greg's initiative, and supported by staff, it was an activity that they were able to maintain in the care home, becoming an opportunity for social engagement with other residents. They moved the furniture around, played ballroom music and danced. In spite of her cognitive and physical limitations, Ella could magically let go of her walker, grab Greg's hand, hold position and start fluidly waltzing, challenging the argument that dementia affects cognitive skills which are necessary to maintain an inner sense of selfhood, and that it is only through cognition that the person is able to present themselves to others (Ballenger 2006). Greg had appropriated this space and had carved a place for them to continue dancing. It was through Ella's embodied memory of dancing that she was reminding the observer of her past biography; they were still a couple. It could be argued that moving in unison with Greg, keeping pace and rhythm, gracefully following the dance, was how Ella was upholding her selfhood and asserting her identity.

In spite of not being a resident, Greg had used the amenities on this floor to recreate and celebrate moments of couplehood; proudly sharing Ella's knitting, boasting to others of what a great dancer she was, were his way of presenting evidence of the continuity of their connection. Greg's delight was congruent with reported findings from other studies, where loving spouses were acutely alert to their partner's retained skills and memories as confirmation of their shared identity (O'Shaughnessy et al. 2010), helping them reinforce their commitment to their respective role as a caregiver. Furthermore, unlike Charles who longed for the life he had with Kate and mourned for the attributes Kate seemed to no longer manifest, Greg endeavored to facilitate and maintain a strong sense of marital cohesion by accepting the change in their previous relationship rituals, using the care home environment to create new routines (Davies, H. D. et al. 2010). Unlike Charles who still kept his family home, Greg decided to sell the family home and buy a condominium across the street from the residence. Nonetheless, Like Charles, Greg shared how overwhelming the burden of caring for their spouse became, prompting him to craft a new daily routine where he had time for himself, yet devoted the rest of the day to Ella:

- Greg: … when we moved her here she was not in good shape. She required a lot of attention, and it took about two months in hospital to get her meds straight. And when we were in the hospital she sometimes just simply refused to see us or…when she first got here, she was pretty bad too. So we had to commit. There was no way I could have her at home in that situation, because I couldn't cope and I don't, and I wasn't going to pay 24 hours a day for someone and bring them in here… I looked a couple of ladies who run organizations which come and spend however much time you want, from zero to 24 hours a day… but my daughter doesn't like that idea so my daughter rules the roost (laughs)... I have my mornings to myself

Greg's new routine had also pushed him to take on new roles, seeking for new ways to relate to Ella, developing new means to communicate, sharing the new environment, enhancing their wellbeing as a couple (McGovern 2011). As much as he acknowledged how much their life as a couple had changed since she was diagnosed – the country club social life, playing golf, dancing and dining out with friends no longer part of their everyday – he had embraced his new role and the care environment, creating new ways of being together. He had willingly and intentionally assumed a more proactive role in prompting socialization, a role that was previously Ella's:

- Greg: … the thing is, as I mentioned before, she loves being with people although she doesn't make an effort herself. If I bring in people, she loves it. It's the same when we sit downstairs and people come up. She doesn't want, she doesn't seem to make the effort to start the conversation, if you will on her own.
- Claudia: Was that the way… always?
- G: Absolutely not… she was the social one…she would talk to anybody anytime, absolutely. Yes, things change…

During my interactions with Greg, his love and devotion to Ella always came through. His desire to ensure she had the best care, that she be motivated to uphold her abilities, to express herself and to engage with others was evident. The most obvious expression of his commitment and devotion to Ella was that he planned his days around her; like clockwork, he visited her daily and had lovingly established a new routine which had provided Ella with continuity of biography. Even though the home they shared as a couple had been sold and the fact that Greg would bring Ella to his new place, an unfamiliar condominium, their new couple routine had built an emotional bridge that allowed Ella to effectively continue her biography by enjoying established familiar domestic rituals, like walking in to the kitchen to help prep dinner, and involving her in activities that would be reminiscent of prior housekeeping (Groger 1995). Greg was keenly aware of Ella's preferences and dislikes, he lovingly recorded television shows that he knew would please her; he spared no effort to make Ella's visit to his condominium as familiar and comfortable as possible. Prompted by his love and devotion to Ella, Greg was upholding her identity, personhood, and agency.

- Greg: I pick her up, we go to the Bistro, we do something and get home around 4 o'clock. Then we, then I say well we are going to eat I should start cooking soon. We just sit and chat. I read and she dozes. And then we start cooking and I don't have to encourage her, she will just come into the kitchen with me and do simple tasks like stirring the pot, and chopping some vegetables, though I notice there, that her strength is not what it used to be, so she doesn't chop as well as she used too.
- Claudia: But she finds herself, her way around the kitchen?
- G: Oh yea, she always wants to be around, she always wants to be in there. And of course I pour a glass of wine…

……………………………………

- Greg: … I also said, you know you can watch TV, but she has never really been a TV watcher. So, I can record some programs at home, which I know she will like, particularly natural history and animals and stuff like that and she just loves that. So, like we have a neighbour in my condominium, Marinka's her name and every Saturday afternoon at 3:30 she arrives with her dog, Sammie. Sammie comes up and tries to pinch all our cookies, but he is a wonderful dog and Ella loves him dearly.

Interview Transcript. August 29, 2019

From a theoretical perspective, one could argue that Greg's acknowledgement of Ella's agency supported the construct that the continuity of a person's identity and sense of self is embodied in the individual (Taylor 1995). The body is agential in preserving the self and helping the person living with dementia make sense of their perceptions; it is part of their personhood. It was with her body that Ella reminded us what a master knitter she was. It was with her body that Ella remembered and displayed her embodied memory of the waltz, silently sharing with others the narrative of how much she enjoyed ballroom dancing with her husband. Beyond intellectual capacity, Ella was situated and embedded in a social, cultural, historical, and familial context where her embodied recollections of her life-history and engagement with others, allowed for the continuity and unity of her personhood and identity, despite her dementia journey (Hughes 2001) and despite her unfamiliar surrounds. Her cognitive decline had not evaporated her personal identity. Her impaired verbal communication skills had not silenced her identity. Together, Ella and Greg were discovering alternate ways to enjoy their 'we-ness', creatively using space to feel 'in place'.

As Greg described a typical day, he recounted their newly discovered routines and preferences, their new way of being a couple. Together they had discovered the Bistro, an amenity area on the ground floor which had been designed for the use of Independent Living residents in mind. It was an open space that had refreshments, snacks, a beautiful view to the street. It was a 'grab and go' concept, thus requiring the dexterity to make your own drinks or to grab the snack of your preference. Designed to encourage socialization amongst residents and their visitors, this was the amenity space that Greg and Ella had come to enjoy in their new routine:

- Claudia: When you come to visit… where do you usually visit?... you said that you usually go to the Bistro before you head out?
- Greg: Yes, we almost always go to the Bistro…
- C: What draws you to that space?
- G: Well usually it's because I want a cup of tea and she wants something or other… We were into cappuccinos but now we've changed so it varies.
- C: So the refreshments
- G: Yes, the refreshments yes, and she you know, she's gotten to recognize that there are some other people in there and she will say hello

Figure 39 - The Bistro

Routines and rituals are important aspects of domesticity, and over time, become emotionally and socially significant (Falk, Wijk et al. 2013). Greg's efforts to uphold their identity as a couple, to morph previous rituals and routines into ones that could be shared within the new environmental, social, and physical context of dementia, provided them the renewed ability to be together in different ways. There was a mutual adaptability that was like a synchronized dance. Despite how unfamiliar the physical environment of Greg's new condominium was, Ella had found familiarity and had felt at home, assuming familiar domestic roles. Likewise, despite Greg's independence, he had become a familiar part of Ella's new physical environment by participating in activities and jointly enjoying the care residence:

- Greg: You got to realize that you got this facility here. Now we do dance here every Tuesday…
- Claudia: Just the two of you or a group?
- G: No… most of them come here and we have, we have Jesse and Rowina… he's a professional dancer… He teaches dancing and Rowina is his partner, and they won the Canadian Pro-Am last September
- C: Oh Wow…
- G: Ah they're good. They are really good. And then there is a lovely lady named Laurie who comes. She's a delight and there is a guy who comes, an older guy called Tom… he likes to come and dance although he is in his nineties he likes to dance. He dances with all the ladies because there are only three guys, myself, Tom and Jesse. But fortunately Laurie is such a good dancer, and so is Rowina they'll take the place of a man. It's a lot of fun…

……………………………..

- Greg: … we walk through the garden and I've said to Ella maybe she should get in the garden, but she has never been interested in gardening. But I've always been interested, for example yesterday we got some beautiful cherry tomatoes from a garden they brought them in, they bring in a lot of fresh produce you know from those gardens… They are wonderful, and they are lovely to walk through too. Yes, we very much enjoy that… and actually the public park across the way is a nice place to walk…

Figure 40 - The Park and Gardens

In direct contrast to Kitwood's suggestion that the untrained carer, often a loved one in relationship with the individual prior to dementia, may exhibit a defensive response when faced with the fear and anxiety of frailty and mortality dementia poses, potentially resulting in exclusion and the undermining of personhood (Kitwood 1997), Greg was sustaining and upholding Ella's selfhood as well as their couplehood. The sense of safety and comfort to be oneself is vastly dependent on the emotional and social context that encourages gratifying relationships (Davis, D. 2004). Greg acknowledged and nostalgically accepted the changes that dementia had brought unto their lives, nonetheless he was relentless in his efforts to have Ella engage with others in familiar ways; be it knitting, dancing, helping in the kitchen, or making new acquaintances in the Bistro, challenging the assumption that memory impairment leads to a steady loss of selfhood or that selfhood is the exclusive privilege of the sphere of cognition (Kontos 2004). His efforts to celebrate Ella's perduring identity were supported by staff and enabled by the physical environment.

Greg had been able to use the amenity spaces in the care home as a resource to prompt social engagement, to promote social interactions with Ella, and to share activities that supported their identity as a couple. When asked what his favourite space in the care home was, Greg associated space with meaningful social interactions:

- Greg: I think for me... the Bistro is the good place because when I bring Ella and I… there are some ladies there who invited us to sit down and they want to know all about her. And she can really open up to those ladies.

So, I think she likes the bistro too and I think I definitely do and I think it's a good spot. I really do.

- Claudia: To meet people and be with people?
- G: Ya… with people, I think that is the important thing. There is a fella called Jim, he is there every evening, and we have a chat together and stuff like that …

The social practices they had as a couple; dancing, having coffee in the Bistro, or taking a stroll in the garden demonstrated how Greg had embraced and adapted the care environment to find ways in which they were able to have some continuity with their past biographies. Their communication and connection was embodied, nurtured by sixty-four years of marriage and shared stories, supporting evidence that suggests that creating a joint construction enables the couple to make sense of their new situation; adjusting to changes, embracing new roles, while managing the inevitable losses due to dementia (Robinson, L. et al. 2005). All communication, be it verbal or a simple but familiar touch, and embodied meaning-making moments, all contribute to the wellbeing of life partners affected by dementia (Phinney, Chesla 2003; Robinson et al. 2005). And while Greg supported Ella's new environment and her dementia journey, connected to her to a point of completing her sentences, the sadness of not sharing a home and not physically living together remained:

- Greg: ... I mean some of it is because she probably can't follow what is going on… I don't know. All I know is when she engages in conversation with us, we have to provide words and you know, guess… and I'm pretty good at this. But she's absent to many, I say the kids are well, she says oh…
- Claudia: Do you think Ella feels at home here?
- G: … Yes, and no. Yes, when I'm here with her for sure. Yes, when you know she's ok. I think she does… but it's hard for her to accept the fact that she comes back here instead of staying with me.

Interview Transcript. August 29, 2019

Conclusion

These case studies provided insight into the complexity of the care experience of individuals living with dementia; an experience that is lived differently, according to unique personal biographies and dispositions and which cannot be normatised. While these personal stories did not render undebatable facts, they opened an opportunity to further the dialogue (Bourdieu and Wacquant 1992; Ellis et al. 2011) around the environmental and embodied experience of living with dementia in a secured care environment, and the potentialities of the environment to enable or compromise the individual's ability to feel emplaced and at home within their new surrounds. Data revealed the importance of 'home', as a concept, as a sense of belonging, as a place where the abstract and the concrete attributes of the environment converge, suggesting the critical importance of advancing knowledge on the emotional, social, spatial, and embodied meaning of home within the context of dementia care.

The ideals of home have long been associated with residential aesthetics and scale. Often, quality care has been linked to the effectiveness of conveying a 'homelike' environment. I argue that further research should explore the assumptions contained in the term 'homelike'; a term that is frequently used by designers, gerontologists, marketers, and which is arguably overused when qualifying care home environments. Data demonstrated that while the material representations of 'homelike' environments was an intentional design and operational strategy, the abstract dimensions of home were absent (Dobbs 2004), as they can only be socially constructed by the self. Not being able to associate domestic embodied experiences to their surrounds caused a sense of displacement in the individual living with dementia, as place must be felt to make sense (Davidson, J. and Milligan 2004). Research could therefore advance knowledge on the environment's potential to prompt habitus. Acknowledging that deeply embodied dispositions can provide alternate and valid ways of expression and understanding of the individual living with dementia, would stress that cognitive memory is not the guarantor of personhood (Katz, S. 2012). This re-discovery of the agential potential of the whole body to reminisce and support selfhood would also influence design practice.

Theorizing that individuals assign meaning to space through embodied selfhood, through social practices and relations, would give the body a deliberate significance in the design process. This stance would sensitize the architect to both the abstract and concrete dimensions of the care place, and to the multiplicity of experiences within the same space, prompting a more reflexive approach to the environmental features that can support the individual's appropriation of the care place as home, and of the process in which they could potentially interpret and experience material space through the lens of their embodied knowledge. Challenging designers to shift from generic design solutions to designing spatialities of home that conceive of impairment as part of domestic being (Heylighen 2013; Imrie 2004), that reflect social practices, that allow for safe but autonomous circulation, access to outdoors, flexibility of space, and that encourage individual interpretations of space by prompting different realms of interaction (ranging from the private, the communal; the quiet, the noisy), would arguably enhance the individual's adoption of space.

Design conceptions also need to consider the plurality of the envisioned users. Evolving suite designs to allow for the flexibility of comfortably housing a couple – even if they are at different stages of ageing, cognitive health, or disability – would result in a more attuned affirmation of home. Likewise, enhanced sensitivity to the need of individuals living with dementia to continue their biographies, should prompt a more comprehensive architectural programme. Providing relatable and comfortable spaces available to families could encourage visits, thus enabling familiar domestic rituals that would arguably provide both a physical and emotional bridge to their new living arrangements.

These are initiatives that would require policy support and alignment of vision with the care organization. Establishing more flexible policies that acknowledge and encourage the valuable contribution to the care experience from their loved ones within the new environmental, social, and physical context of dementia, would arguably facilitate the abstract attributes of home. Allowing families to watch television as a group, actively involving them in leisure programming, encouraging social practices and activities reminiscent of their prior home life (like inviting them to come help prepare and serve meals with their loved ones), are all suggestions of how resident's sense of belonging could be supported. A flexible and less rigid institutional disposition would help recalibrate the current power structure of a single administrative authority, to a more inclusive administration, one which welcomes staff and family input and one where the importance of place-making, of belonging, of wellbeing informs regulations.

Goffman (1961) theorized on the characteristics and effects of 'batch living'. The vignette of Sara rejecting the cup of coffee – as it does not taste as strong as she is used to, and which is poured in a yellow cup which she says looks nothing like the ones she had at home – illustrates the tension of communal living and the risk of applying generic therapeutic goals without accounting for personal preference and embodied selfhood. I argue that a relaxation of curated procedures and aesthetics - typically infused with marketing ideals and operational efficiencies - and a proper contextualization of therapeutic goals to the individual, could ensue a shift in power that would benefit all user groups. It would also mitigate the pressures staff experience by being obligated to maintain the care floor tidy and show-ready, while allowing the resident to have an enhanced sense of control, which could arguably heighten their sense of belonging.

Data provided strong evidence of the need to enable embodied identity as a means to uphold personhood. This finding repositions the individual living with dementia from a passive recipient of care to a sentient individual who actively constructs place through social relationships. It also highlights the individual's ability to convey identity, be it through the value and meaning associated to objects (like Nina's hats), or by articulating past identity through new routines (like Kate re-enacting her head nurse routines by pacing the corridors, or Greg and Ella's waltzing and Bistro routine). These representations of self call for a closer and more intimate knowledge of the individual, demanding organizational frameworks that allow staff to get to know the individual they are caring for. A closer evaluation of how caregivers are assigned to residents could prove a solid foundation for a relationship-centred care approach. In-depth knowledge of the individual would also help staff enable the resident's embodied identity, hence providing some continuity of experience in an otherwise disconnected and unfamiliar setting. Tensions and gaps surfaced through the stories shared in the vignettes, stressing the need for a more empathetic design process, one which is more in tune with the individual and different users, where their actual needs and plurality can be better assimilated and less orchestrated.

Chapter IX

DISCUSSION AND RECOMMENDATIONS

The chronic and progressive nature of dementia is a strong predictor that the person living with dementia will eventually need specialized care in a dedicated dementia care environment. The public care infrastructure shortfall in Ontario has created a market opportunity for private care operators, accelerating the pace of development to claim a share of the dementia care market (Senior Housing News 2016). This race to build care environments makes it critical to better understand design challenges within the context of the relationship between the built environment and dementia care, given the evident effect the physical environment has a on the quality of life, care, and wellness of the person living with it (Davis, S. et al. 2009).

The aim of this study was to gain further knowledge on the impact architectural conceptualization and production of dementia care environments has on the user's embodied experience, while aiming to understand how the 'user' was conceptualized during this process. It endeavored to understand this embodied experience by studying how they responded to the designed environment, gaining insights into how they adapted and appropriated space and on how environmental design features enabled or compromised their experience. The knowledge produced from the immersive ethnographic fieldwork, suggested that these aims fell short in capturing how deeply connected the embodied experience of the resident living with dementia was to the experience of those sharing the space; staff, caregivers, family, visitors. Expanding the field of observation to include these groups emphasized the need to consider the field of study as a 'milieu'; an environmental conception of space where the relationship of surroundings and circumstances were also acknowledged (Canguilhem and Savage 2001).

Data gradually revealed how disconnected the overall design process was from the reported experience of different user groups, a consequence of assuming needs and requirements. Most significantly, the person living with dementia emerged as a multi-layered individual, capable of expressing preferences and asserting themselves, ably conveying their identity, while using resistance strategies to communicate their will. Sharing their struggles to feel at home and their challenges to affirm their autonomy amidst the ambivalence of a milieu that straddled residential attributes with healthcare cues, produced rich personal stories, prompting a more holistic and empathetic understanding of their experience. Their circumstances suggested a construct of the environment as a social and relational place which is constantly evolving over time; a milieu which encompasses the concrete, abstract, dynamic, relational, and transient dimensions of space and place.

An Embodied yet Flawed Process that Essentializes the User

The way in which a person experiences their surroundings starts to be predetermined on the design drawing board. Supportive of Merleau-Ponty's (1962) stance that we live and experience the world through our bodies, and acknowledging that our particular perspective and view of the world is influenced by the social, cultural and political currents that engulf us (Casey 2001; Wilde 1999), this thesis has argued that design is an embodied endeavor. Throughout the design process, the architect envisions and conceptualizes the body as the vehicle by which the user is expected to move and sense space (Buse et al. 2017). Likewise, embracing the theoretical stance that submits that the places we 'inhabit' (from the Latin etymology 'to have' or 'to hold') remain held both in our cognitive memory as well as in our bodies through its sensory means (Casey 2001), the architect inevitably and continuously references their embodied knowledge and experience when determining how space will be structured and presented for use (Buse et al. 2017; Imrie 2003).

It is in the initial stages of design, where the architect is negotiating parameters and constraints within the context of their personal lived experience, with limited, if any, input from different user groups, that the typification and objectification of the individual is shaped (Buse et al. 2017; Hall, P. and Imrie 1999; Imrie 2004). As discussed, this essentialization of the individual and the disconnect between the architect's design vision and the user's bodily experience of space, has been criticized by theorists who advocate for a more inclusive and empathetic design process (Heylighen 2013; Imrie 2003; Imrie 2004). Nonetheless, architectural practice relies on expedient strategies to develop an architectural programme; allocating areas to specific tasks, relying on typological precedents to categorize space, and defining collective categories of users which are predetermined according to the building's function, such as residents, 'staff', 'visitors', 'back of house', 'private' or 'public' spaces (Buse et al. 2017). This process of categorization is echoed by the commonly used homogenizing term of 'people with dementia'; a tag that is seldom broken down to a more granular understanding of the individual behind the term. Therefore, during the design process, the designer thinks in terms of composite characters, distilling into this process the pressures exerted by regulations, competing agendas, and financial targets. Heavily relying on personal experience to translate into built form their vision of how space should be used (Blythe and Wright 2006), the proposed ideologies of care find their concrete expression in the built care home (Martin et al. 2015).

The user is hence introduced into the design process through the use of typificatory structures (Blythe and Wright 2006; Buse et al. 2017; Koubaa et al. 2017). As discussed in Chapter II, codes and standards conceptualize the user as a human body with predetermined proportions and functional dimensions typically based on a male, abled individual, presenting the user as a lifeless and ahistorical subject (De Carlo 2005; Imrie 2003; Imrie 2004). Focused on meeting prescribed standards through the design process often exonerates the design team from further scrutiny and dialogue on who the actual user is, producing environments that, once interpreted and experienced by individuals, are considerably different from the designers' intentions (Crilly, Good et al. 2008; Crilly, Maier et al. 2008; Crilly et al. 2013). The resulting design misses, see Chapter VII, highlight the challenges caused from the disengagement of designer and user experience. Data revealed the stresses that this disconnect produced; a bathing spa design oblivious to the emotional angst of a person living with dementia sitting in cold water, waiting for the tub to fill; an open-concept dining area meant to emulate a domestic kitchen island which posed risks to residents and burden to staff; or the beautifully appointed lounges which remained unused.

Likewise, space was planned in terms of bodily functions; a sleeping area, an area to lounge, a space to eat, an area to bathe. And while the organization of space influenced the experience of those using it, the design process focused on the corporeal dimensions of the body, undermining the rich and individual embodied experience of the user. Findings suggested (see Chapter VII) that while the architectural design process is by nature an embodied effort, it was ultimately a flawed process that seemed to disregard the potentiality of individual circumstances as evident in Charles's predicament, where his ability to visit with his wife was limited by the spatial structuring of care. His mobility issues magnified the distance he had to travel to meet Kate. The associated pain and fatigue he expressed would not have been captured in the design standards used to plan the residence, highlighting the need to corporealize design standards to reflect the heterogeneity of the individuals consuming the space.

By conceiving architectural space, through their assumptions of use, attempting to regulate activity, orchestrating movement, the architect influenced everyday practices of how care was delivered and received. And while the designer did have the user in mind when organizing space, the user remained imaginary, normatized, essentialized; not fully understood as a sentient individual, with only some anatomical actions acknowledged. Moreover, architectural drawings did not capture the social complexities of the relationships that took place within the space (Latour and Yaneva 2008; Martin et al. 2020; Misra 2002). In addition, the designer's understanding of dementia and how people can live with it, also influenced design decisions. The resulting architectural form expressed these values, suggesting how others should be cared for, while also incorporating the organization's vision of structuring care and place.

The Tensions Behind a Displaced Typology

The architect's use of relevant typologies helps distill aesthetics and starts to give space form. Borrowing from residential cues, while introducing healthcare components, resulted in a hybrid physical environment; not really a residential home as one would expect, and not truly a clinical setting (Örulv 2010). Herein lies one of the most basic tensions found in the care residence; the ambivalence and ambiguity of place. A place where neither the logics nor activities of dementia care were purely those of home or of a healthcare institution. Similar research supports this finding, noting the discrepancies between domestic and institutional influences in care settings: risk versus security; privacy over surveillance, and normalization versus specialization amongst others (Peace and Holland 2001; Peace et al. 2006), suggesting the assertion of homely residential care environments as an oxymoron.

This hybridity is market driven, a consequence of the need to present a warm and welcoming environment that uses domestic features as a way to prompt residential cues, combined with the elements of a healthcare setting which often demands particular requirements for the efficient execution of specific functions (Andersson 2015; Barnes 2002; Buse et al. 2017). One aesthetic is driven by the soft and familiar sensorial prompts of 'feeling-at-home', while the other is informed by the practical clinical aspects of healthcare; both within the added pressure of organizational expectations of operational expedience, fiscal restrictions, and profit targets. The concrete aspects of domesticity were present in the care home; furniture and objects placed and staged to emulate a residential setting. Nevertheless, the tension between a regulated care organization and what would be an ideal family-like home setting was evident by the lack of the abstract meanings of home, such as autonomy, independence, and choice (Dobbs 2004; Groger 1995). The effect of these tensions, noted by others as an asymmetry of power (Buse et al. 2017; Jones 2014; Massey 1996) and an issue that merits further exploration, were manifested in the data, as residents belongings were circumscribed to their suite, with the organization regulating aesthetics of all common areas.

Findings from this research support the position that cultural acceptance of privatization and commoditization of care has influenced the way care is delivered and experienced (Brennan et al. 2012; Greener 2008). Although the vision of later life showcased in the residence was akin to a hospitality model, the organizational focus remained on financial results and aversion to risk; an approach to care that is representative of the ethos of the private retirement sector (Buse et al. 2017; Simmons 2011). Therefore, the underlying organizational policies, and their effect on both the user experience and the structuring of the physical environment, cannot be underestimated. These are watermarked from the beginning of the design process, through design metrics and financial targets. Data generated in this work indicated a clear tension between the desire to control and mitigate risk; between wanting to provide personalized care to residents within the allocation of available resources and having to adopt routines based on efficiencies. During fieldwork, participants expressed their individual challenges, sharing how these tensions affected their experience.

As discussed in Chapter VII, the desire to mitigate the perceived level of operational risk informed the internal structuring of the residence into separate care environments based on physical abilities, proposing a distinctive categorization of residents based on cognitive dexterity. The dementia care floor, designed and operated as a secured environment, physically segregated residents from the rest of the population. This assignment of location based on condition expressed a social power which arguably encouraged social boundaries that were based on disability-related distinctions like cognitive impairment and autonomy. Data indicated that spatial and social segregation were closely linked to access control. As such, the regulated access to spaces and activities unwittingly fostered labelling processes within the residence, prompted by signs of disability, such as mobility issues and disorientation. Furthermore, this spatial organization arguably contributed to social segregation and unequal opportunities and experiences for the individual living with dementia.

The mediation of attempting to meet organizational expectations while truly committed to the welfare of the resident, often resulted in management making decisions that clashed with the individual's values and meanings of 'home'. 'Feeling at home' is shaped by both the concrete and the abstract (Dobbs 2004; Groger 1995), existing both in the imagination and memories of the individual (Chaudhury 2008; Massey 1996). It is a place typically associated with autonomy, privacy, convivial social relationships, and control in all aspects of life. The care residence had many design features that alluded to the concrete meaning of home; furniture, scale, textures, and objects. Nonetheless, it lacked continuity of the abstract values of home, given established routines and regulations undermined personal preferences.

Management often felt they had to default to routinization and standardization to exert control and to effectively manage resources, affecting the user experience by making life uniform through organizational routines that homogenized the resident collective. This resulted in tensions that were discussed during interviews, where staff and residents shared their respective challenges in trying to balance autonomy and restraint; of wanting to cater to the individual yet having to adhere to schedules and policies; of residents knowing they needed care and assistance yet wanting to remain in control and assert their identity. These tensions, along with the ambivalence of place, impacted the reported experience of the user.

Congruent with other studies, this dissonance of place contributed to disorientation, leaving people living with dementia not knowing where they were, or what kind of place they were in, or unsure of how to conduct themselves (Örulv 2010), as exemplified in Sally challenging the caregiver's suggestion the residence was her home, rather referring to it as an establishment, given she was charged for meals. Thus, to make sense of their plight, participants used different strategies to appropriate the spatial experience, as represented by how Nina had transformed her suite into her personal haven, or how staff had adopted the dining area as their central hub of operations. These adaptations suggested that the effectiveness of the functionality of space was relative to individual demands, preferences, biographies, and needs.

Most importantly, through their own accounts, it became clear that the individual experience of place could not be stereotyped. It could only be understood as multiple experiences which cannot be standardized, nor dictated, nor controlled. And while susceptible to the influences that affect spatial design, their experiences were at times parallel, at times convergent, and other times divergent. Each person assigned meaning to their experience and interpreted their surroundings based on their individual context, motivation, and values. This is an important insight worth further investigation within the context of architectural practice, as the individual interpretation and adaptation of space was the most tangible example of how the environment was affected by these care relationships.

These spatial adaptations highlighted the disconnect between designer and user. They reaffirmed how architecture influences people's experiences, and although residents and caregivers lacked professional design expertise, they possessed an embodied knowledge which informed their consumption of space. This finding supports those advocating for the transferring of the spatial bodily experiences of individuals living with disability to better inform architectural practice (Heylighen 2013; Imrie 2003; Imrie 2004), positioning the body as a site for embodied practice and experience; constituted by the social, physical, and emotional biography of the individual (Heylighen and Strickfaden 2012).

It is therefore posited that the space occupied and navigated by the body, the experience of it, as well as its perception, is influenced by the user's needs, their social and cultural context, and their perceived meanings. Consequently, the environmental experience will vary within and between the different user groups, as each will abstract cues from it that are relevant and congruent with their own personal needs and experience. However, these experiences were challenged by the hybridity of the care home, where domestic and healthcare functional requirements collided into hybrid practices and aesthetic renditions that were not clearly legible to the user. This collision of logics contributed to the person living with dementia's disorientation, as places are anticipated to be charged with cues and expectations that relate to meaning of place, helping the user decipher what kind of place they are in (Calkins 2001; Milligan 2003; Örulv 2010). The care home presented itself as a cozy domestic environment, but upon closer experience of place, the social situations and practices associated with home were superimposed with practices that responded to the clinical and institutional; regulations, collective activities, and clinical practices. The lack of congruence in environmental and social cues presented a rupture in the embodied constructs of 'home', impeding the individual living with dementia to interpret the reality of their new living arrangements as home. The residence was an environment with rules, policies, and schedules; where the individual was cared for by strangers, where their private life had become communal. Similar to other studies, there was a clash between the time and resources demanded for the provision of a truly relational and person-centric care, and the reality of a profit-driven care delivery model (Schillmeier 2017) . It was a place lacking personal memories or associated emotions, where the individual experienced limitations of space, of choices, of privacy; an environmentally ambiguous place that directly impacted the experience of space.

I have argued in this thesis that typically, buildings and the social fields they are planned to accommodate, are instilled with unique logics and practices that attempt to reflect and suggest their intended use. This argument is consistent with other studies which assert that places are more than geographical locations; they are embedded with social meaning, practices, and relations (Biehal 2014; Falk et al. 2013; Heylighen and Strickfaden 2012; Massey 2001; Örulv 2010; Pallasmaa 2007). In the case of the care home, these logics were intertwined, with the environment being pressed to function as a home, a healthcare environment, and a workplace, making it difficult for the individual living with dementia to feel 'at home', or 'in place'. Consequently, the milieu was a place that was often associated with deep loss. Loss of a past familiar life, loss of possessions, loss of identity, loss of social networks, loss of relationships, loss of status.

Data suggested that this dissonance contributed to a sense of 'being out of place', prompting the individual to constantly express nostalgia about their past lives, to feel the need to assert their personhood and to preserve their identity by manifesting resistance to place through different strategies, lending for different interpretations of place, as captured through the individual stories. Sally did not want to be defined as a person with dementia, continuously expressing her desire to leave the residence. For her, home and possessions were emblematic of identity and autonomy. Her rejection of place was so deep that she intentionally refused to personalize her suite, reflecting her lack of attachment by refusing to showcase personal mementos; a resistance strategy reported in similar studies where the individual actively refrained from personalizing their private space as a way to assert that home was elsewhere, and that their stay in the care place was temporary (Falk et al. 2013). Nina always ate by herself at her chosen table; a strategy that allowed her to experience a level of familiarity in an unfamiliar place, while asserting herself and retaining control over who she chose to associate with. Betty communicated her resistance to the environment by longing to go home. Reminding everyone of her past achievements and prior autonomy, fetching her coat, purse, and keys, she overtly expressed her eagerness to leave, as she felt she did not belong in the care residence. It is therefore argued that the care milieu's physical and abstract cues of place conveyed different meanings and experiences to different people, suggesting that multiple interpretations of space are possible, and are often disconnected from the initial homogenized experience envisioned by the designer. The interpretation of place is therefore informed by a context that is constantly evolving through the different perspectives of the different users. Affected by their interactions, influenced by the physical environment, predisposed by embodied memories, suggesting that the experience of space is in constant flux. As Massey has argued (1999), space is always in a process of becoming. This mutability of use, the plurality of meaning and experience, happen through interaction and develops through time.

The Assertion of People Living with Dementia

Designers must negotiate organizational, technical, financial, and legislative constraints, all of which influence both the spatiality and experience of the environment. Nevertheless, the individual input and specific requirements of the different users were not canvassed during the design process, a disconnect identified as a critical flaw in the design process. This estrangement from the user arguably resulted in conceptualizing the user as just another scenic prop; a passive, portable body, whose movements and experiences were predetermined. However, the designer’s intentions and the user’s interpretation of space was not as predictable as assumed. Each individual interpreted and derived meaning of space based on their own embodied knowledge, actively constructing their experience as they engaged with both the physical and social environment. This interpretation and experience of place was not done in a void; it was contextualized within the individual biographic narrative. Herein lies one of the most salient opportunities to introduce a more collaborative and user-centric design approach; understanding the dementia care milieu as constituted by individuals that should not be typified, acknowledging them as biographic individuals who are still capable of design collaboration by expressing preferences and identity.

The personal stories shared by participants, provided a glimpse to their particular narratives, demonstrating their ability to actively engage in their social world. Participants living with dementia emerged as individuals who adopted strategies of resistance and of survival; both at a personal level, as well as in collaboration with others, as evident in Betty and Daisy’s collusion to disengage the keypad by the exit door. Congruent with other studies, data revealed how individuals living with dementia implemented problem-solving strategies, displaying a systematic desire to make sense and to try and understand their current situation (Örulv 2010). By expressing their needs, desires, and preferences, these ‘people’ living with dementia were individuals who remained active agents in the world. They were not passive vestiges of the person they once were, nor static bodies situated in a controlled environment. Their identity transcended cognitive lucidity and their essence of self was embodied and socially situated. And while their new living arrangements, along with their cognitive condition, may now have them socially situated as chronically ill, their personhood remained intact. Their individual stories are a reminder that identity and sense of self are hard won through life experiences and that these cannot be dismissed. Adam, a decorated pilot whose biography was associated to authority and action refused to be infantilized, commanding respect; asserting his identity. Likewise, data supported similar studies, where the fragmentation of continuity, the disorientation and displacement a person living with dementia may experience, was counteracted through social interaction (Örulv 2010). As evident in Greg's care of Ella, his continuous efforts to engage her with others and to prompt her to join in familiar and shared activities, bridged her past biography to her present condition, effectively upholding her personhood.

A Relational Space

The experiences staff shared in their stories provided insight into their inner conflicts; wanting to adhere to policy and targeted efficiencies, while trying to genuinely provide the best care possible to the residents. Their emotional connection to those they cared for suggested an ethics of care which recognized care as an action and practice, not as a set of tasks. Their assumed responsibility to meet their needs, and their acknowledgement of the potential role of creating relationships through caregiving, supported the stance that care was not a unilateral and unidirectional endeavor, it was reciprocal and socially constructed (Tronto 1998). Similarly, family members describing their sense of loss and their commitment to caring for their loved ones, were a testament of how they actively shaped the individual's experience of living well with dementia, supporting Tronto's argument (1998) that embracing care as part of life establishes relationships of giving and receiving as a way to cope with human vulnerability. Therefore, establishing new relations with those involved in the care relationship contributed to the co-production of the care environment; both being affected and affecting the care milieu.

These findings support the argument that the care experience is co-constructed (Fine, M. and Glendinning 2005; Graham and Bassett 2006; Milligan and Wiles 2010), as there is a give and take that affects and touches the experience of both the caregiver and the care recipient. The dementia care floor, where these experiences evolved and these social actions took place, is thus submitted as a place of connections, of contact, both physical and emotional, where mutually impacting relationships are established and lived; a social world where relations emerged. This construct of care places the delivery of care as a social action or process, and the care home as a relational space, a stance that will be supported throughout this discussion. This care environment is a complex social environment which can also be described as political, given the myriad of social boundaries and power manifestations that were evident. These boundaries were often physical, like regulating mobility by allowing inclusion or exclusion, or through domesticated aesthetics that maintained a certain appearance, while other power manifestations were tacitly embedded in the policies the organization endorsed, effectively shaping the lived experience of care. Therefore, I posit that the care milieu is a place where connections, meaning, and communication transpire. And as supported in similar studies (Graham and Bassett 2006), it is a place where caring relationships and shared meaning are still possible despite cognitive decline.

Borrowing from Bakhtin's theory of how meaning is achieved through dialogue (Bakhtin 2002) at whatever level that dialogue takes place, I argue that in the care experience, there is an embodied dialogue transcending words, where meaning is conveyed and received. Fieldwork revealed that there was a reciprocal dependence between the recipient and provider of care, supporting the argument that care was being co-produced at all time through relational interaction (Fine, M. and Glendinning 2005; Tronto 1998). The following passage exemplifies a corporeal dialogue that transpired between two individuals, Ella and her caregiver, which transcended words yet was equally poignant to both interlocutors. It established a connection that allowed for a meaningful relationship that went beyond the expected duty of care, as narrated by Greg:

> So one night, and sometimes it happens, she's upset when I leave, and they had to settle her down and put her to bed… Michelle said, "You had that lovely Nivea cream there" so she said, "I knew Ella was tired so I got her into bed and I rubbed her feet with the Nivea cream" she said "She was gone"
> Now I thought what a lovely thing to do to rub somebody's feet… and secondly… Emily told me … "I couldn't get her to settle down, so I decided to lie there beside her and oh that settled her nicely." She said, "To such a degree that I almost fell asleep myself."

Interview Transcript. August 29, 2019

These moments capture a connection and communication that did not rely on words or rational reasoning, but relied on a shared knowledge of sensory experience where the body knew what to do without forethought with the caregiver using their own bodily dispositions to make meaningful connections with the resident, bringing to life Konto's arguments on tacit knowledge (Kontos and Naglie 2009). A type of knowledge that while not explicitly articulated, was a corporeal recognition that derived from the embodied experiences of the self, facilitating an exchange that invoked meaning. A communication beyond cognitive dexterity, bridging any distance between oneself and another by eliciting a caring response in which selfhood was manifested and upheld in gesture and action.

Moments like these conveyed the richness of the established relationships within the care environment. Any attempt to understand the user experience of the person living with dementia in the care residence had to also acknowledge anyone within their domain involved in the care relationship, framed within the space where the experience and relationship was taking place. This wider lens of observation provided a more complete understanding of how every encounter helped shape the experience of care, while also shaping the place where they transpired; building upon the theory that space is needed for these and all relationships to take place and to be experienced (Lees 2001). Likewise, the interpersonal relationships that were established in this care milieu also prompted a people-place relationship, whether this relationship was reported as positive or negative, there was an inescapable connection of relationships and place. This perspective of space endorses the idea that architecture is performative, as it holds social practices that continually shape the inhabited space (Lees 2001).

As different relationships were further understood through fieldwork, the architectural approach of designing an environment believed to be complete, which anticipated and orchestrated use, seemed dissonant from reality. This finding challenges the Modernist theoretical proposition that architecture is a tool used to organize and shape space to fashion people's lives in novel ways, infusing desired social effects, as it is a stance that dismisses the multiple ways in which individuals use, interpret, and experience spatial arrangements (Heynen 2013). Instead, the care place was found to be a milieu best explained as open, unfinished, and unpredictable, even suggesting an element of chaos. An open social system that constantly absorbs new agents and relationships, which touch and are touched by the environment, supporting Massey's construction of space as a product of interrelations (Massey 1999). This is a construct that is supported by this study, as it proposes space as the realm of the possibility of multiplicity, where different trajectories coexist and where different perspectives are absorbed; a stance that is concerned with differences and which acknowledges plurality, thus dismissing the tendency for normatization and essentialism. As confirmed through the narratives of different participants, the same spatial articulation meant something different to the individual. The same residential suite was adopted/adapted, used, and experienced very differently by Sally and Nina. Sally, associating her ideal of home to her lost autonomy, presented her suite in a sterile, stoic aesthetic, devoid of any personal mementos, intentionally resisting personalizing it. While Nina, who associated home life with enduring relationships and memories, presented her suite in an explosion of colour and textures, where personal objects disclosed her identity. The same physical area rendered a totally different experience, both from the perspective of what the user of that space offered, as well as what the visitor experienced. This finding supports the theoretical framework which argues that space is always in the process of becoming, it is not static nor a dead surface; it is a living and changing entity that evolves through time as it is constituted by the relationships that constantly emerge and develop (Massey 2001).

The Dynamic and Kinetic Dimension of Space

As discussed in Chapter II, architecture is socially produced, given that all design activities are embedded in negotiated social processes (Sharrock and Anderson 1994; Yaneva 2008). Likewise, the resulting architectural object, in this case the care residence, was a milieu that was transformed over time by the social processes that took place. The concept of space being socially produced and in constant evolution is supportive of De Carlo’s construct, where the user adapts space to their needs, transforming space through the meanings and aesthetics the individual imposes on it, while also being stimulated through the architectural qualities the space transmits (De Carlo 2005). For example, Sally experienced her suite as a cell where she felt captive; an enclosure of blank walls that she rejected as a place that could evoke home. Nina conversely, used the blank canvas of her suite to populate it with objects invested with meaning and memory, providing a material testament of her biographic identity, a strategy used to transmit her personal history and to evoke the notion of ‘feeling at home’ (Hecht 2001); claiming her suite as her domain, asserting her identity and self-determination through objects of significance.

The design of suites as spatial units was a Cartesian approach to space, rationalized through pre-established metrics associated to financial targets and spatial efficiencies. The user was proposed as a 'resident' with no specific gender and no particular biography, that would be assigned a floor area. Having visited both suites, I can attest to how different my experience was. Sally's suite made me uncomfortable, anxious, and restless. My visit with Nina was fun, easy, and relaxed. The same spatial unit, interpreted and transformed by the user, dispensed a different experience to the casual visitor. Having participated in the design process, I can confirm that the multiplicity of experience and the evolution of space through time was never anticipated.

Different theorists have tried to understand the relation between people and space. Heynen (2013) critically discusses different approaches to understanding space; space as a receptor, space as an instrument, and space as a stage. Identifying the limitations of envisioning space as a static receptor of social relations and reacting to how the power imbalance of assuming space will structure social processes, Heynen favours the theoretical model of understanding space as a 'stage'. A stage on which social processes are enacted, framed by spatial structures in much the same way the stage allows or limits the interactions within a theatrical production. Nonetheless, this thesis has shown that while this latter interpretation of space attempts to recognize the social interactions that take place in a milieu, it does not entirely convey the extent of its agency or its kinetic dimension. It suggests a predetermined setting that will contain the social processes that are played out, but one that will potentially remain circumscribed to its predetermined limits. Instead, I argue that findings from this study are supportive of the framework that both, as a practice and as a product, architecture is performative, as the multiple social practices that emerge and take place within, continually shape the space (Lees 2001). Unlike a theatrical stage where the setting is predetermined to contextualize action, my findings are supportive of Massey's theories which present space as unfinished, as always in the process of becoming; where space is conceptualized as open and unpredictable due to the unexpected relational processes that transpire (Massey 1996; Massey 1999; Massey 2001). It is therefore argued that the care residence, as any other building, cannot be fully mastered by the designer (Yaneva 2008), as the milieu is in constant evolution.

The interpretation and appropriation of the dining area as the hub where people gravitated to engage in different social activities. The way in which Kate navigated the corridors of the care floor to reenact her past nurse routines. The creative ways in which Greg used the amenities in the buildings to prompt social engagement and uphold Ella's personhood. All these adaptations of space are examples which support the argument that the physical environment is more than a predetermined, static, physical object. It is an active agent that evolves through time - it enables or hinders, promotes, or demotes - and it is experienced, adopted, and interpreted by users in multiple ways. For Sally it was her prison; for Kate it was a domain that allowed her to reenact her identity as a nurse. Greg had adopted the care residence as a place of encounters, reinventing his couplehood. For Edith, the environment had failed her, compromising her ability to perform the level of quality care she wanted to deliver.

This plurality of experience resonates with the proposition that the relationship between self and place is one of reciprocal influence; a milieu of many actions that are constitutive to place, where every individual impacts the experience of the other (Casey 2001). Place was adopted, interpreted, used, modified, and translated based on individual needs and preferences establishing a reciprocal relationship where the individual affected the milieu, as much as it affected the self, and where all constituents interrelated in constructing a place. Where the individual controlled and modified elements of the environment, while adapting to conditions that could not be modified, supportive of Merleau-Ponty and Sack's proposition that just as places need action of individuals to exist and have effect, selves cannot be sustained without place; and that while places are located within a physical space, they cannot be amalgamated or experienced as one (1962; Sack 1997).

This multiplicity of experience is in direct conflict with the architect's tendency to approach spatial design through a homogenizing lens in which users are categorized in batches that suggest a common experience - for instance 'residents', 'staff', or 'visitors' – grouped according to imagined overarching assumptions that anticipate specific movement, reactions, and experience. This finding is supportive of critics that argue that designer's intentions of conveying a certain meaning, along with their intention to control how an object is to be used and interpreted, is a misconception (Crilly, Good et al. 2008). The user of the designed object is not a passive recipient but is instead an active interpreter that engages with the design in sometimes unanticipated ways. Moreover, the designer is separated in space and time from the eventual user of the environment, further supporting the stance that it is only through interaction, which occurs through time, that the user fully engages with the milieu and constructs their own meaning and experience, abstracted from the architect's intentions. This supports the position that the designer cannot presume the intended meaning of their design will hold once the user engages with it, as interpretation of the given space will be influenced by personal context (Julier 2013; Krippendorff 1989). As the care residence evolved through time from conception to construction, and then to adoption and engagement, the design intentions and the user experience did not always align, suggesting that the production of space and place was equally indebted to those who designed it as it was to those using it (Krippendorff 1989; Whyte 2006). As exemplified in the way the dining area was used for eating, for leisure activities, or to visit, space was adapted by the users, with its use changing over time. It is therefore argued that the way in which the care residence was experienced evolved through time; it could not be anticipated, assumed, dictated, or fixed.

Through fieldwork, it became evident that temporality was a dimension that needed to be part of the critical discussion of space and place. The element of time, its effect on the user experience, on the adaptation and use of space, and on the possibility of place-making, was an unexpected and novel finding. This prompted me to look at other fields of study which have also theorized on the relationship of time and space, like Bakhtin's literary theory of the chronotope (Bakhtin 2002). This theory explores the relationship of literary genres within the context of how time and space connect the temporal and spatial relationships that are intentionally arranged or expressed in a story to convey a certain meaning in the narrative. Bakhtin argues that once the author decides on a literary genre, its compositional structure, its length, its ending, can be predicted, asserting that the genre has an embodied intention that helps shape the logic of the narrative and the behavior of the characters. Furthermore, adopting the literary conventions of each genre will also influence how time and space are used, helping determine the perspective from which the story is told, all in support of the meaning being conveyed by the story (Bakhtin 1986; Öhman 2020; Whyte 2006). These concepts resonated with my findings on how the ambiguity of building typology – residential or healthcare – collided in experience and meaning, prompting me to argue that genre is to literature, what building typology is to architecture. In literature the meaning of a story changes if the narrative is extracted from its genre and transposed into another, with the narrative critically dependent on the perspective from which it is being told. Similarly, I posit that the meaning and experience of architecture is also dependent on the logics of building typologies and on who is using the space.

Architects rely on design precedents for the initial conception of designs (Moraes Zarzar 2003). By reinterpreting design elements, architects draw on established typological knowledge and design principles to overcome functional programme difficulties that could erode time and resources, thus allowing the architect to focus on design innovation (Bay 2001). Once the architect has identified the appropriate building typology, the logics used by the architect to arrange spaces are infused with expectations and intentions that imply a determined user experience of space and place. Nevertheless, similar to how the meaning of the narrative and the behavior of the characters in a novel will depend on the perspective from which the story is being told, findings from this study suggest the same holds true in terms of the user experience. The reported user experience differed depending on the individual's perspective, on who was 'telling the story' – a resident, a visitor, or a staff member - and the context from which the story was being shared; whether the context was understood as home, workplace, or a place to visit.

Similar to how literature has different genres that subscribe to specific literary rules, architecture has distinct building typologies that assume certain logics of aesthetics to associate space to certain meanings and expectations, providing cues to what kind of place it is (Milligan 2003; Örulv 2010). When the genre rules are shifted in literature, the meaning of the story changes and in some cases, is lost altogether. Likewise, when architectural typologies are transposed, meaning of place can evade the user, causing a sense of displacement and a disruption in embodied practices (Angus et al. 2005; Bourdieu and Wacquant 1992; Milligan 2005), supporting the construct that space and place are not the same. Acknowledging the argument that all social activity is 'emplaced', as it needs to happen 'somewhere' and it involves 'material stuff' (Gieryn 2000), and assuming Massey's argument that the articulation of interrelations 'produces' the space

(Massey 2001), I would argue that the 'somewhere' is the space, the given, while place is only produced over time.

As discussed in Chapter VI, the user was presented with a milieu that at times felt displaced, or out of place, as the space being presented as 'home' competed with the clinical aspects and activities of a health care environment, and the organizational pressures of a workplace; tensions that only became evident once the space was in use. Therefore, this thesis demonstrated that although place is substantiated by physical space, place becomes through time; after the user engages with the environment, with both contained space and objects, and engages in social practices, encounters, and relations. This speaks to the dichotomy of the building, that while appearing to be fixed and static, it remains open to interpretation and in constant construction, thus suggesting that the built environment is at once fluid and agential; it generates action and reaction (Latour and Yaneva 2008; Martin et al. 2015). This construct would be supportive of Massey's theoretical framework which presents space as unfinished, since it can never have complete simultaneity in which all interconnections have been established (Massey 1999). In particular, the care residence will experience changes over time due to physical retrofits and visitors, resident, and staff turnover. These changes have an impact on both the physical and relational makeup of the milieu, supporting De Carlo's position which maintains that an architectural object will change through time, as the user imposes on it or adapts to it, with the user being affected from the stimulation and prompts that are inherently transmitted by the physical environment (De Carlo 2005).

Findings from this study challenged the construct of designed artefacts being transmitters of messages infused with assumptions and intentions that are meant to shape an experience (Crilly, Maier et al. 2008), as exemplified by the many design misses discussed in Chapter VI. As powerfully revealed by the data, the designed space was adopted and adapted according to needs; the dining space became the hub of activity where staff carried out tasks amid impromptu social activities that were beyond the assigned function; the lounge transformed into a ballroom, while the corridors were used for exercising and social encounters. Resonant with Massey's suggestion that places are both materially and imaginatively constructed through time (Massey 1996), this thesis has argued that more than a passive receiver of meaning, the user is a translator of both tangible and subjective cues. The rich and novel data from this study, as illustrated in Chapter IV, suggested that everyone's biographies and experiences converge in place-making, actively constructing their own meaning and interpretation of the milieu based on their identity and perspective.

The Agential Potential of the Body-Environment Dyad

Acknowledging the agentive potential of space and objects, while recognizing the embodied and subjective dimensions of the physical environment as prompts that help stimulate embodied memory, I argue that there is an element of creativity, subjectivity, and impressionism that is available to the person living with dementia. This construct can contribute understanding of how recognizing corporeality as an expression of agency that sustains selfhood at a pre-reflective level (Kontos 2012), can enable embodied memory and support the individual in their experience with dementia. I therefore posit that present and tangible sensations can be contextualized as opportunities to prompt impressions of the past, bridging past biographies to current experience; an argument that draws from the theoretical framework of embodiment, critically discussed in Chapter II.

Embracing Merleau-Ponty's theory of embodied connection (Merleau-Ponty M, Smith C, trans. 1962), and Katz and Kontos' construct of embodied memory (Katz 2012; Kontos 2004; Kontos 2005), the body as a whole is acknowledged as a source of agency and identity. A vessel through which selfhood is maintained and manifested despite dementia. Kontos' work advances the construct of how body manifestations reveal embodied selfhood (Kontos 2004; Kontos 2005; Kontos 2012), an argument supported by my findings as shown in Chapters VII and VIII. As shared in the respective vignettes, Ella's knitting and Joan's artwork demonstrated how their embodied selfhood was reproduced through corporeal actions, ably asserting their identity without relying on cognitive dexterity. Their embodied memory of knitting and painting were corporeal expressions and actions that actively sustained their selfhood, conveying individuality, enabling them to engage in their new milieu, despite living with dementia.

As discussed in Chapter II, architecture heavily relies on the body and its senses for its use and interpretation (Negus 1998; Pallasmaa 2005), yet as noted by critics, the attention to the body and the range of bodies in the architectural design process is limited and often undermined (Imrie 2003; Imrie 2004; Imrie and Luck

2014). Supportive of the construct of embodiment, and of the stance that all sensory experiences are modes of relating, this thesis has uniquely demonstrated that the sensual qualities of architecture, which rely on the body as the locus of reference, of memory and imagination, could intentionally be used in design to improve the person living with dementia's experience of place by relying on the body's ability to store and process responses (Pallasmaa 2005). Trying to further conceptualize the relationship of body, environment, and sensory memory, of how present sensations can be effective stimuli to retrieve past impressions, I again lean on literary theory, where the relationship between memory, space, and time has also been explored. In particular, Proust's 'impressionism' theory resonated with my findings and with the theoretical framework of embodiment.

Proust suggests that involuntary memory is prompted by direct and indirect associations from present sensations which lead to re-experiencing moments from the past (Brodsky 1987; Proust 2016; Rawlinson 1984); a construct akin to Kontos' theory of how embodied selfhood is reproduced through corporeal actions (Kontos 2012). I argue that both these theories attempt to conceptualize how the memory of senses can render a continuity of life by acknowledging the body's ability, in its entirety, to record and remember sensations. Past sensuous impressions constitute embodied memories that exist beyond the mind, and as Proust suggests, are past moments (involuntary memories) that are revived under the pressures of present sensations to which the body is exposed (Bogousslavsky and Walusinski 2009; Proust 2016; Rawlinson 1984). Therefore, relying less on cognition, memory is preserved and prompted by bodily sensations that respond to its surrounds; smells, vistas, objects, voices, textures, among others. In the following excerpt, Proust describes how these memories, prompted by the material present, can be reconstructed through the impressions and sensations of the lived or embedded past:

> *"Many years had elapsed… when one day in winter, as I came home, my mother, seeing that I was cold, offered me some tea, a thing I did not ordinarily take... She sent out for one of those short, plump little cakes called 'petites madeleines'… And soon, mechanically, … I raised to my lips a spoonful of the tea in which I had soaked a morsel of the cake. No sooner had the warm liquid, and the crumbs with it, touched my palate than a*

> *shudder ran through my whole body, and I stopped… An exquisite pleasure had invaded my senses…*
>
> *I was conscious that it was connected with the taste of tea and cake, but that it infinitely transcended those savours…. And I begin again to ask myself what it could have been, this unremembered state which brought with it no logical proof of its existence, but only the sense that it was a happy, that it was a real state in whose presence other states of consciousness melted… Undoubtedly what is thus palpitating in the depths of my being must be the image, the visual memory which, being linked to that taste, has tried to follow it into my conscious mind...*
>
> *…suddenly the memory returns. The taste was that of the little crumb of madeleine which on Sunday mornings … when I went to say good day to her in her bedroom, my aunt Léonie used to give me, dipping it first in her own cup of real or of lime-flower tea...*
>
> *And once I had recognized the taste of the crumb of madeleine soaked in her decoction of lime-flowers which my aunt used to give me… immediately the old grey house upon the street, where her room was, rose up like the scenery of a theatre to attach itself to the little pavilion, opening on to the garden, which had been built out behind it for my parents… and with the house the town, from morning to night and in all weathers, the Square where I was sent before luncheon, the streets along which I used to run errands, the country roads we took… in that moment all the flowers in our garden and in M. Swann's park, and the water-lilies on the Vivonne and the good folk of the village and their little dwellings and the parish church and the whole of Combray and of its surroundings, taking their proper shapes and growing solid, sprang into being, town and gardens alike, from my cup of tea." (Proust 2016, p.42)*

Proust explored how memory could be stimulated by bodily sensations, considering humans as amphibious creatures; simultaneously immersed in the past and in the reality of the immediate moment (Proust 2016). This passage illustrates how past experiences and places are held in the body in a virtual state, sedimenting themselves lastingly, with the body and its senses bearing the traces of lived experiences, awaiting to be revived (Rawlinson 1981). I argue that Proust's 'impressionism' could be applicable and useful in conceptualizing how memory, experiences, and impressions of someone living with dementia could be prompted by sensations of their milieu. My findings would support this stance, as I draw the similitude of this passage to Sally's vignette, in which she associated the taste of strong coffee to her previous home.

Therefore, the corporeal manifestation of identity, rooted in the individual's embodied memory, and the sensual potential of the body and its embodied practices, emerge as invaluable opportunities for the care environment to be a dynamic agent in enhancing the experience of the individual living with dementia. The environment's potentiality to help revive past impressions through design interventions that offer meaningful sensorial stimuli could potentially enhance the milieu experience by recapturing embodied sensations and practices that enable personhood, making possible the bridging of present and former selves (Rawlinson 1984). Similarly, it would shed light on the impact environmental effects (acoustics, odours, décor, etc.) have on their everyday experience. Acknowledging the body as a receptor of sensations and as a repository of impressions and lived experiences, is also congruent with the construct that place is imaginatively and experientially constructed (Massey 2001; Rawlinson 1984); a perspective that acknowledges the person living with dementia as capable of imagination, of reconnecting to past biographies, of expression, and agency.

Findings from this study, see Chapter VIII, also confirmed that individuals living with dementia can assign meaning to their surrounds. At times resisting place, exemplified by how Sally and Betty resisted the care residence as their new home, or at times adapting to it, like Nina did. Surrounding herself with cherished objects from her past supported Proust's assertion that the past is more than a mental state; it exists in things, with objects having the power to reveal sensuous qualities and impressions of a former self (Proust 2016). These vignettes support the argument that there is an impressionism and presence of place that is embodied; tacitly held in the body long after it has been experienced, set to be recovered when the suitable impression or sensation arises (Casey 2001; Rawlinson 1984). It also stresses the dynamic nature of place, supporting Massey's argument that space is produced by relations and interconnections that are never finite, never finished, thus suggesting that place is always in the process of becoming (Massey

1999). This insight suggests that the design process could be more responsive to the fluidity and dynamism of space by acknowledging that the architect is unable to orchestrate movement, dictate experience, or dictate the terms under which place is adopted by the intended users.

I posit that architects, when planning space, can only help mediate encounters, facilitate recollections, prompt impressions, and provide an array of sensations for the user of that space to discover, to experience and to construct place according to their biography. Furthermore, suggesting that place is unfinished, renders the person living with dementia the opportunity to interpret, adapt, adopt, embrace, experience, reminisce, or resist place based on their personal identity and dementia journey. This position is aligned with Kitwood's theoretical perspective of the importance of the relational and social context of dementia (Kitwood 1993; Kitwood 1997), reaffirming that the individual living with dementia can maintain their personhood; capable of engagement, despite their condition. Yet it goes a step further by recognizing the continuing creative agency in the individual, acknowledging their ability and potential to contribute to place-making according to their identity, through their embodied memory and experience of place.

My Evolution

This research study has transformed my personal and professional understanding of dementia, design, and place. Previously comfortable using normatizing terms like 'the person with dementia' or acronyms like PWD (person with dementia), this study has profoundly affected my sensibility towards the individuals that find themselves living with the condition of dementia. The assumption that I was going to uncover 'the' embodied experience of the person with dementia relative to the environment exemplifies how I essentialized both the individual and their journey with dementia, assuming this experience would be singular and homogenous. This mindset was informed by years of design work in which as a contributor, I believed space could be programmed in a way that would deliver an optimum and efficient experience for residents and staff, orchestrating movement and use of space based on preconceived standards and design guidelines that had been previously established by anecdotal inferences of user needs. This approach lends credibility to critics' arguments that architects have limited understanding of the human body and condition, or at best, use a reductive approach to design (Imrie 2003; Imrie 2004), where the user is envisioned as a malleable and docile actor that should easily intuit how space was meant to be used. Nonetheless, this study allowed me to have meaningful encounters, helping me understand that people living with dementia are individuals capable of resistance, of humour, of self-expression, whose identity remained intact.

During the design process, industry terms like 'end user' or 'project closeout' are used with conviction, revealing insights on how space and place are typically conceptualized; a closed and finite milieu, where function is allocated to space and meaning is pre-assigned to place. This myopic understanding of space and place disregards the multiplicity of users and their individual experiences, asserting that an environment can be designed and completed; finished. Massey's theoretical framework of space challenges this perspective, arguing that space cannot be conceptualized as a fixed or static surface containing objects, proposing a construct of space as the possibility of interaction, a source of new relations, where multiple histories are possible and are always in the process of being made (Massey 1999). It is a construct that has shifted my understanding of the environment and of care home design practice by highlighting the plurality of experience within the care home, and the unplanned and creative ways in which space is adapted and used. It has led me to understand physical space as a milieu; a social place that becomes through time and use; a consequence of social encounters and relations. It has altered my understanding of the architect's role and ability to establish limits of space, use, and experience, leading me to reinterpret the architect's role as a facilitator of space that is proposed as unfinished, allowing individuals the autonomy to assume it and to experience it; to materially and imaginatively construct it with their identity as context (Massey 1996; Massey 1999; Massey 2001). It is a mind shift that directly responds to the array of experiences collected in the data, highlighting the imperative need to revisit key architectural design principles to allow space the possibility of chaos, able to absorb the unexpected, while embracing the unscripted.

Acknowledging the subjective aspect of architecture, where art is part of the technical and scientific application of design, I have borrowed concepts from other arts - music, theatre, and literature – to critically sustain my argument. Like architecture, these creative expressions of the human condition attempt to understand time, space, and meaning of shared experiences, expressing through different mediums a particular narrative, attempting to decipher how best to connect these dimensions. The following passage - referring to an operatic libretto - resonated with my evolved conceptualization of space and place:

> *"Taken on its own a libretto rarely adds up to much. The text as narrative is often disjointed, repetitive and lacking depth... a libretto is not intended to be analysed in isolation. It demands to be analysed in action. How it is integrated into the dramatic action on stage, how it relates to the melody and rhythm of the music, how it is called upon (recruited) and manipulated by the singers, how it is performed – all of these are of primary importance. Its substance as displayed on the inert page is of only secondary concern." (Prior 2003, p. 173).*

This explanation is analogous to how design documentation could be conceptualized. Floor plans and construction documents are like a libretto. They are an inert representation of action, of movement, of the multiplicity of experiences that happen inside the building and that will differ through time. New relationships will be established each time a resident moves in, or when new staff members join the team. The milieu will render a new experience every time furniture is rearranged, or when space is adapted for a different use. The shell of the building is captured in these construction documents, but the life inside of the building, what is to come and become, is impossible to capture or predict.

This work has prompted me to re-evaluate my practice as an architect, providing me with a humbler perspective of the designer's role. It has provided insight on the need to embrace the multiplicity of actors in the field, confronting me with the need to understand the person living with dementia as an individual with identity, capable of expressing preferences, able to retain memory despite their condition. It has humbled me into acknowledging the expertise derived from use by individuals who could meaningfully contribute during the design process. In short, this study has provided me the opportunity to mature from knowing about design, care, and people living with dementia, to empathetically feeling what it is to live and work in a contained dementia care environment.

Reflections on Moving Forward

This thesis was never meant to be an architectural audit of practice nor a post-occupancy evaluation of the dementia care residence. It did not aim to produce a compendium of design guidelines, therapeutic goals of care standards. Instead, the aim of this research was to reflect on current design conceptualizations of dementia care environments as they relate to the envisioned user and on how the overall design process and production of architecture influenced the care experience. The focus of this study was always about uncovering aspects of social life in a very particular setting, aiming to better understand social causes and human experience in relation to current approaches to the architectural production of dementia care environments.

This thesis has advocated for the repositioning of critical elements that conform the dementia care milieu; conceptualizing architectural production and care provision as social processes. Challenging traditional design processes that conceive space as 'finished', inhabited by 'end users', it proposes a construct of space as malleable and of place as always being in the process of becoming. It has critically discussed the consequences of the abstraction and normatization of the individuals using the space, and has advocated for the rediscovery of the body - in all its dimensions - as a critical design consideration and as a valuable source of embodied personhood in bridging past biographies to current condition. Findings from this study have provided evidence of the tensions and challenges that result from the architect's estrangement from the realities of dementia care, documenting the impact of decontextualized and disembodied design interventions and of the application of generic design guidelines on everyday life experiences. Findings have also demonstrated the need to prioritise the voices of the individuals who share this social world, who are in relationship, influencing each other's experience of care; including the individual living with dementia.

The mid-1990s heralded a 'culture change', an era of research, creativity, debate and innovation to dementia care and design. Thirty years later, many of the issues and challenges that were initially identified seem to unresolved. Moreover, findings suggest that architectural practice has arguably relented to the effects and pressures associated to the commodification of care; like overly relying on design precedents and abstracted guidelines for the sake of design expediency, financial objectives, and of idealized (unrealistic and unrelatable) visions of care. As such, it is critical to evolve design practice to a more collaborative and co-produced approach, in which individual needs, preferences, and embodied biographies are acknowledged, ensuring key stakeholders involved in the care experience participate early in the design process, acknowledging their particular expertise. This would help bridge the distancing between designer and user groups, providing a balanced context during design, where too often financial targets and operational efficiencies influence decisions which ultimately affect the quality of experience.

Findings from this study support Massey's construct of space as unfinished and evolving (Massey 1999), suggesting that buildings are fluid and agential; generating action and reaction (Gieryn 2000; Latour and Yaneva 2008). The construct of an open-ended place that is in constant flux could be a catalyst for designers to conceptualize the physical environment as the possibility of encounters and interactions, capitalizing the physical environment's potential to prompt habitus, facilitating recollections, prompting impressions, mediating encounters, and providing an array of sensations. Conceptualizing dementia care environments as physical spaces that present a symphony of stimuli through intentional design features and multi-sensorial prompts, could potentially enable the individual to experience place through their body as a whole, relying less on intellectual dexterity, and more on embodied memories and sensations. This approach would enable a closer person/environment relationship, situating the individual as a sentient being, able to respond to the environment according to their identity, freed from orchestrated experiences to determine how to best feel in place, if at all.

This thesis has also identified a dialectical relationship between user, space, and practice; where time becomes an unquestionable dimension that affects space and place-making. It is through time and use that architectural space is transformed by the user and relationships are established, transforming space into place. Incorporating time as a design criterion could be a valuable foundation for a more reflective architectural practice, where the designer 're-visits' or 're-searches' the impact of assumed architectural design principles. Evaluating how the space has morphed into place, how the different user groups have adapted or appropriated space through time, or understanding the operational challenges associated to spatial planning, would facilitate the integration of embodied practices, contributing knowledge to the next design generation, while sensitizing the designer to the qualitative and experiential aspects of dementia care. Hence, a closer relationship between ethnographic research and architectural practice is advocated as a strategy to help align design intentions and therapeutic goals to actual experience. Likewise, I posit that architectural practice would benefit from refining architectural academic training to prompt a more reflexive approach to design by encouraging philosophical and sociological debates, advocating for a more empathic approach to design.

Design ethnography is also suggested as a more immersive and experiential methodology to advance knowledge through praxis (Müller 2021). Recognizing the practical challenges of taking extended periods of time for research, post-occupancy evaluations (POEs) could be useful for re-evaluating the designed environment at different cycles after building occupancy. Although their value is widely recognized, they are seldom used due to cultural attitudes in the field ranging from complacency, fear of blame, insurance liability concerns, or the cost of undertaking them (Hay et al. 2017). Similar to most design and therapeutic guidelines, POEs often focus on physical comfort only (lighting levels, thermal comfort, acoustics, etc.), demoting the emotional, social, and cultural aspects of the environment (Ellsworth-Krebs et al. 2019). Acknowledging this limitation, visiting the care home after construction, and being temporarily immersed in the social world that evolved through time, would provide the designer insights into the established relationships and into the adaptations of use that have taken place, stressing the need for space to be flexible, capable of absorbing the unexpected, and of embracing the unscripted. While the current market conditions, where demand for dementia care has resulted in a shortfall of infrastructure, offers little incentive to course-correct design processes, a more robust endorsement of qualitative insights from the different regulating and advocacy bodies such as architectural schools and associations, dementia advocate organizations, or care licensing bodies, could be instrumental in encouraging a more corporealized design methodology.

The demand for dementia care will only continue to rise, therefore, we need to collectively work towards environmental solutions that capture both qualitative and quantitative markers; that are viable, economically feasible, but above all, that are experientially appropriate and inclusive. The quest for quality dementia care environments must therefore evolve from searching for a one-solution proposition to a holistic understanding of the complexity of the individual experiencing the condition. The duty to deliver quality, dignified, and humane dementia care is our collective responsibility. The physical environments where this care is delivered should matter to society at large, emphasizing De Carlo’s plea (De Carlo 2005), that architecture is too important and too impactful to be left to architects alone.

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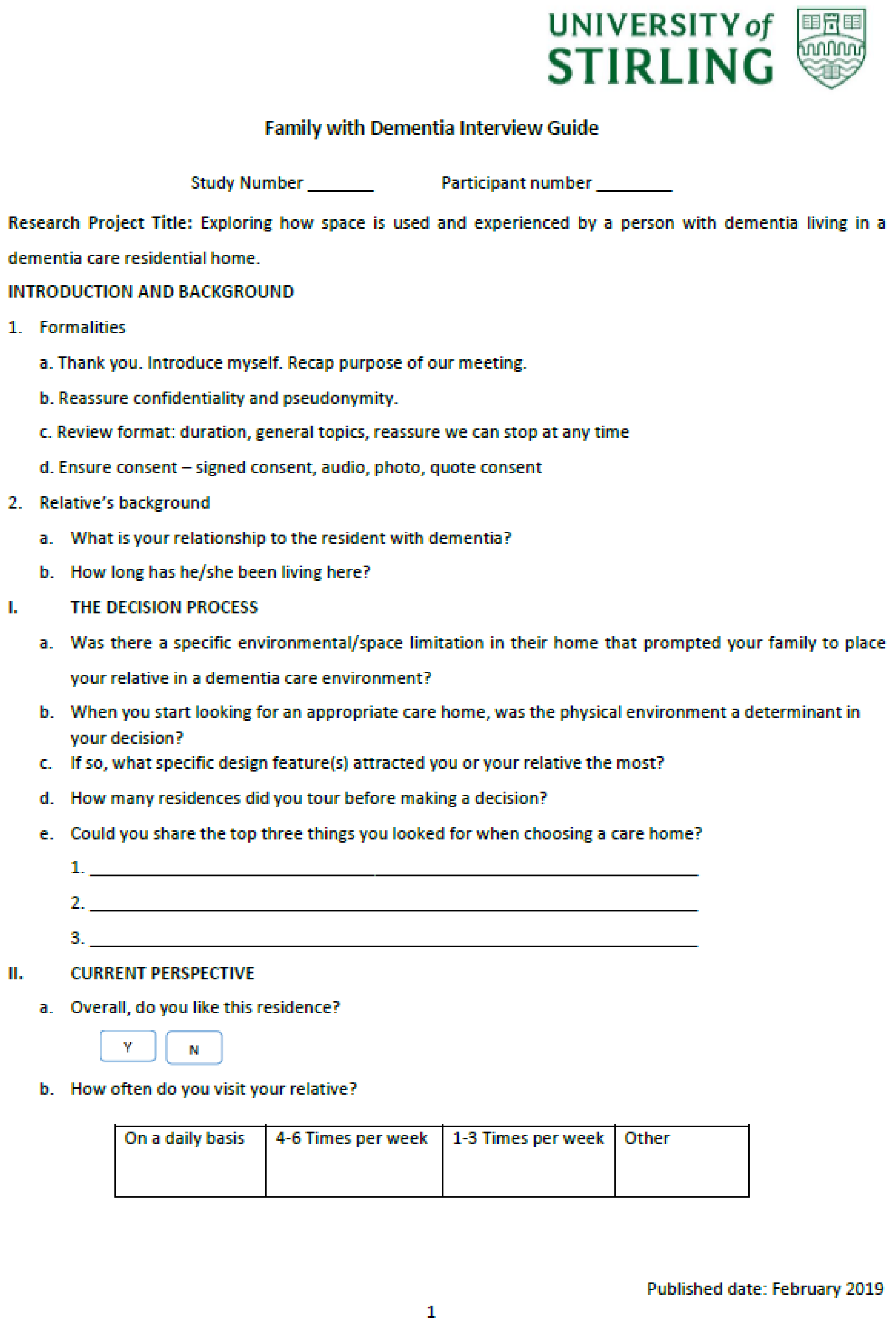
APPENDICES

Appendix A



UNIVERSITY of STIRLING

Family with Dementia Interview Guide

Study Number _______ Participant number ________

Research Project Title: Exploring how space is used and experienced by a person with dementia living in a dementia care residential home.

INTRODUCTION AND BACKGROUND

1. Formalities
    - a. Thank you. Introduce myself. Recap purpose of our meeting.
    - b. Reassure confidentiality and pseudonymity.
    - c. Review format: duration, general topics, reassure we can stop at any time
    - d. Ensure consent – signed consent, audio, photo, quote consent
2. Relative's background
    - a. What is your relationship to the resident with dementia?
    - b. How long has he/she been living here?

I. THE DECISION PROCESS

- a. Was there a specific environmental/space limitation in their home that prompted your family to place your relative in a dementia care environment?
- b. When you start looking for an appropriate care home, was the physical environment a determinant in your decision?
- c. If so, what specific design feature(s) attracted you or your relative the most?
- d. How many residences did you tour before making a decision?
- e. Could you share the top three things you looked for when choosing a care home?
    1. ______________________________
    2. ______________________________
    3. ______________________________

II. CURRENT PERSPECTIVE

- a. Overall, do you like this residence?

    ☐ Y ☐ N

- b. How often do you visit your relative?

On a daily basis	4-6 Times per week	1-3 Times per week	Other

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c. How long do you usually stay for?

1 hour or less	2 to 3 hours	Half day	Other

d. When you come to visit, where do you usually visit?

Resident Suite	Dining Area	Lounge	Outside Patio	Other

e. What draws you to that space?

f. What space do you think is your relative's favourite area?

g. Why do you think it is their favourite spot?

h. What parts of the building or décor do you feel most comfortable with? Why?

i. What do you like to do when you come visit?

III. HINDSIGHT

a. If you were looking for a place for your relative today, would you factor in different criteria to make the choice?

b. Do you like coming to the care floor to visit? ☐ Y If no, why not?

c. What space or environmental experience do you miss the most from when your relative was living at home and you visited then?

d. If there is one thing you could change about the design of this place, what would it be?

e. Do you think the physical environment is important for your relative's wellbeing?

☐ Y ☐ N

f. From an environmental perspective, knowing today what you didn't know before, what would be your top three things you looked for when choosing a proper home?

1. ______________________________

2. ______________________________

3. ______________________________

Appendix B

Version date: May 2018 Published date: February 2019

UNIVERSITY of STIRLING

Participant Information Sheet

1. **Research Project Title**

   Exploring how space is used and experienced by a person with dementia living in a dementia care residential home.

2. **Background, aims of project**

   We would like to invite you to take part in this research project which has been prompted by a desire to understand how the physical environment can best contribute to a rich resident experience that will help enable residents living with dementia. Given the effects of dementia on the individual, studying how the environment is navigated and appropriated by the person living with dementia, understanding obstacles and opportunities, can result in valuable lessons to be incorporated into future designs so as to contribute to a more positive experience and an enhanced quality of life of the resident.

3. **Why have I been invited to take part?**

   You have been invited to contribute to this research because you have been identified as someone who can help us understand the everyday issues the person with dementia and other users of the space face. By being a stakeholder in one of the different user groups of this space, you are close to the everyday challenges and issues the designed space presents. As such, your unique perspective is critical to the overall understanding of the user.

4. **Do I have to take part?**

   No. You do not have to take part and this will not affect you in anyway. Whether you are a resident, a member of staff, a family member or a close friend, your decision will be respected and it will not affect you in any way.

   If you do decide to take part, you can withdraw your participation at any time without needing to explain and without any issue, simply advise the researcher of this decision. You can also withdraw your data within a month of having provided it. You will be given this information sheet to keep and you will be asked to sign a consent form, verbally confirming your consent throughout different stages of the research.

5. **What will happen if I take part?**

   If you do participate in this project, you will be invited for an in-person interview with the researcher. The interview should take approximately one hour. The study will take place at the community and all interactions, aside from being confidential, will be scheduled around your availability. If there is information that needs elaboration, you may be asked for a second interview to ensure the data being collected is truly reflective of your sentiments.

6. **Are there any potential risks in taking part?**

   The one risk that has been identified in taking part in this study is an emotional one. Depending on your role and perspective, you may find some topics emotional. To help prevent this risk the researcher will work closely with the Memory Care Coordinator to ensure adequate calming strategies are available.

7. **Are there any benefits in taking part?**

   The benefits of taking part in this research is that your opinion and voice will be heard and will contribute to the benefit of future residents. Even though there may not be an immediate direct benefit to you from taking part in this research, the fact that your perspective, experience and expertise is contributing to providing a better physical environment for dementia care, will undoubtedly result in personal gratification.

8. **Collecting Personal Information**

   As part of the project we will be recording some personal data relating to you; all information and data will be protected and kept confidential. To ensure this, pseudonymisation will be used to replace all identifying fields, using artificial identifiers, numbers or pseudonyms. Nonetheless, the collected data will be processed in accordance with the General Data Protection Regulation (GDPR). Under GDPR, the official authority of the University and the legal basis for processing your personal data, collected information will be public interest.

9. **What happens to the data I provide?**

   All participants will be assigned a number to protect their identity, informed by the principles adopted as compliance guidelines in the different legislation applicable to this study: The Personal Information Protection and Electronic Documents Act (PIPEDA) (Government of Canada 2015) at a federal level; the Personal Health Information Act at a provincial level (Government of Ontario 2018), and The Retirement Homes Act (Government of Ontario 2017) as Ontario-licensed operator of retirement care homes.

As per the company's Incident Reporting protocol and policy, should there be any information related to physical abuse of vulnerable residents or any information that would suggest risk to harm to anyone, confidentiality would have to be foregone in order to escalate and report an incident. In addition, this study will follow the guidelines on ethical research provided by British Sociological Association, available at:

https://www.britsoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf

Personal and confidential information will be safely stored. In collaboration with Amica's IT Department, a secured virtual locker in the mainframe of the server will be enabled in the network for the secured storage of data. Your personal data will be kept for two years and then will be securely destroyed. If applicable, participants will be asked for their permission to use direct quotes.

10. **Recorded media**

Participant's permission will be obtained to audio record interviews. These recordings will be used as reference to ensure transcripts are accurate and that words and intention of meaning are properly contextualized. This will be a valuable tool when analysing collected data, as there may be extended period of times before information is classified from when it was collected.

As per company policy, all photographs will be devoid of people. Specific permission will be obtained for any photos taken within the privacy of a resident's suite.

11. **Will the research be published?**

Once the research project is completed, an executive summary will be presented in the community. This research may also be published in academic journals or disseminated at design conferences. The University of Stirling is committed to making the outputs of research publically accessible and supports this commitment through the online open access repository STORRE, meaning this research will be publicly disseminated through the open access repository.

12. **Who is organising and funding the research?**

This research project is being sponsored by Amica Senior Lifestyles to advance knowledge in the area of design of dementia care environments.

13. **Who has reviewed this research project?**

This project has been ethically approved via The University of Stirling General University Ethics Panel.

14. **Your rights**

You have the right to request to see a copy of the information we hold about you and to request corrections or deletions of the information that is no longer required. You have the right to

withdraw from this project at any time without giving reasons and without consequences to you. You also have the right to object to us processing relevant personal data however, please note that once the data are being analysed and/or results published it may not be possible to remove your data from the study. Please note, all data will by pseudonymised when recorded and safely stored to protect privacy.

15. **Who do I contact if I have concerns about this study or I wish to complain?**

If you would like to discuss the research further, please feel free to contact the lead researcher, Claudia Salgado, at clc3@stir.ac.uk. If you have any concerns about this work, please feel free to reach out to Vera Kovacevic, Memory Care Coordinator at v.kovacevic@amica.ca.

You have the right to lodge a complaint against the University regarding data protection issues with the Information Commissioner's Office (https://ico.org.uk/concerns/). The University's Data Protection Officer is Joanna Morrow, Deputy Secretary. If you have any questions relating to data protection these can be addressed to data.protection@stir.ac.uk in the first instance.

Thank you for your participation.

Appendix C

UNIVERSITY of STIRLING

Participant Ethical Consent Form

Study Number ________ Participant number _________

Research Project Title: Exploring how space is used and experienced by a person with dementia living in a dementia care residential home.

	Please initial box
I confirm that I have read and understood the information sheet dated February 2019, explaining the above research project and I have had the opportunity to ask questions about the project	
I understand that my participation is voluntary and that I am free to withdraw at any time during the study and withdraw my data within one month without giving a reason, and without any penalty. I understand that beyond this timeframe, when data analysis has started or results have been published, it may not be possible to remove my data from the study.	
I understand that my responses will be protected and kept confidential. To ensure this, pseudonymisation will be used to replace all identifying fields, using artificial identifiers, numbers or pseudonyms. I give permission for members of the research team to have access to my pseudonymised responses.	
I consent to being audio recorded	
I consent to having photos taken and I understand how photos will be used in research outputs	
I understand how audio recordings will be used in research outputs. I am aware that I will not be named in any research outputs but I could be identified by people I know through the stories I tell.	
I give permission to be quoted directly in the research publication	
I agree for research data collected in the study to be given to researchers, including those working abroad to be used in other research studies. I understand that any data that leave the research group will be fully pseudonymised so that I cannot be identified.	
I understand that my General Practitioner (GP) will NOT be informed of my participation in this study. However, if the researcher has any concerns regarding information about me and/or any measurements that are taken as part of this research, I will be advised to contact my GP	
I understand this study will follow the guidelines on ethical research provided by British Sociological Association	
I agree to take part in this study	

Name of Participant **Signature:**

Date: Click here to enter a date

Name of Researcher **Signature:**

Date: Click here to enter a date

EXEMPTION – Please note that despite all efforts to pseudonymise data, identity and the field of investigation, there is a possibility that the residence may be identified through the images and descriptions provided in the findings. Therefore, complete anonymity and confidentiality cannot be guaranteed.

Version date: May 2018 Published date: February 2019

Appendix D

UNIVERSITY of STIRLING

RESIDENT INTERVIEW GUIDE

SEQUENCE	QUESTIONS/SCRIPT	PROMPTS
INTRODUCTION	• Thank you • Introduce myself • Recap purpose of our meeting • Reassure confidentiality and anonymity • Explain format – duration • Ensure consent – signed consent and audio consent • Reassure we can stop at any time	
TRANSITION BASIC FACTS	• Age/Gender • Confirm diagnosis • How long have you being living/working at Amica?	
QUESTIONS 'SAFE'	• Tell me what it is like to live here at Amica? • What has helped you feel settled? • Can you share with me if you liked the place when you first came to live here? • Tell me about your days here at Amica. Do you like to change things up or do you enjoy a specific routine? • What do you and your family like to do when they come visit? • Has coming to this care home made it easier to make new friends?	• Can you think of an example that can help me understand what you mean? • Can we chat a bit more about that? • Why is that?
QUESTIONS 'ALERT'	• What is your favourite place here? • What space or design feature do you miss the most about your previous house? • What parts of the building or décor do you feel most comfortable with? Why? • Is there a special place in the building you like to go to that makes you happy? • If there is one thing you could change about the design of this place, what would it be?	• Would you like to take a break? • Would you like some water?
CLOSING	• Recap next steps. Provide contact info again • Thank you	• Anything else you would like to share with me?
DURATION	• 60 MINUTES	• Break as needed