A Phenomenological Investigation of Architecture in Dementia Facilities

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Declaration

I declare that this thesis, A Phenomenological Investigation of Architecture in Dementia Facilities, which I hereby submit for the degree of MTARCR- M.Tech: Architectural Technology in the department of Architecture in the faculty of Informatics and Design at Cape Peninsula University of Technology has not been submitted for a degree at any other tertiary institution for any other degree, diploma or qualification.

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The work attached is my own, original work, i.e. free of plagiarism. All sources used in this work have been referenced, using the **Harvard** system of in-text and end-of-text referencing.

Izoné van der Vyver (McCracken)

2020-03-18

IMCracken

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Acknowledgements

It would not have been possible to write this thesis without the help and support of the people around me. I dedicate this work to my grandmother Eapé Kruger, mother Edene du Toit and my loving husband Colin McCracken. I would also like to thank my employer, Ebesa Architects for their support and assistance. Thank you all for your unwavering support, and most of all, grace through this research journey.

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Chapter One

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

"You must do more than simply keeping your occupant in mind while you design- you must understand what it is like to be them."

(Lehman, 2010:9)`

Being a designer and a master student in architectural technology, I am very aware of my environment and the challenges it poses. Ironically, I was somewhat unaware of the battle my grandmother was facing when she was diagnosed with dementia; her struggles only became evident once I personally got involved with her caretaking process while she was in a care facility for the aged.

Consequently, I decided to investigate care facilities for people living with dementia through an architectural phenomenological perspective, as most of her challenges were centred on her experience and interpretation of her environment. Place, a phenomenological construct, is essentially about the experience of the material world in combination with mental constructs in a space; which motivated this investigation specifically for people living with dementia. Additionally, this investigation is promoted by supporting evidence that in first-world countries, such as America, a person develops dementia every sixty-five seconds (Alzheimer's Association, 2017). In the United Kingdom, similar statistics indicate that the number of people living with dementia is expected to rise from eight hundred thousand to one million people by the year 2021 (Ryder, 2016:264). The World Alzheimer Report in 2016 stated that in South Africa approximately one hundred and eighty six thousand people live with dementia, and the figure is predicted to rise to two hundred and seventy five thousand by the year 2030 (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016:96). The need for better care facilities is evident, and dementia is a significant risk for institutionalisation (Von Kutzleben, Schmid, Halek, Holle & Barthlomeyczik, 2011:378).

1.2 THE PROBLEM STATEMENT

1.2.2 THE ENQUIRY OF ARCHITECTURE AND DEMENTIA

The task of caring for people with dementia is increasing globally (Ferretti, Sarti, Nitrini, Ferreira & Brucki, 2018:2). This increase provokes designers to find new ways of designing for an older population. The number of people with dementia in low- and middle-income countries is also increasing, but with limited resources available in such countries, appropriate design solutions are rare (Walker & Paddick, 2019:538).

South Africa has a diverse population with limited public healthcare services; making the task of designing better facilities by architects and designers even more difficult. Only a small percentage of the population in South Africa is able to afford well-resourced privately- owned healthcare services; leaving the majority of the population relying on under-resourced public healthcare services. There is little awareness of dementia in South Africa, impacting the resolution and adaptation of dementia facilities; resulting in limited services and facilities orientated towards dementia care (Prince *et al*., 2016:97). This is not to say there are not any specialised facilities; in a desktop investigation I was able to list thirty-five facilities in South Africa that provide dementia care. These facilities are, however, a small number in comparison with the rising dementia population in South Africa.

It is evident that international healthcare design and systems, such as in Switzerland, are constantly evolving and aiming for better solutions in the medical realm, but also more recently started to initiate programs that focus on services and facilities specifically focused on dementia care (Prince *et al*., 2016:97). What is missing though, is the fact that architects do not actively involve users in the design process, as many institutions are designed claiming to be dementia-friendly, but do not perform well when occupied by people living with dementia as residents (Greenhouse, 2012). It has rather become a fashion for many designers and developers to claim that a building is dementia-friendly by promoting it through using superficial design tactics (Greenhouse, 2012). Working with end-users during the design phases of a project can ultimately provide insight into what is really needed, and not how to adapt the design of an environment to enable the user (Media, 2016).

Identifying specific occupant needs are crucial in architecture. Architects often design spaces for a specific function, such as dining, playing, learning or healing. But do they truly consider integrating these objectives with a sincere focus on optimal experience and function whilst designing? (Lehman, 2019).

As a further enquiry pertaining to designing for specific needs and situations, designing facilities for people with dementia is a topic that only produced a few qualitative studies in the last decade (Mjørud, Engedal, Rosvik & Kirkevold, 2017:1). There is a need in articulating a method which architects can use to understand and design homes for people living with dementia, which speaks to architectural design methodologies (Van Steenwinkel, 2015:289). Supplementary to this, a phenomenological development by Jordaan, the placial triad, urges architects to research how the framework can be used in empirical cases (Jordaan, 2015:224). For the purpose of this research, such an empirical case can be the design considerations and understanding of dementia facilities.

"The human brain directly affects the work that you do as an architect, and the work that you do as an architect directly affects the human brain"

(Lehman, 2010:18)

Dementia is the medical term used to diagnose a set of symptoms relating to the various cognitive and social dysfunctions that can be relieved or even reversed. Dementia does not have a specific cause and is rather the result of a series of systems within the brain not functioning correctly due to various diseases (Healthline, 2017). Diseases known to be the underlying cause of dementia are: Alzheimer's disease, Parkinson's disease, Lewy body disease, strokes, other forms of brain injury and substance abuse (Alzheimer's Association, 2016: 459). Depending on the underlying cause, a person can have various types of dementia where some cases of dementia are reversible (Healthline, 2017).

People living with dementia are at high risk of being physically injured, getting lost and being exploited. This risk is due to the person with dementia's lack of being able to reason, being physically impaired and becoming aggressive. The problem is evident. The design of most dementia facilities focuses on risk avoidance rather than emotional well-being (Jenkins & Smythe, 2013:17). Care facilities for people living with dementia are usually focused on providing enough space for certain activities and equipment, rather than allowing for individual development and most importantly for a sense of place.

As a consequence of this realisation, it is evident that the philosophical discourse of phenomenology has an important place in architecture. Since there is this notion that architecture for dementia facilities are mostly focused on risk avoidance, I contend that the importance of the study of phenomenology in architecture, its history and ideas, lies in how it can contribute in providing architects with insight into the design of facilities for people living with dementia.

1.3 RESEARCH QUESTION, SUB-QUESTIONS AND OBJECTIVES

TABLE 01:

RESEARCH PROBLEM	People living with dementia often lose their sense of place within their concrete environments. This loss of place, emotionally and physically, interferes with the quality of their daily lives. The persons involved in the care of persons with dementia have to do this within the physical place and it is not clear how this influences the care. It is also not clear how architects consider the needs of dementia care from the perspective of the persons involved in design of dementia facilities.	
RESEARCH QUESTION	What are the design considerations from an architect's perspective to design person-centred dementia care facilities?	
SUB-QUESTIONS	**OBJECTIVE**	**RESEARCH METHOD**
What are the post diagnostic facility care options for people with dementia?	To determine what type of facilities are suitable for dementia care.	**Literature Analysis**
How could the placial relationships of persons with dementia correlate to architectural elements of dementia facilities?	To establish how architecture evokes various placial relationships.	**Literature Analysis** **Preliminary Investigation** -Persona development **Design Ethnography**: -Observations Studies -Scenario Based Design -Mock-up & Prototyping -Tentative Design Principles
What are the challenges experienced by persons involved in dementia care in a specific place?	To determine the challenges experienced in dementia care by caregivers and family in a specific facility.	**Literature Analysis** **Preliminary Investigation** -Persona development **Design Ethnography**: -Observations studies -Scenario Based Design -Mock-up & Prototyping -Tentative design principles

1.4 CURRENT STATUS OF THE RESEARCH AREA

1.4.1 OVERVIEW

In *Offering Architects Insights into Living with Dementia*, Van Steenwinkel (2015:289) stresses the lack in articulating a method which architects can use to understand and design homes for people with dementia, specifically for architectural design methodologies. In *Constructing*

Place, Jordaan (2015:224) develops an architectural framework, the placial triad, for understanding place-making, and urges future researchers to use the framework for investigating empirical cases.

Ironically, the nature of Dementia is that of confusion, the loss of self through the inability to identify oneself with a specific place, space, group of people, area or surroundings (Healthline, 2017). A loss and confusion of place.

The concept of place-making intertwines with theoretical aspects of other disciplines such as Philosophy (Trigg, 2012:5). In philosophy, phenomenology is the theory of experience, perceptions, perspectives and understanding of situations and places. Phenomenology is about spatiality, relationships, temporality and corporeality (Trigg, 2012:7). In this regard, phenomenology serves an important vantage point for understanding dementia, in relation to architecture, as it provides a strong theoretical background.

The architectural concept of place-making is often perceived to be a vague and ambiguous concept, as it incorporates so many disciplines. This concept explores the relationship between human beings and their surroundings, the quality of the relationship between a human being and a place, general feelings about a place, physical interaction between humans and place, and the mental paradigms formed by humans due to a particular place (Jones & Garde-Hansen, 2012:99). The concept often becomes confusing, and the lines between architecture and other disciplines become blurred.

Consequently, the understanding of place is extremely difficult and complex. It cannot be reduced to a single attribute, idea, or concept. It must be understood as a multi-dimensional idea. Trigg (2012:17) describes the multidimensional idea of place as follows:

"… *place is fundamentally a porous concept, falling in-between idealism and realism. What this means is that any given place is never autonomous in its unity, but forever bleeding and seeping into other places…*"

This multi-dimensional idea can be best understood in the analysis of key phenomenological concepts, and by looking at how architecture can be a phenomenological mechanism.

1.4.2 KEY PHENOMENOLOGICAL CONCEPTS

1.4.2.1 TRANSCENDENTAL THEORY AND THE PHENOMENOLOGICAL REDUCTION

Transcendental phenomenology is one of the most particular types of phenomenologies (Kauffman & Gare, 2015: 221). The transcendental phenomenological theory was developed by Edmund Husserl, also known as the father of phenomenology, who wanted to use phenomenology to account for certainty (Kauffman & Gare, 2015: 221). It encompasses the idea that apart from experiences and specific thoughts, there are edifices of consciousness

(Jordaan, 2015:39). Consciousness, as Husserl referenced the work of the French philosopher Franz Brentano, is always directed at something other than itself (Kauffman & Gare, 2015: 221). Jordaan (2015: 39) elucidates this consciousness as the act where the mind interacts with reality as an alternative to creating it. In other words, reality exists irrespective of the mind. The mind just refocuses its subject and interacts with reality by means of its focus.

With Husserl's transcendental phenomenology came the quest for reduction. Husserl's aim with this reduction was to review the pre-given assumptions of the world (Trigg, 2012:19). The reduction embraces the idea of forgetting all traditional beliefs and ideas about an object and to rather analyse and see things from a fresh and new perspective (Jordaan, 2015:41). With a further understanding of the phenomenological reduction, Seamon explains that there are in fact two reductions put forward by Husserl.

The first reduction is an eidetic reduction. The eidetic reduction is the absolute suspension from all essential apparatuses of the phenomena (Seamon, 2013:147). The second reduction is the transcendental reduction, which is a broader and more insightful understanding of the phenomena (Seamon, 2013:147). This broader understanding, which is differently noticed by Trigg, is bound to experience and bodily dimensions, realising the potential of a reduction (Seamon, 2013:147). Trigg (2012:20) maintains that the impossible eidetic reduction does not suggest that Husserl's transcendental phenomenology is a failure, but it rather shows its diverse nature and potential. In effect, the aim of Husserl's phenomenology was to clarify the central edifices of consciousness, being able to consist of its own composition (Kauffman & Gare, 2015:221).

1.4.2.2 THE LIFEWORLD

The lifeworld is the world as it is experienced every day. It is the automatic, unnoticed life experienced as normal. According to Jordaan (2015:39), the lifeworld is a valuable pre-epistemological resource for phenomenological enquiry. In other words, it's a body of knowledge already at hand in understanding experience, perceptions, perspectives, situations and places.

It proves to be very difficult to describe this already-always-there of the world. Seamon describes it as a "people world emersion": where a two-entity concept is existentially one (Seamon, 2013:144). It is only when this "person-intertwined-with-the-world" becomes disrupted, that the normality of the lifeworld becomes present (Seamon, 2013:145). Trigg (2012:25) better describes the notion as "a phenomenology of the uncanny". It is only when this pre-given normality is disrupted, for example by means of losing a home, becoming ill, the passing of a loved one etc., that the disturbance of the pre-given becomes very perceptible.

1.4.2.3 PLACE

Architects are increasingly adopting the concept of place, as meaningful and significant spaces in the creation of space (Jordaan, 2015:1) Seaman (2013:149) maintains that humans and their surroundings are interwoven. Place emphasises the close relationship between people and their worlds (Seaman, 2015:149) In *Emotional Geographies*, a distinction is made between land and landscape in an effort to explain the concept of place (Davidson, Bondi & Smith, and 2005: 77). Land is the physical tangible entity, whereas landscape refers to dwelling; where life patterns are uncovered and activities resonate with one another (Davidson *et al*., 2005:77).

Place is by no means an easy concept to grasp; it consists of several dimensions and was explored by Jordaan through a placial triad. The placial triad specifically looks at three dimensions: the lived dimension, material dimension and mental dimension of place (Jordaan, 2015:51). Yet the various dimensions of place are always bound to a person. In other words, place must be thought of as person-in-place, as suggested by Seamon.

Merleau-Ponty, a phenomenologist and follower of Husserl's work, was the first to highlight the importance of the body-in-the-world, body-subject, or the person-in-place notion. (Trigg, 2012:22). In *Neuroscience and Architecture: Seeking Common Ground*, it is further noted that there is a clear difference between space and place: place is situated within spatial environments where individual interaction is critical (Sternberg & Wilson, 2006:240). Merleau-Ponty noted that the body-subject is a collaboration of body gesticulations and corporal actions (Seamon, 2013:149). Place is therefore bound to bodily engagement.

Keeping in mind that place is bound to bodily engagement, I would like to discuss place in the three dimensions mentioned above as follows: a person's lived dimension, a person's material dimension and a person's mental dimension of place. These dimensions are closely intertwined, and in some instances also overlap.

1.4.2.4 DIMENSIONS OF PLACE

The lived dimension of place is bound to things happening to, and in place (Jordaan, 2015: 51). A person's lived dimension of place can be portrayed in the story of a man who reminisces over experiences and images of his childhood home on a farm (Davidson *et al*., 2005:217). The farm was redeveloped little by little to make way for a growing city; leaving only a few pictures and personal memories of what used to be: "*I get a feeling of panic, that my whole existence is thinned as the spaces of the past have been eradicated*"(Davidson *et al*., 2005:217).

Another analogy of a person's lived dimension of place is the relationship of the home environment in the life of a person with young-onset dementia. Mary, a lady living with dementia, had to forfeit her ability to organise her home to keep an intimate connection to her environment (Van Steenwinkel, Van Audenhove & Heylighen 2014:5). Mary had to trust that

caregivers would organise her laundry etc. in accordance to her standards, so that when she no longer had the capacity to remember or do it herself, the connection to her environment could be somewhat maintained.

The lived dimension of place can also be understood through Seamon's *time-space routines*. The time-space routines consist of a range of bodily activities that are performed over an extended period of time, such as getting ready for bed, going to church on a Sunday and having lunch (Seamon, 2013:149). These types of routines display the lived and spatial reality of the body in place (Seamon, 2013:149).

Physical attributes of such routines in certain spaces can be connected to the materiality of that space and routine. A person's material dimension of place has to do with physical characteristics of place that brings forth an experience of that place (Jordaan, 2015:51). It will be argued that material objects within a space greatly contribute to the making and understanding of that place. Many studies have been conducted that investigated geriatric living spaces; these studies are frequently more focused on safety and comfort as opposed to emotional well-being (Davidson *et al*., 2005:135). Many living facilities provide small compartmental living solutions, consequently allowing for little to no space for personal memorabilia and objects (Davidson *et al*., 2005:135). Material objects, such as clothes, clocks, photographs, ornaments etc., hold the ability for people to connect with other places or even hold a connection to a passed loved one (Davidson *et al*., 2005:136). The materiality of spaces and objects help to maintain personal bonds and the remembrance of people or even other places. In contrast, material objects can also be eradicated or changed in order to aid better living solutions. As in the case of Mary, the young-onset dementia patient mentioned above, the rearrangement of chairs and changing of wall paint colours in her home, helped to orientate and calm her (Van Steenwinkel *et al*, 2014:6). Keeping together her sense of place: *"The house contained "little worlds" for Mary, spaces that were narrow enough to provide a sheltering environment and that offered personal places where Mary had her belongings ready at hand."* (Van Steenwinkel *et al*, 2014:8).

The materiality of a space also holds the ability to evoke memory. Memories are essentially spatial; they are engraved in our bodies ready to be retrieved, although they also remain dormant and submerged in areas we are unaware of (Trigg, 2012:45). The spatiality of memory can even be evident in questions on how memories interact or coexist in areas of storage (Trigg, 2012:45). Do memories cross, circulate, encapsulate or just sit next to one another?

The present is not disconnected from the past; in fact, it is a continuation of interaction with memories of the past (Davidson *et al*., 2005:206). More importantly, memories have the ability to stir up emotions, images influencing events in the direct present. Subsequently, emotional spatial

experiences influence how we spatially operate and further experience the world (Davidson *et al*., 2005:206).

Memory is also bound to place. How difficult is it to remember a life-changing event that is not bound to a specific place? Or how do we remember a childhood home without a set of emotions that accompany it? It is impossible. The same can be said or asked about our imagination and dreams.

Memory and place endorse each other, but what happens when memories fades or gets lost? Dementia patients' memories often get disrupted, or become hazy and confused (Van Steenwinkel *et al*., 2014:3). The dream-world of people with dementia is very important, just as in studying mythology when looking at the Greek culture, as it directly affects a person's lived and material dimension of place (Van Steenwinkel *et al*., 2014:8). Theory, independent constructs and rationality should identify the role of emotions and memory as an edifice of the world (Davidson *et al*., 2005:206). In other words, rational organisation of material objects in a home and not necessarily a house (such as in the distinction between land and landscape), have a direct influence on the spatial practices of a person with dementia.

1.4.3 OCCUPANT CENTRED DESIGN AND DEMENTIA FACILITIES

With increasing statistics, showing that the current dementia population of forty-seven and a half million people worldwide are anticipated to increase to sixty seven million in 2030, it is evident that the need for dementia care facilities will grow (Mjørud *et al*., 2017:1). As previously mentioned, in South Africa approximately one hundred and eighty six thousand people are living with dementia with an expected figure of two hundred and seventy-five thousand by the year 2030 (Prince *et al*., 2016:96).

Occupant-centred design is a growing phenomenon within the architectural sphere and correlates with the notion of person-centred care. Person-centred care in dementia focuses on caring for the unique person as opposed to caring primarily for dementia (Mitchell & Agnelli, 2015:46). Similarly, occupant-centred design, for the purpose of this study, focuses on the occupant as the primary; where there is more to the person than their dementia symptoms and manifestations. Therefore, it can be argued that it's designing with an intricate balance to first consider the unique person, but also being aware of their dementia.

Maria Lenora Lehman (2010:18) notes that architects should understand how the human brain works in order to establish how occupants think, and how their needs can inform architectural design. Ironically, the consideration of human bodies in architectural design is often a gender, race and physically absent Cartesian body (Buse, Nettleton, Martin, & Twigg. 2017:1439). Even when architects design for an imagined body, they tend to draw on their own experiences and references for insight (Buse et al., 2017:1441). Unfortunately, architecture focusing primarily on

places for dementia patients, is still very poorly accommodated in South Africa (Prince *et al*., 2016:99). This accounts for both government, and non-government organisational facilities (Prince *et al*., 2016: 99). The reason for this may be contributed to the lack of professionals specialising in South Africa in dementia care; with fewer than ten geriatricians and five old-aged psychiatrists (Prince *et al*., 2016: 99).

In institutional facilities, such as dementia facilities, occupants can experience these environments as constricting and debilitating if it is not properly designed (Innes, Kelly & Dincarslan, 20-11:548). Innes *et al*. (2011:548) states: "*People with dementia are users of the physical environment, therefore just as quality of care can impact on their experiences, so can the quality of environmental design*". Hence, if a building is designed with the occupant as the central focus, the building has the ability to promote well-being (Innes et *al.,* 2011:548). Maria Lenora Lehman (2014:9) confirms this ability of a building to promote well-being for aging occupants: "*Find ways to use the design of their environment to make possible what may not have been possible in their "other" space. You aren't just designing a building; you are designing architecture that makes a positive difference.*" In an evidence-based study conducted it is proven that people with dementia have a better quality of life in special care facilities as opposed to traditional care facilities. (Marquardt, Beuter, & Motzek, 2014:133). This evidence-based outcome is based on randomised well-designed experimental studies with results compared to parallel studies, and case-controlled studies conducted through literature reviews and theoretical frameworks (Marquardt *et al*., 2014:130). This outcome can possibly be attributed to design that promotes a positive difference. Investigation of occupant-centred design driven by narrative, through collecting and understanding the occupant's story, will enable architects to design for a positive difference (Lehman, 2014:9). Therefore, architects should take time to listen and gather the life stories of the occupants they design for.

Further concepts that emerged from previous studies, which are essential to the phenomenological composition of place, are listed as follows: identity, quality of interaction, sense of belonging, privacy, personal belongings and loneliness (Mjørud *et al.*, 2017:1). Many occupants of dementia facilities cope by merely accepting their fate and trying to make the best of the situation (Mjørud *et al.*, 2017:1). In *Mary's Little World's*, similar aspects are noted as the author states that people living with dementia often lose their relationship with the world, and effectively also their extended consciousness thereof (Van Steenwinkel *et al*., 2014:8). Practical implications of such results can be attributed to buildings and spaces that do not provide secure spaces for personal belongings, privacy when staff enters bedrooms and adequate outdoor spaces (Mjørud *et al.*, 2017:6). Consequently, building design should not be merely centred on control and surveillance, but rather endorse engagement (Innes et *al.,* 2011:548). The description of a home lies in the distinction it provides from any other person's

home. When dementia occupants were asked why they preferred the specific facility they were situated in, it was noted that occupants felt it did not matter as most facilities are generally the same (Innes et *al.,* 2011:549).

In addition, dementia care, especially in the Netherlands and United Kingdom, is increasingly leaning towards person-centred dementia care (Ryder, 2016:465). Person-centred dementia care focuses on involving patients and families in decisions regarding care protocols, consideration of personal history and ensuring a "sense of belonging" (Ryder, 2015:465). In the Netherlands, the Dutch Government has funded an alternative to traditional Dementia care. This care facility is described by Jenkins & Smythe (2013:14) as the: "Hogewey Alternative". This radical care facility, Hogewey Village, concentrates on how to create a sense of place for dementia patients. The aim is to improve the quality of life for dementia patients by engaging them in a community setting, considering their specific backgrounds and enabling patients to take care of themselves as far as possible (Planos, 2014). The thinking behind the design of the village is to enable people living with dementia to freely roam the environment and to be able to sustain and run their own households as controlled residents of the village (Chrysikou, Tziraki & Buhalis, 2018:16). Residents are able to move freely and independently, with grocery shops, theatre, coffee shops and streets to mimic the life of a village, or small town (Chrysikou *et al*., 2018:16). This promotes maximum independence for residents where caregivers are dressed as civilians or rather as a part of the community (Chrysikou *et al*., 2018:16).

Research indicates that there can be connections between significant memories and neural connections of the brain through interventions such as smell, sound or vibrations (Lehman, 2014:18). Perhaps the neural connection triggers can possibly enhance placial possibilities for dementia-architecture. Such design approaches that involve light, objects of orientation, and redesigning of corridors etc., seem to also seek for outcomes of a sense of place by creating practical and comfortable environments (Marquardt *et al*., 2014:141). Design interventions, as mentioned above, deem to be individualised, where the degree of response on the various interventions is dependent on a patient's background and severity of dementia (Soril, Leggett, Lorenzetti, Silvuis, Robertson, Mansell, Holroyd-Leduc, Noseworthy & Clement 2014:10). Moreover, it is important to note that some facilities claim to be dementia-friendly, although the design is not evidenced-based, resulting in a possible failure when evaluated in accordance to the Stirling Principles (Greenhouse, 2012).

The Sterling Principles are based on the complex working and understanding of the brain, researched in the field of neuroscience. Neuroscience, especially when combined with architecture, can shed light on scientific ways to design creative spaces, and teach architects about the inner workings of the human mind and behaviour (Lehman, 2010:17). The Sterling

Principles attempt to establish how to better design through using neutral design principles (Sterling & Laughlin 2015: xv). The process of deriving these neural principles in design is also referred to as "reverse engineering" (Sterling & Laughlin 2015: xv). In other words, only starting to design, or designing only when the complexity of the brain is studied in reaction neural design. The reason why neuroscience can offer such intricate understandings is due to the fact that it has the ability to unite architecture and technology (Lehman, 2010:19). Innovation is found where architecture, technology and architecture overlap (Lehman, 2010:19).

1.5 RESEARCH DESIGN

1.5. 1 INTERPRETATIVE RESEARCH

Jürgen Habernas offers three divisions of cognitive interest: firstly *empirical-analytical interest*, secondly *historical-hermeneutic interest*, and thirdly *critically-orientated* interest (Du Plooy-Cilliers, Davis & Bezuidenhout 2014: 21). For the purpose of this study, historical-hermeneutic cognitive interest is best suited for the in-depth understanding of the phenomena of the philosophical position of phenomenology as well as the nature of the dementia. The reason for this is that interpretative research methodologies allow for understanding and meaning of the human as the centre of explanation (Du Plooy-Cilliers *et al*., 2014:27). People make sense of their worlds and environments through language, objects, space routines and interaction. People also attach value to these sets of sense-making systems. Hence qualitative data allows for richer descriptions in order to gain the insights necessary for understanding the phenomena.

By investigating literature that possesses various ideas, theoretical constructs can be uncovered, relating to each other and then illuminating a theoretical conceptual model. The theoretical conceptual model will set the basis in order to derive design concepts in the form of design considerations. Qualitative research methodologies allow for flexibility as the nature of the study is concerned with the phenomena of human experience, narrative and perception of place. The qualitative research will therefore contribute to better inductive research outcomes.

1.5.2 DESIGN ETHNOGRAPHY

Ethnographic research allows the researcher to better understand a particular culture through the direct understanding of the people involved in their lived space. In other words, knowing and understanding human behaviour in relation to the context or in relation to the environment it occurs in (Du Plooy-Cilliers *et al*., 2014:176). Whereas design is concerned with creating, changing and improving for a means of function, system or service (Ylirisku & Buur, 2007), design ethnography allows one to understand the context and intricacies for which architects ought to design for, while identifying design objectives.

For this study, design ethnography is used to understand the future users of dementia facilities. This research method will allow the researcher to identify with dementia patients from the perspectives of informal caregivers, family and professional caregivers, identifying their experiences and views. Ethnographic research allows for the understanding of people with dementia from an intricate perspective while uncovering the structure and relations that govern their experiences. The design ethnography is done in four phases as outlined and discussed below.

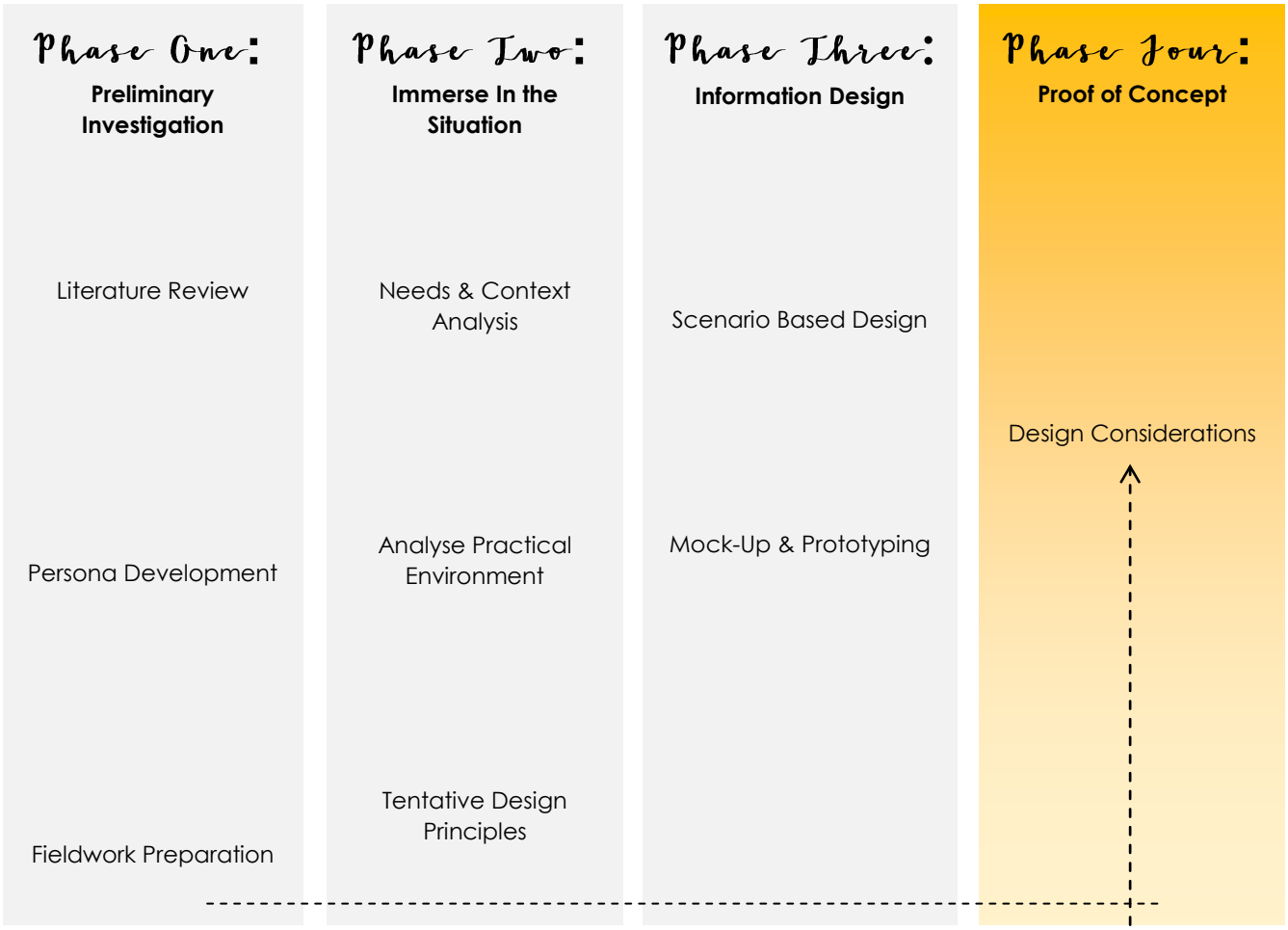


Figure 01: Design Ethnography Diagram

1.5.2.1 PHASE ONE: PRELIMINARY INVESTIGATION

A) Literature Review and concept validation in order to determine the current knowledge available and the state of dementia facilities.

B) Problem Identification in Context

The space, for the purpose of this study, will be one non-governmental organisation dementia care facility in Cape Town, South Africa. The reason for looking at a non-governmental organisation care facility is due to the fact that they are usually more user focused (Buse *et al*., 2017:1450). The target group that will be included in the study will be primary caregivers, family and professional caregivers.

C) Persona Development

Dementia personas developed is used as probes for the collection of data in phase three. The dementia personas are used in scenario-based design sessions as well as mock-up and prototype sessions as Ethnomethodology's basic premise (Crabtree, Rouncefield & Tolmie, 2012:2). In other words, to uncover the daily routines and lives of people living with dementia. The personas are specific for a non-governmental facility in the South African Context.

C.1) Literature Review

Literature was reviewed to identify elements of dementia facilities; the challenges that dementia care providers experience; and the underlying characteristics of people living with dementia as well as dementia as a syndrome. The review of the literature serves as the basis for the development of the personas.

C.2) Iteration One

Iteration one was done to develop an outline of a dementia persona; consequently, a dementia persona template based on the literature reviewed was developed.

C.3) Iteration Two

Expert input is gained in iteration two in order to establish if the template developed can be used for the collection of data.

C.4) Iteration Three

Further expert input is gained to establish if the persona template, and ultimately personas' information is correct, applicable and relatable for the collection of data.

D) Fieldwork Preparation

In order to collect data at a non-governmental dementia facility it was needed to find a facility that is open and available for the collection of data. Consequently, three dementia facilities were contacted, of which only one was willing to participate. As a result, the head manager of the facility as well as the matron gave a letter of permission that was submitted to the ethics committee in order to proceed with the research.

1.5.2.2 PHASE TWO: IMMERSE IN THE SITUATION

A) Needs and Context Analysis

The non-governmental facility is a nursing home facility consisting of apartments, free standing houses as well as a frail care facility with a complete separate ward for people living with dementia. The main focus for the data collection process is the frail care unit with the dementia ward. It is necessary to understand the environment before interacting with staff; this will allow for the correct approach for scenario-based design and mock-up prototype sessions.

B) Analyse Practical Environment

The practical environment is intricately studied through observation studies to establish how and when the best time will be for scenario-based design and mock-up prototype sessions. It is also studied to gain better insights through observing daily activities and routines first hand. Apart from the sessions mentioned, observation studies are also an important part of design ethnography. As for anthropologists, who often use design ethnography as a research methodology, observation for architects is also very important. It is through observation where one grasps and feels the world of those one is studying; to understand how their worlds are assembled and how it can be reassembled (Crabtree *et al*., 2012:16). Consequently, observation studies form an important part of the research methodologies.

C) Tentative Design Principles

The nature of the study is concerned with the phenomena of human experience, narrative and perception of place. The phenomena of experience, perception and narrative are something that is not necessarily treated chronologically or paradigmatically. Therefore, the use of the framework, developed by Jordaan, is a means to thematically organise and interpret data, but also to use as an analytical lens to gain essential insights. The framework has been adapted to stress the importance of an occupant-centred design approach. The framework will merely be used to explore the various dimensions of place and to guide the research process. Consequently, the study will not test the framework, but will be a means of thematically organising data and viewing information through a specific lens. However, it is important to note that other emerging themes will also be used for the thematic framework analysis, since only

using the framework might risk missing interesting findings. Phenomenology is a very broad field and therefore the placial triad, developed by Jordaan, focuses on specific dimensions of place which is relevant to architecture. There are three dimensions of place in this placial triad.

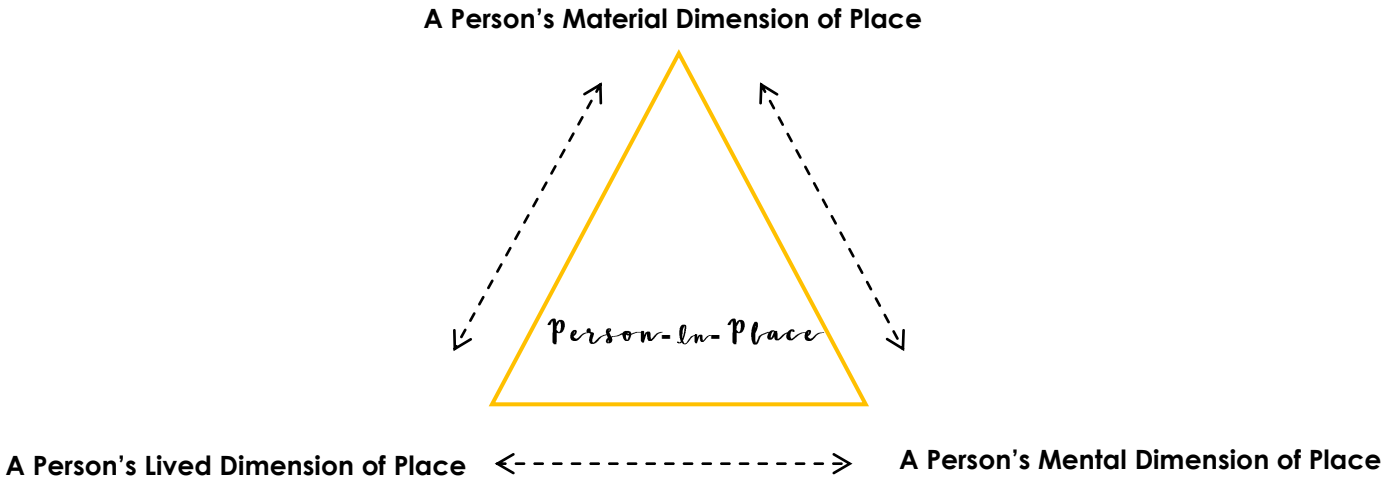


Figure 02: Adapted Placial Triad for Interpreting Dementia Facilities (Jordaan, 2015: 53)

The first dimension is the material dimension of place. This dimension has to do with physical characteristics of place that brings forth an experience of that place (Jordaan, 2015:51).

The second dimension is the lived dimension of place. This dimension is not stagnant; it has to do with things happening in and to places that influence our experience thereof (Jordaan, 2015:52).

The third dimension is the mental dimension of place. It is about memories of place, our imagination and perception of place. It is also about how we project our perception, imagination and dreams onto places (Jordaan, 2015:52).

A second model that will be used in the thematic framework analysis as an analytical lens is the person-environment-occupation model. It is a very popular model used to access and enhance the occupational abilities of people. The model consists of three entities namely: the person, the environment, and the occupation. The model aims to elucidate the occupational performance of a person (Strong, Rigby, Stewart, Law, Letts, & Cooper. 1999:123). This is done by looking at the person as an individual that encompasses a person's cultural, historical, physical and mental status (Strong *et al*., 1999:123). The environment is evaluated as the physical entity in which the person is situated, as well as where the occupation is occurring. The occupation is the point of importance in order to establish, in coordination with the person and environment, how the specific task at hand is performed and how well it is performed (Wong & Leland, 2018:2). Lastly,

the model is also used to track the occupational output of the daily lives of people, which inherently connects to the concept of the lifeworld.

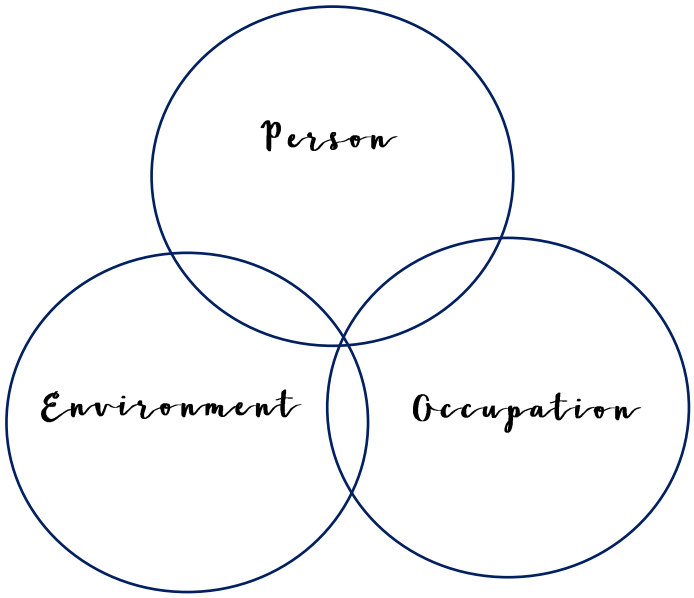


Figure 03: Person-Environment-Occupation Model Wong & Leland (2018: 2)

1.5.2.3 PHASE THREE: INFORMATION DESIGN

A) Scenario-Based Design

The scenario-based design consists of affinity sessions that are conducted in two sessions with caregivers of the non-governmental dementia facility. The sessions are structured by using the personas as probes where certain questions and scenarios are used to uncover placial understandings. The sessions and the respective questions or scenarios are structured in line with the two theoretical models.

B) Mock-up and Prototyping

The personas will be used as probes in a mock-up session with two professional architects. The session comprises the mock-up of a home for each respective persona with Lego blocks in order to look at how architects understand and design for people with dementia.

1.5.2.4 PHASE 4: EVALUATION OF PROOF OF CONCEPT

A) Design Considerations

The data collected using the various research methodologies will be used to develop architectural design guidelines for the design of dementia facilities. The data gained through the investigation of the personas will be analysed in stage one, using the person-occupation-

environment model and the placial triad. The data derived from stage one will be used in stage two to create design considerations for architects. The data collected from the ethnographic methods will be used to derive the findings, and consequently discuss the findings.

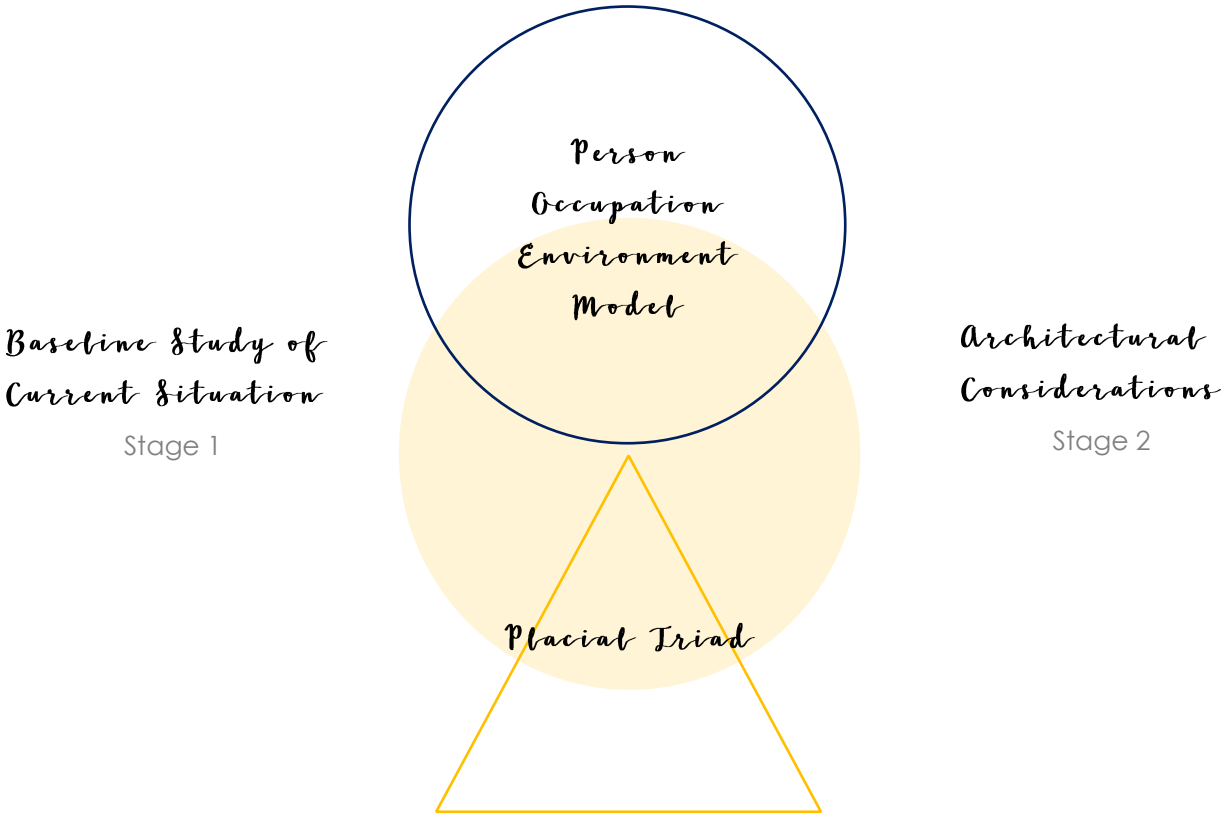


Figure 04: Proposed Method of Data Analysis and Development of Guidelines

1.5.3 RESEARCH PLANNING AND PREPARATION

With the establishment of the final persona templates a research plan was drawn up to ensure that the data collection process was well-planned and prepared for. The plan was organised in a tabulated structure looking at: methods, materials to be used for capturing data, and aims to ensure relevant data collection. The plan was sent to the study leaders of this paper for consent prior to commencement with data collection. NRFC consent forms were also prepared and it was established that the data collection process would start with observation studies to slowly become familiar with the facility, as well as enable caregivers and other staff of the facility to get used to me and ask questions should they feel the need to. Prior to commencement with the data collection the matron of the facility briefed all staff particular of the day of my whereabouts and intentions. It is also important to note that staff members at the facility work in day and night shifts as well as weekend and week shifts.

TABLE 02:

	STAKEHOLDER	ACTIVITY	METHOD	DURATION	OUTCOME	MATERIALS
1	Caregivers, Family and other Facility Staff.	**Observation Studies**	Drawing, photographs and writing.	2-6 hours	To obtain and understand the connection between the environment and activities and dementia patients.	Camera for capturing the environment. Notebook/journal and pens for making field notes and drawing of architectural diagrams.
2	Caregivers	**Scenario Based Design =Affinity Sessions:**			To uncover stories and insights through the perspective of caregivers.	
		a) Introduction - short explanation about the research and the personas.	Discussion	10 min		
		b) Icebreaker		5min		
		c) Questions	Predetermined questions in line with the Placial Triad and PEO Model.	5min		Posters with Personas.
		d) Answering questions	Write findings/ and answers	15min		Post-its and A4 papers to write and draw on.
3	Caregivers, Family and other Facility Staff.	**Informal Interviews**	Discussion/conversation (no formal prepared questions) Personas to be used as prompts to identify the type of dementia relevant to the discussion.	10-15 min.	To build a narrative and get "snapshots" of the lives of moderate and severe dementia patients.	

4	Professional Architects	**Mock-up and Prototyping**				
		a) Introduction - short explanation of the research and the personas.	Discussion	10 min.	To establish a basis and start a point of reference for the mapping process.	Video Recorder: to capture participants discussion and actions around the whole mapping exercise.
		b) Mapping the daily life of a dementia persona in accordance to morning, mid-day and evening routines for a specific persona.	Physical building of a space individually	40min.	To establish the material environment and human interaction in order to seek placial understandin g. To identify objects and concepts and that play an integral role in the daily routines	Clock/Timer: to keep track of activities Lego to map and build the physical environment in accordance to the routines
		c) Concurrently with the mapping identify key concepts and discussing them: -Action -Pain points -Touch points -Dreams and Needs	Writing key concepts on paper.	15min.	To discuss and understand what objects and concepts belong where and why. The formalisation of the concepts will also help streamline data analysis.	A4 papers and pens

1.6 DELIMITATIONS

The main focus of the study is a phenomenological investigation of dementia care facilities. Therefore, the study will interpret findings in accordance to the proposed placial triad and the person-environment-occupation model in order to discover overlapping new possibilities. It is important to note that the study does not intend to exclusively test the placial triad or the person-environment-occupation model, as it is only a means for interpretation of data. Coherently, the table provided below outlines subjects that will not be discussed, as it does not aid the phenomenological investigation of dementia facilities.

TABLE 03:

SUBJECT	REASON
Drug Therapy/ Medications used to alleviate dementia symptoms.	The study focuses on the phenomenological aspects of dementia facilities.
Home-based/ private care.	The study focuses on intuitional type care facilities as these types of facilities often pose problems with the key phenomenological concept of the study: "a sense of place".

1.7 ETHICS

In accordance with Welman, Kruger, & Mitchell (2005:201), the following ethical principles should be considered when doing design ethnographic research:

a. Informed Consent
b. The right of privacy
c. The protection from any harm
d. Participation of the researcher

The study will adhere to the above-mentioned ethical principles, while acknowledging that mental illness is in fact a pivotal point of consideration.

1.7.1 INFORMED CONSENT

People living with dementia are not necessarily competent to understand and give consent. Approval will be sought from the relevant authorities for observing people living with dementia. Under no circumstances will people with dementia be directly involved in the study. The personas will not be based on a specific person, but rather a representation of the characteristics of a person with a specific stage, stage four to seven, of dementia. Consequently, people with dementia will be studied through the eyes and experience of the proposed target group.

All participants will be informed both verbally and in writing. Consent forms can contain much writing and unfamiliar jargon, proving to be very difficult to understand. Therefore, consent will be thoroughly explained, pausing at each point to check the understanding of the undertaking (Byrne, 2014:49).

1.7.2 THE RIGHT OF PRIVACY

The identity of all participants involved will be protected by keeping their personal information confidential. In assuring confidentiality, it is meant that the identities of the participants will only be known to the researcher and that their identities will not be revealed in the research (Cilliers *et al*., 2014:268).

1.7.3 THE PROTECTION FROM ANY HARM

All participants will be protected and not subjected to any form of harm; physically and emotionally. As noticed in other studies where patients with mental impairments have been researched, some patients and family members have willingly over-disclosed themselves, or have silently unwillingly participated in the study due to various reasons (Byrne, 2014:50).

The decision of excluding persons with dementia as participants in the development of dementia personas is a practical decision and does not mean that their participation is not important (Swaffer, 2014:714). There is no health professional in the team conducting the research to supervise and to look after the interests of persons with dementia as would be required by the ethics board of the university. Additionally, it is also important for me as the researcher to ensure no stress and harm is caused to people living with dementia as a result of the research.

1.7.4 PARTICIPATION OF THE RESEARCHER

I, the researcher, will undertake not to produce unethical research as set out in the following unethical demarcations in accordance with Cilliers *et al*., (2014:269) and Welman *et al*. (2005:201):

a. Distortion and fabrication of information to suit the study subsequent to biased beliefs or understandings.
b. Misusing of information for any other purposes other than the purpose of this study.
c. Using inappropriate research methods that are not suited to this study.

1.8 CONTRIBUTION TO THE RESEARCH

This study will specifically look at how architects can understand and interpret facilities for dementia, by looking at and understanding the concept of place in its various dimensions. The understanding of dementia facilities, through place, aims at architects creating better future spaces and ultimately places when designing for people living with dementia. Therefore, the research will aid in a solution of a practical problem in the field of architecture. Most importantly the research will contribute to providing insight and solutions for dementia facilities in South Africa by developing design considerations for dementia facilities. This research can also provide some insight into other fields relating to dementia such as nursing and other medical and psychological realms.

Chapter Two

ARCHITECTURE, PLACE, REALITY AND DEMENTIA – A LITERATURE REVIEW

2.1 LITERATURE APPROACH

In *Constructing Place* Jordaan (2015:10) contends that architectural education teaches notions of place-making, but how it is exactly done remains unclear. Place-making receives isolated treatment in architectural education in relation to other constructs such as space and form-making (Jordaan, 2015:10). As an architectural student I was also taught notions of place-making intertwined with notions of space; this resulted in a confusion of space and place. This confusion, also partly being responsible for this study, was further expanded for me as a practising architectural technologist and student of architecture to uncover how the academic investigation of place can be used in practice, especially in design considerations for people living with dementia. In order to understand place as a part of user-centred architectural design considerations for a non-government dementia facility the literature will be reviewed in two parts. The first part will deal with architecture, notions of place and the realities endowed within the architectural practice. The second part will focus on the design of caring facilities for people with dementia and emerging design strategies that interrelate with occupant-centred design concepts. The literature is an extension of the concepts discussed in the introduction of this paper.

As a point of departure for the review of the literature, I will start at looking how architectural ideas are conceived, taught and engaged within architectural training as well as practice, and from there uncover spatial and placial understanding. This understanding will build on the key phenomenological concepts discussed in the introduction through the review of various architectural literature, drawing on space and placial understandings. In juxtaposition to the discussion of spatial and placial literature I will also look at problematic notions in architecture, such as form-making, the Bilbao effect and ocularcentrism.

With a good understanding of architectural methodologies, philosophical underpinnings and the problem within the reality of architectural practise, design for dementia facilities can be reviewed and understood in reference to these ideas and problems in part two. I will also include literature on continuous and renewed architectural discourses related to dementia and placial development in part two as a means of demonstrating practical architectural insights. Please note that additional literature is reviewed in chapter three for the development and understanding of dementia personas; this literature focuses primarily on the characteristics of the dementia syndrome as well as how it manifests in people living with dementia and will therefore not be discussed as a part of this chapter

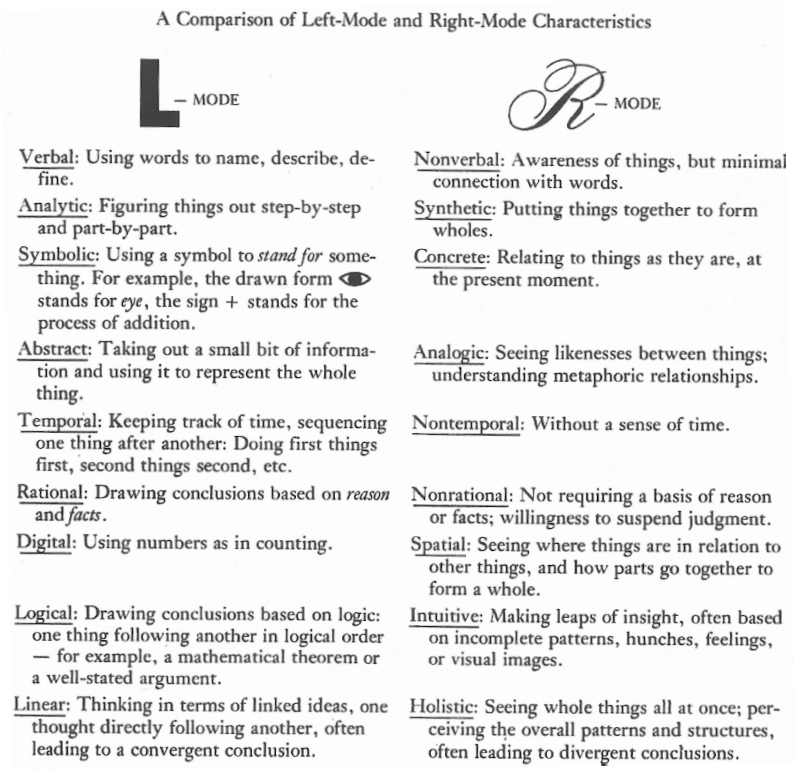
2.2 PART ONE

2.2.1 CONCEPTION OF ARCHITECTURAL IDEAS

"Design is a process: it implies that it is active and dynamic, not static. It is a doing thing rather than a knowing thing" and *" …of engaging with a problem or a set of problems: This means that an essential aspect of design is to determine what the problem is."*

(Righini, 2000:156)

When we as architects know what the problem is, we can start to solve it by means of various processes. In the process of solving problems we create and conceive ideas. According to Paul Righini (2000:165) ideas are generated in two major ways. It is generated using rational references such as context, programme and precedent studies that relate closely to one or all parts of a building such as: programme, typology, materiality and context. The second way of generating ideas is a non-rational way through actions such as illustration, building models and collages (Righini, 2000:165). Samdanis & Lee (2017:75) confirming that architecture is a synthesis of processes and structures that originate through conceptualisation that is inherent to an architectural school of thought driven by a specific problem.



A Comparison of Left-Mode and Right-Mode Characteristics

L – MODE	R – MODE
Verbal: Using words to name, describe, define.	Nonverbal: Awareness of things, but minimal connection with words.
Analytic: Figuring things out step-by-step and part-by-part.	Synthetic: Putting things together to form wholes.
Symbolic: Using a symbol to *stand for* something. For example, the drawn form 👁 stands for *eye*, the sign + stands for the process of addition.	Concrete: Relating to things as they are, at the present moment.
Abstract: Taking out a small bit of information and using it to represent the whole thing.	Analogic: Seeing likenesses between things; understanding metaphoric relationships.
Temporal: Keeping track of time, sequencing one thing after another: Doing first things first, second things second, etc.	Nontemporal: Without a sense of time.
Rational: Drawing conclusions based on *reason* and *facts*.	Nonrational: Not requiring a basis of reason or facts; willingness to suspend judgment.
Digital: Using numbers as in counting.	Spatial: Seeing where things are in relation to other things, and how parts go together to form a whole.
Logical: Drawing conclusions based on logic: one thing following another in logical order — for example, a mathematical theorem or a well-stated argument.	Intuitive: Making leaps of insight, often based on incomplete patterns, hunches, feelings, or visual images.
Linear: Thinking in terms of linked ideas, one thought directly following another, often leading to a convergent conclusion.	Holistic: Seeing whole things all at once; perceiving the overall patterns and structures, often leading to divergent conclusions.

Figure 05: Left and Right Brain Characteristics for Rational and Non-Rational Processes of Design

(Righini, 2000:187)

Noble (2014:114) elaborates on this process when looking at architecture and identity in a post-apartheid South Africa by noting that the design process consists of a series of interactions with representations, ideas, documents, but most importantly humans. In a further explanation it is noted that this means of making is not unique to architecture, nevertheless architects are trained to understand the process as an open-ended process (Noble, 2014:115). This notion is imprinted in the rational and non-rational processes. Righini (2014:188) explains that there is an interrelation of the two processes through an incessant shift between the right and left cortex of the brain; where design is the ability to analyse and imagine. This process is imaginably and inevitably open. In architecture it's the opportunity to change possibility into purposeful action (Noble, 2014:115).

Recently architectural design and its processes have gained the advances of digital technology. The digital component is a paradigm shift in architectural design from the industrial epoch to the information age (Samdanis & Lee, 2017:74). In constructing place this also referred to as the scientific paradigm (Jordaan 2015:154). The inclusion of digital technology is often associated with Deconstructivism; an architectural movement pushing design conceptions and methodologies (Wilkinson, 2010:196). Deconstructivism is also associated with the term "free form architecture." According to Wong (2010:240), in his review of four Deconstructivist architects or rather free-form architects, the digital process "*legitimises*" intricate and complex forms by allowing architects to have control over them. Frank Ghery, Zaha Hadid and Peter Eisenman have all used digital processing in practising architecture. The conception of the Bilbao Guggenheim museum by Frank Ghery would not have been possible without the inclusion of digital advances (Wilkinson, 2010:240) Digital media have the ability to convey information to its users in a clear, concise and rational manner, making the information accurate and efficient, allowing users to understand and formalise the construction of such complex buildings such as the Bilbao Guggenheim Museum (Samdanis & Lee, 2017:76). Zaha Hadid also created new building conceptions through using open-ended software that converts sketches into information (Samdanis & Lee, 2017:75). The translation of design information to data is known in architecture as parametric design (Samdanis & Lee, 2017:76). Peter Eisenman has in fact developed software that allows architects to design through interacting with it, also known as remediation, in other words human and computer interaction (Samdanis & Lee, 2017:75).

What is strikingly dialectical about parametric design is Righini's (2014:188) inference on a designer's cognitive shift; where too narrow descriptive analyses is unproductive in the generation of imagery, or where overtly imagined imagery is not susceptible to reason; consequently the designer's ability is to do both. Digital processing is either aiding or destroying the process, reason and ability of the designer. Samdanis & Lee (2017:75) notes that parametric design merely returns control to architects where digital tools are a means of including more agents in the design process. These additional agents seem to be a problem for Juhani

Pallasmaa. In one of many of Juhani Pallasmaa's books, T*he Eyes of the Skin: Architecture and the Senses* (Pallasmaa, 1996:12), he argues that the implication of digital agents comprehensively diminishes the designers' sensory abilities. As Tamari (2017:91) confirms it is digitally rendered images that deteriorate primary sensory modes, with the exception of sight. It is the digital object that excludes the body from engaging in the design process where a gap is created between the body and object due to vision dominating the process (Pallasmaa, 2009:97). This split between the body and mind, or rather where the mind takes precedence over the body, has been adopted in architectural discourse (Jordaan, 2015:154). This notion is also known as the Cartesian split of mind and matter which is responsible for creating dysfunctional and hostile buildings (Jordaan, 2015:154).

It is quite clear that the conception of architectural ideas has close references to the discourse of phenomenology; the shift between rationalisation and fantasy. Drawing back to Merleau-Ponty, importance of the body-in-the-world, body-subject, or the person-in-place notion Pallasmaa also agrees that the body is a pivotal part of the conception of architecture. When drawing, the object is in direct contact with the skin; there is a constant shift between the left and the right cortex intertwined with the motion of the hand and arm drawing (Tamari, 2017:93). When this automatic process occurs, without digital agents processing information, the image emerges as an automatic projection of the mind; known as "the ecstasy of work" (Pallasmaa, 2017:104). It is muscle memory, an automatic response of the body remembering and transferring emotional, spatial and placial qualities (Tamari, 2017:93). Though somewhat different, it also closely related to what Seamon & Nordin (1980: 35) refer to as place-ballet; where muscle memory inherently draws to, reacts to, and remember spatial and placial nuances. In Constructing Place, Jordaan (2014:156) refers to Peter Zumpthor, with whom she conducted an interview, noting that architects often feel the need to explain and rationalise how their ideas were conceived or why a building is a certain way, rather than speaking about their surreptitious desire that inspired it. It is in memory of our bodies and as Jordaan explains (2014:156) that we perceive places, and consequently rely on to conceiving ideas.

2.2.2 UNRAVELLING SPATIAL AND PLACIAL THEORY

In architectural discourse space seems to be very important and often concentrated on. The creation, interpretation and one's position towards space have been something that was heavily concentrated on during my architectural education. It was only through the investigation of the literature that I have gained insights and began the process of unravelling space and place; finding why they are different and where they long for integration. In the introduction of this paper I enunciated that space is the environmental setting whereas place refers to dwelling and the uncovering of the lifeworld within that setting. In order to understand this distinction made I will start by discussing how space is used and understood in architectural theory.

Jordaan (2015:35) notes that space is a realm without meaning; something that refers to geometry and volumes. It is noted that in *Constructing Place* the word space is used throughout the dissertation with the inference that it includes meaning, thus that space is included in the configuration of place (Jordaan, 2015:35). This notion is very much alike in various architectural readings where space and meaning are often intertwined without mentioning place. Steven Holl's conception of space closely relates to this notion where space is described in his work Parallax (2000:22) as being "both intrinsic and relational." What he means by this is that space, especially in architecture, can be very rational, formal, and bound to material and geometry. Alternatively, it can also be intrinsic, illogical and ineffable as it is also bound to the human as the centre of space (2000:10). In the same way Laszlo Moholy-Nagy notes that space is a reality that is experienced through the senses that can be understood and arranged in accordance to its own laws (Moholy-Nagy, 1939:162). He notes that a point of departure to understand space is physics by understanding space as the relation between the localities of bodies (Moholy-Nagy, 1939:163). In other words, space is the creation of relationships in reference to the human body (Moholy Nagy, 1939: 163). These relationships refer to physical objects, bodies, moving and extending through space and understanding space through all the senses. Holl takes it further by introducing the concept of the elastic horizon where imagination is the only limit to spatial creation (Holl, 2000:10). It is perhaps this elastic horizon that Zumpthor refers to in questioning why architectural students often feel the need to rationalise their thought process and designs. The following quote contextualises the dynamic of the elastic horizon where the senses are connected and feelings are related to thought processes, and subsequently space. *"In the twenty first century, the horizons of our fundamental experiences have expanded and continue to expand. We experience and think differently, therefore we feel differently. How elastic is our minds? How far can we stretch them?"* (Holl, 2000:10)

The paradox for Bernard Tschumi is between the real and the ideal. Drawings and concepts as the ideal in contrast the experience of the everyday or what reality makes as the real. Tschumi contends that the combination of space and movement creates event (Tschumi & Walker 2006:119), as consequence architecture for Tschumi constitutes what happens in space (Bernard Tschumi Architects, 2019). The Manhattan Transcripts is an exemplary example of Tschumi's paradox between the real and the ideal; the drawings are not depicting reality, but are also not fiction (Bernard Tschumi Architects, 2019). The drawings are greatly influenced by the introduction of the camera and cinema in architecture. Film played such an important role in the development of the Manhattan Transcripts and found its importance when Bernard Tschumi discovered a body of literature about film in New York. He tried to find parallels between what was already done in film and what he was trying to achieve in architecture. There was an interest in montage as opposed to composition that had already been done by so many

architects such as Le Corbusier. Accordingly, film brought about the interest of a dynamic component in the debate of space through event or movement in the Manhattan Transcripts.

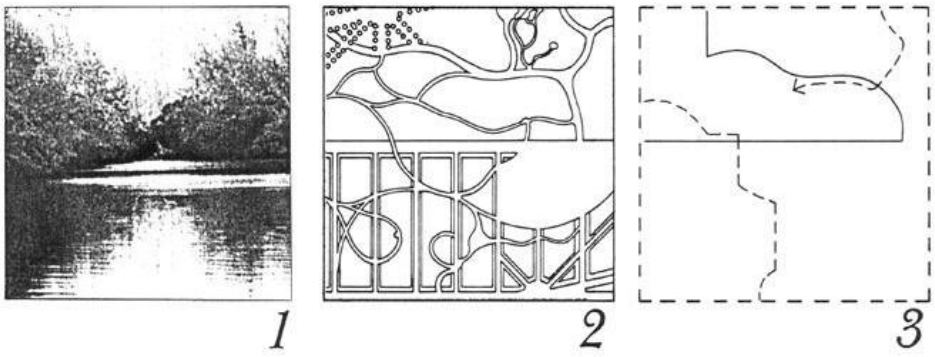


Figure 06: Translations of the Natural World as Interpreted for Different Perspectives (Bernard Tschumi Architects, 2019)

In the figure above there are three translations of the image, the first is the environment as naturally seen, the second is the environment abstracted in architectural means of representation and the third is an abstract diagram indicating movement. Although Bernard Tschumi is considered a deconstructivist, it is important that his notion in deconstructing space, event and movement allows him to see the new relationships between these components in their independence (Bernard Tschumi Architects, 2019). Tschumi's wish to develop a new definition of architecture was a conscious one; the past always referred to architecture as a static thing where Tschumi aimed and at defining architecture as a dynamic mechanism through the implication of event. The following quote displays the meaning and ground-breaking implication the *Manhattan Transcripts* had for Bernard Tschumi and his understanding of architecture: "*I would say that my work is about designing the conditions, rather than conditioning the design. In other words, if I take a certain spatial condition and combine it with a certain programmatic condition in a certain way, that relation might help me design the conditions for an event to occur. But ultimately that will always be an unknown because events are not predictable in any way*." (Tschumi and Walker, 2006:119)

With reference to meaning Christian Norberg-Schulz was the first author in my spatial exploration as an architectural student who writes about space with meaning in *The Phenomenon of Place*. There is a definite shift from space to place making with reference to what is known as *genius loci*. The term *genius loci* according to Righini (2000:228) were referred to as the "spirit of place" by the ancient Romans. There was a belief, by the ancient Romans, that it was necessary for survival to mediate a healthy relationship with place in the physical, spiritual and psychological

sense (Righini, 2000:228). The differentiation between land and landscape, as introduced in the beginning of this paper, is noted by Norberg-Schulz (1976:414) as an all-inclusive phenomenon. According to Norberg-Schulz (1976:414): "*A place is therefore a qualitative 'total' phenomenon, which we cannot reduce to any of its properties, such as spatial relationships, without losing its concrete nature out of sight.*" This concrete nature is what enables people to dwell; it's as if architecture brings together elements of the lifeworld. This concretising of the lifeworld is distinguished in *Constructing Place* by Jordaan (2015:44) at looking at the fourfold and how architecture possesses the ability to create place. Jordaan, similar to Norberg-Schultz, uses Heidegger's analogy of a poem to illustrate how emotion and concrete environments are merged through language. It is important for architects and planners to understand the world as poetry does, beyond objective scientific analysis, in order to concretise the totalities that evade science (Norberg-Schultz, 1976: 415). It is about understanding the lifeworld, the things that are so evident but not captured by scientific analysis.

A Winter Evening

***Window** with falling snow is arrayed,*

long tolls the vesper bell,

*The **house** is provided well,*

*The **table** is for many laid.*

Wandering ones, more than a few,

*Come to the **door** on darksome courses,*

Golden blooms the tree of graces

Drawing up the earth's cool dew.

Wanderer quietly steps within;

*Pain has turned the **threshold** to **stone**.*

There lie, in limpid brightness shown,

*Upon the **table** bread and wine.*

-Georg Trakle-

(Norberg Schultz, 1976:415)

The words in bold in Trackle's poem showcase how architecture concretise the intangible. Ironically it is the materiality that enables light, darkness and an atmosphere to become present, nevertheless this sensation is captured and explained so vividly through literature. Architecture is able to revive and create space with distinct character- place (Righini, 2000: 281). It is like the entrance to a building, shapes our perception and expectations of it, influencing how we perceive what is to be found or experienced on its inside (Hornecker, 2005:1). In *Space and*

Place: Setting the Stage for Social Interaction Hornecker (2005:1) continues to say that places have an atmosphere as the result of intangibilities; it's the relationship between social, physical and aesthetic features of the space. This is evidently phenomenological, where the lifeworld, objects, mental abstractions and architecture converge.

Noble (2014:119) captures this concept through discussing the role of time, community and paradigms in the seeking of identity through architecture in a post-apartheid South Africa. Firstly, it is noted that a "sense of belonging" is linked to the past realised in the future, but must be able to project aspirations for the future (Noble, 2014:112). As in *Emotional Geographies* the memory of the past translated to the present through reminiscing over a childhood farm home being redeveloped into a city that submits a feeling of a thinned existence (Davidson *et al*., 2005:217). Secondly, it is very important that all members of the community participate in the debate on what identity in South Africa is, but that the debate is open-ended and that reality must emerge from this lifeworld (Noble, 2014:119). Lastly Noble (2014:120) notes that the past is continually appropriated from the present. In other words, the past is also remembered in the view of the present, presenting reality from a certain perspective or certain paradigm.

It is imperative to understand that the work of Bernard Tschumi, Steven Holl and Moholy-Nagy is very much described through and focused on the word "space", although there seems to be a strong phenomenological undertone – mindful or not. It is this subconscious phenomenological approach to architecture which is often lost, and not placially focused in architectural education and theory. This is also the reason why I, as a student of architecture and practitioner of architecture, never understood what place-making really entails or even how it is practised. As a result, I would argue, from both the literature and experience, that place-making in architectural discourse and practice is misunderstood.

2.2.3 THE BILBOA EFFECT AND OCULARCENTRISM

The Bilbao effect came in to play after the design and construction of the Bilbao Guggenheim Museum by Frank Ghery. The museum was designed as part of a scheme to upgrade and attract tourists to the Basque country and de-industrialised city. In the first year of opening the Bilbao Guggenheim museum received a million visitors, where only four hundred thousand visitors a year was initially anticipated and managed to make enough revenue to pay for the museum that cost a hundred million dollars (Franklin, 2016:80). The success has mainly, and I would argue not thoroughly informed, as stated by Adrian Franklin (2016:80) been attributed to construction of this very fluid and large architectural pioneering museum. Plaza & Haarich (2013:1456) notes that the academic response to the Bilbao effect has very much been divergent; that of arguing that the museum was an instigator of outrageous architecture commissioned by cities seeking economic gain from them by commissioning famous architects, also known as starchitects, to design them. The commissioning of architecture such as the

Bilbao Guggenheim Museum has been attempted by other cities with less success: the Sheffield National museum of Popular Music bowed within a year whereas the Milwaukee Art Museum by Calatrava, and KIASMA Museum of Contemporary Art failed to achieve high visitor numbers (Franklin, 2016:80).

There are two outcomes or perspectives surrounding the success of the Bilbao Guggenheim Museum. Firstly, Franklin argues (2016:91) that there are many factors contributing to the success of the museum that are not emphasised when considering the building's success. Its success is deeply rooted in Bilbao's cultural landscape as well as its historical heritage and support from the global art infrastructure associated with the Guggenheim. Successively the number of visitors attracted to the building is not solely based on the design, or the distinctive fluid appearance of the building, but rather supported by other tourist attractions. Secondly, and sadly, this is not necessarily understood and the commissioning of museum architecture and architecture in general, aims to be centred on creating form-based design. This approach is confirmed by Wong (2010:237) where he implies that the end of the twentieth century introduced a new way of architectural "form-making" being a radical departure from previous rectilinear and geometrical pure forms. Although it is strongly advocated by Wong (2010:239) that "free-form architecture" is visionary architecture that also manifests in the un-built form, as related to conceptual ideas and investigations by Tschumi, this type of architecture is grounded in embracing the postmodern contradictions as well as having in-depth understandings behind its complex architectural forms. However, it is poorly understood by architectural students, and I would also contend, by the general public as well.

This misapprehension of the Bilbao effect or so-called "free form architecture," have indeed led to architecture being degraded as a purely visual element; also called ocularcentrism. What I intend to showcase by discussing this notion is that placial understanding becomes completely removed from architecture. This happens when an economic miracle is expected by commissioning the design of an art museum in the way of purely visual aesthetic architecture (Franklin, 2016:80). This also happens when members of the private and public sector wish to put a signature on their region by commissioning starchitects to design a specific building; noting a building that must be outrageous and visually enticing (Wong, 2009: 238). Architecture as a purely visual discipline is a problem, as sight detracts from a person's multisensory experience in which space, and evidently place is experienced (Jordaan, 2015:14). This notion of ocularcentrism sits close to the practice and design methodologies of Pallasmaa; where only using vision and no other senses lead to feeble and inhumane architecture. One of the consequences of this visual-driven domain of architecture is that young architects and architectural students become strongly influenced by provocative-looking architecture; often not understanding the ideas behind the form (Wong, 2009:238). As previously mentioned, it is advocated that "free-form architects" do consider numerous things and their buildings are not

purely driven by form. However, Pallasmaa (1996:12) advocates that these technological advances, such as parametric design, cause an "imbalance of our sensory system": putting vision and form at the front of architecture. Jordaan (2015:12) concurs that architectural photo-realistic renderings also contribute to architecture as being visual-dominant discipline; where scale, the real world of people and places are removed leaving fantasy buildings with no purpose. Pallasmaa (2012: 20) describes this impression so accurately by remarking: "*The task of architecture is not to create dream worlds, but to reinforce essential casualties, processes of rooting, and the sense of the real. The fascination with novelty is deeply connected with the self-destructive ideology of consumption and perpetual growth. Instead of contributing to meaningful and coordinated landscapes and cityscapes, the structures of today's businesses (and almost everything is considered business in the world of fluid capital) turn into self-centred and self-indulgent commercial advertisements.*"

2.3 PART TWO

2.3.1 DEMENTIA IN SPACE AND PLACE

2.3.1.1 TRANSITION

"The physical, emotional, and economic demands of caring for someone with dementia often exceed the capacity of family members. Special care units (SCU) exist to meet the specific care requirements of patients diagnosed with middle and late stages of dementia and represent one of the fastest growing segments of the nursing home business."

(Mobley, Leigh & Malinin, 2017:49)

The need for dementia care facilities, or special care units, has already been established in the introduction of this paper and confirmed in the quotation above. The focus is to investigate how a person living with dementia in space, and evidently place, can be unravelled and understood. Mobley *et al*. (2017:50) notes that there is no single instrument or system that yet exists supporting assessment for the quality of life for people living with dementia. This is remarkable considering that the transition for a person with dementia from their residence to a care facility will almost affect every aspect of their environment and consequently their quality of life (Mobley *et al*., 2017:52). To discuss a person with dementia in place I would like to start discussing the role of the body, more specifically the person with dementia, in architectural understanding and design pertaining to care facilities.

2.3.1.2 UNDERSTANDING THE BODY IN DESIGN

The construction of bodies in the design process can be complicated, there are many stakeholders to consider, each with competing demands in order to service one body while

ensuring all bodies are content and working in harmony (Buse, *et al*., 2017:1435). The body, and I would like to argue the *person* in space, is closely related to Moholy-Nagy's conception that a body is an extension of space, and that space can only be perceived through the body. In addition, the word and concept of the body seem Cartesian and undefined; for that reason the body must be considered as someone specific with needs and preferences. For Buse *et al*. (2017: 1436) this is also the case; it is articulated that architects consider ideological practices of care while designing for various types of abstract bodies. It is the design tension of providing for perfect care practices manifesting in the lifeworld. As Seamon (2013:144) puts it: "*lifeworld is the lived body, which through unique modes of encounter and interaction with the world at hand, contributes to each person's and group's experiences, understandings and lifeways.*" It is further reasoned that bodies are in an intimate relationship with their environments or world they find themselves in, which in turn point towards place (Seamon, 2013:144). However, in the design of facilities and environments, especially dementia care facilities, architects and designers consider various types of bodies such as the: 'lived-body', 'mechanical-body', and 'measured-body' (Buse *et al*., 2017:1438). Some of these bodies, mechanical- and abstract bodies are intellectual and virtually detached from personality and character. The mechanical-body is used to describe diagnostic practices whereas the lived-body is used to describe patients in later life care facilities (Buse et al., 2017:1438). It is imagined bodies that we as architects so often rely on when designing, it is differentiating bodies that we categorise and design for separately instead of cohesively and integrated. Pallasmaa (2017:97) describes a different duality where the body are separated into two categories: the first is the aesthetic and erotic quality of the body, and the second is the intellectual creative quality of the body. This idea is described as the dilemma of the embodied existence where the mind and the body is treated separately; it's a denial in understanding the full human condition (Pallasmaa, 2017:97).

In *Where Memories Go,* Magnusson (2014) makes an interesting analogy where she comments that the aesthetic is perceived by noting that elderly people are treated as if they are barely human; hardly the full human condition. The elderly are considered to be children of the nineteenth century impoverished, considering that Oliver Twist was at least cute, and society today rage over pandas or seals as being cute but the elderly not even human (Magnusson, 2014).

"*They were dreadful. One of them [a doctor] said to Graham, 'now if you don't get out of bed today, I'm going to take a big stick to you! … it's just the strange way they treated him, like he wasn't a human being or someone with a bit of intelligence, he was just that thing in the bed.*" (Davidson *et al.,* 2005:50)

There is a deep-rooted misapprehension in architectural design when considering who we are really designing for, as well as how we interpret the people we are designing for while living and

coexisting with other people. People are the full embodiment, who differ but work and live in the same space. How do architects even begin to understand and unravel place for people living with dementia? What stands out in many of the literature writings dealt with since the introduction of this paper, is the task of decorating spaces with familiar objects; making the room or larger environment of the dementia facility feel like a home. For Mobley *et al*. (2017:65) it is about uncovering creative design strategies that go beyond the simulating residential character using furniture, millwork and adopting a sense of home.

2.3.1.3 THE HOME AS A COMMERCIAL COMMODITY

This sense-of-home has also been largely advertised in the design of architecturally designed dementia facilities, and other care facilities to the point that a sense-of-home is a consumable and consequently a business. Buse *et al*. (2017:1437) states that healthcare facilities must attract patients by presenting itself as a hybrid of a hotel and a mall. It's again the separation of intellect from the entire embodiment where the patient and family members, especially in the case of a dementia person not being able to make their own decisions, are reconstituted as consumers of practices of healthcare facilities in the morphs of consumption (Buse et al., 2017:143). For Pallasmaa (2017:98) it boils down to architectural methodologies and the understanding of the person, environment and being. It is contended that mechanical, digital, information and consumer driven culture of our architectural educational systems and daily lives have diminished our ability to connect with the natural world and its complexities (Pallasmaa, 2017:98). In a further elaboration in reviewing the task of architecture Palsamaa (2012:20) states that instead of architecture being mediums for meaningful landscapes and cityscapes, it is selfish and self-indulgent and merely commercial advertisements.

On the other end of the spectrum these consumer-driven care facilities are projects that promote the feeling of home, having evidenced based researched that sense-of-home has an effect on the well-being of people with dementia. In the investigation of retrofitting existing care facilities for people with dementia, it is eminent that residential character and signage was some of the best practices for adapting the existing environments into special care units (Mobley *et al*., 2017:59). In addition, it was observed that people with dementia practise habitual activities in areas such as the kitchen and corridors, referring to reminiscent engagements of home life and environments (Mobley *et al*., 2017:63). In a study conducted accessing elderly people without dementia, in relocating from their residences to a facility, interventions were done to test the response to 'home-like' facilities and 'hotel-like' facilities (Cerina, Fornara & Manca, 2016:212). It was established that by creating waiting rooms that mimic the look of Victorian sitting rooms for a 'home-like' feeling, or more contemporary spaces for a 'hotel-like' feeling the 'home-like' aesthetic appealed to residents more, but only by an inch of a hair more than 'hotel-like' aesthetics (Cerina *et al*., 2016:213).

2.3.1.4 NARRATIVE, ARCHITECTURE AND DEMENTIA

The question really is what is beyond this material aesthetics, what is the lifeworld consequence of the interactions that manifests from these material architectural characteristics for elderly and specifically for people with dementia? What the question is inferring is the connection and mental abstracts formed from the material and lifeworld interactions, how it is concretised, architecturally, and if there is a real impact for people living with dementia. It is complex: it's emotional, physical, material, occupational, and sometimes intangible. Perhaps it can be better understood through stories as so many of the literature indicate. I will share a few narratives from the literature introduced to explain this complexity as in the poem of Georg Trakle. Pallasmaa concur (2012:20) that meaning, whether being art or a poem, is epic in the way it is a metaphor for human existence in the world. All the narratives do not necessarily encompass all the elements mentioned, but give good insight as a point of departure to uncover how these complexities can eventually be understood in the architectural sphere and evidently as the aim of this paper.

The first story I would like to share is that of health and emotions in later life. This story is a glimpse through the eyes of a caretaker in a nursing home noting care practices and emotions related to them for both the caregiver and patient (Davidson et al, 2005:49). The following passage depicts this intense emotional reaction of a caregiver interacting with the vulnerability of elderly people in an institutional setting, although the elderly person is not mentioned to have dementia, emphasising the emotional content in a place with objects:

"he's become incontinent…and ooh, how humiliating, he is sitting with this green gown on and the catheter hanging down out on the floor- he had no RUG over him and no pyjama coat –it was just- ooh, I just felt so HUMILIATED for him when I went in" (Davidson *et al.*, 2005: 49).

Emotions in later life and dementia are somewhat different for Mary as described by Van Steenwinkel *et al*. (2014:6): Mary and her husband have reorganised their lives, values and home to make life worth living for 'in the moment' as opposed to have long-term plans and savings as Mary might not live to see her sixtieth birthday. The home was adapted to have a bigger spatial feeling, staff was employed to take over errands and home chores, nevertheless emotions are still part of the vulnerability dementia places a person in:

"When *it becomes really oppressive, although all the people who work here know and it's quiet here, it's calm, but when I'm in such a situation that is too oppressive, and my husband also knows, I get nervous, tense, and either I start to get angry, or I start to cry, or I just run away. I can't manage anymore… It's beyond my control*" (Steenwinkel *et al*., 2014:7).

In *Where Memories Go* Magnusson (2014) describes the feelings and emotions of her mom suffering from dementia, but as well as her own being part of this path of deterioration. Take

note of the various descriptions made to capture both their experiences and literature background as a means of understanding the complex tangibilities and intangibilities emotionally charged. For Davidson et al. (2005:50) emotions and feelings are learned ways of responses, and with changing lifeworlds these responses differentiate with age and understanding. This is evident for Magnusson (2014) in:

"… poured over musty records, I soon had names and places and a historically context in which to set the misty heritage Annie had bequeathed us…I couldn't wait to tell you what I had found, but something was wrong. You ought to have been thrilled, but you weren't engaging with my research. Given how often you regaled me with the exploits of the homesick cow; I was puzzled even a little hurt to find you so detached. I found myself grappling with a sensation I cannot identify…mmm you said with 1851 senses I have placed before you… I was dizzy with excitement…that's interesting you said politely sounding if it wasn't really, this was baffling."

In the task of architecture Pallasmaa (2012:20) argues that buildings facilitate deep narratives of place, time and culture. This notion is demonstrated in *Geography and Memory Explorations in Identity, Place and Becoming:* the Graffiti House is positioned as a place of memory where the station was once occupied by Civil War Soldiers (Jones & Garde-Hansen, 2012:140). Although being a very literal example and not associated to dementia, I would regardless like to point out how the building facilitates memory, ongoing conversation and the creation narrative. The walls of the house consist of inscriptions made by both the soldiers, who occupied the structure, and recent visitors in an attempt to continue and construct a multi-authored, co-constructed and narrated place of remembrance (Jones & Garde-Hansen, 2012:140). It's seen, remembered and narrated differently in one place. In commenting on how extremely consumable and selfish architecture has become, Pallasmaa (2012:20) maintains that responsible buildings are rooted in their time and place, they constructively underwrite a sense of time and belonging as a cultural breadth, as opposed to contemporary monuments of selfishness, and flattened uniqueness of time and history.

Davidson *et al.* (2005:206) explains the manifestation of narrative as a way of conveying meaning that devoid theory and extensive analysis; allowing a full account of feelings, memories and emotions. These memories and emotions are bound to its concrete space; becoming place. It's by and through remembering and experiencing being-in-place that emotional geographies are established, and perhaps for people living with dementia the quality of being is established (Davidson *et al.*, 2005:212).

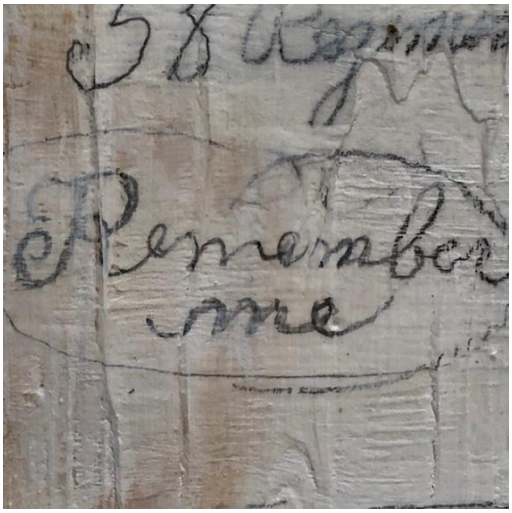


Figure 07: Graffiti on the Walls of Blenheim, Virginia (Johnston, 2019)

2.3.1.5 PLACING DEMENTIA IN ARCHITECTURE

Place is the key concept of understanding, the unravelling of the philosophical, medical, physical and spiritual realm of dementia and architecture within the visible and invisible structures or systems of place. Architecture inherently has the power to enhance the quality of life for people with dementia by *placing* them. These structures revolve around objects, emotions and processes within a building's space. It is important to understand that *placing* people with dementia is a contribution to something better, and not a solution of reversing or eradicating the effects of dementia. Buse *et al*. (2017:1444) puts these complexities forward by saying that the negations of what home, or rather place is, and the meaning thereof for people living with dementia and their families, is accompanied by complex entanglements of bodies, things, and emotional challenges.

> "…*care as an art of dwelling that enacts-being-at-home by reassembling bodies, emotions, technologies, and places in highly specific, complex ways and often fragile and precarious ways*"
>
> (Buse *et al*., 2017:1444)

Chapter Three

UNDERLYING CHARACTERISTICS OF PEOPLE LIVING WITH THE DEMENTIA SYNDROME AND DEVELOPING DEMENTIA PERSONAS

3.1 OVERVIEW

Emphasis is mainly on elderly people with physical and mental deterioration, and not specifically on people with dementia (Jais, Hignett, Eatupinan & Hogervorst, 2018: 216). People with dementia are primarily occupied with daily activities and are very often not sure of their placial surroundings (Jais, Hignett & Hogervorst, 2016:3). It has been established that people living with dementia have a better quality of life in facilities specially designed for dementia as opposed to traditional nursing homes (Marquardt, *et al.,* 2014:133). Marquardt *et al*. (2014:133) also suggest that using literature as a basis for research with expert input, might be more beneficial as opposed to using focus groups. The personas, as introduced in chapter one, would only represent the case for private healthcare and without the participation of persons with dementia.

The underlying characteristics of the dementia syndrome and the manifestation thereof can be categorised into three spheres: biomedical, social and political. The biomedical sphere looks at the medical realm of dementia exploring the causes, symptoms and diagnoses. The social sphere concentrates on the manifestation of dementia, its various stages and the impact of dementia on family members as well as caregivers. The last sphere, the political sphere, concentrates on how various countries prioritise dementia and distribute funding for dementia care. Moreover, the political sphere also focuses on how dementia is used as a tool for political gain. The three spheres identified in the research are outlined highlighting the key ideas identified as potential persona informants. The three spheres are also in line with the type of research anticipated; and in turn also reference the two proposed theoretical models.

A literature review was conducted to identify the connection between the framework derived and architectural entities of dementia facilities, the difficulties caregivers experience and the symptoms of the dementia syndrome. In preparation for the development of the personas, eighteen relevant online journal articles listing the possible underlying characteristics mentioned above were reviewed. The content was divided into themes which emerged from the literature, together with dementia syndrome symptoms, dementia- types, diagnoses, care facilities, caregivers, political support, treatment, and therapy for people living with dementia. The literature was summarised according to these spheres.

3.2 UNDERLYING CHARACTERISTICS OF THE DEMENTIA SYNDROME AND THE MANIFESTATION THEREOF

3.2.1 THE BIOMEDICAL SPHERE

The manifestation of dementia is more than a single disciplinary problem. The risk of developing dementia can be attributed to an individual's genes, lifestyle and environment (British Psychological Society Dementia Advisory Group, 2016:5). In the medical field factors such as diabetes, midlife hypertension, midlife obesity, physical inactivity, depression and smoking can further be attributed to dementia (British Psychological Society Dementia Advisory Group, 2016:5). As mentioned, there are various types of dementia relating to other medical conditions, or even mixed with age-related medical conditions such as: vision, hearing and mobility impairment (Grey, 2015:7). Dementia is referred to as an umbrella-term defining a set of symptoms interrelated to a vast set of medical problems, which manifests in the social, emotional, private, and daily realms of people's lives.

According to Brankaert (2016:47), preceding a dementia diagnosis, there is a realisation phase. This is when people who display dementia symptoms, as well as members of society, become aware of irregularities and abnormal behaviour. The behavioural abnormalities detected are mostly identified in the social, emotional, private and daily realms of people's lives. Behaviour that is described as abnormal is: mysterious short-term memory loss, difficulty in finding appropriate words, change in mood, apathy, confusion, difficulty in following sequential themes and storylines, dwindling spatial orientation, becoming repetitive and an immense fear of change (Healthline, 2017). These abnormalities are the first signs of the illness.

When behavioural abnormalities are detected and dementia is diagnosed there is a feeling of disbelief and denial relating to the stigma of dementia as a disease (Wiersma, Sameshima, Dupuis, Caffery & Harvey, and 2014:5). However, Jill Manthorpe and Steve Iliffe (2016:5) argue that dementia is in fact not a disease, but rather refers to it as a syndrome, that cannot be diagnosed but only recognised. This view is also inferred by Brankaert (2016:32) stating that a diagnosis of Alzheimer's is quite difficult and can only be conclusively established post-mortem.

Yet, early screening for dementia, due to a common consensus that dementia is under-diagnosed, has become a very high priority; especially in the United Kingdom (Manthorpe and Iliffe, 2016:16). Screening for dementia in the United Kingdom is regulated by diverse screening criteria in order to determine if screening is useful, necessary and ethical. Currently it appears that the screening is homogenous and barely provides substantial benefit for the people being screened (Manthorpe and Iliffe, 2016:16). Dementia can be misdiagnosed causing needless emotional turmoil, or even life-changing decisions.

There are no disease markers through means of a blood test available for the purpose of general population screening (Manthorpe and Iliffe, 2016:17). Perhaps screening might omit important factors relating to other health and psychological issues. According to the *British Psychological Society Dementia Advisory Group* (2016:5) a dementia diagnosis can be made through a neuropsychological assessment that evaluates the mental ability of a person identifying patterns of strengths and difficulties. Psychiatrists are the only professionals that can undertake a neuropsychological assessment and have the necessary skills to undertake therapeutic intervention. (British Psychological Society Dementia Advisory Group, 2016:6). Dementia is rather the umbrella-term that describes a series of cognitive and psychiatric symptoms that affect the daily lives of people differently (Hendriks, Wilkinson & Schoeman, 2017:22). It is important to note that dementia is progressive and early signs are very hard to detect; dementia slowly but severely affects a person's brain (Brankaert: 2016:16).

Mild Cognitive Impairment (MCI) is seen as the sign state of dementia. This proves to be problematic, since many people with symptoms of mild cognitive impairment, such as short-term memory loss, often return to leading a normal life defeating the purpose of early recognition (Manthorpe and Iliffe, 2016:17). As a result, a diagnosis, or how the anomalies are defined, usually only occurs in the late stages of a person's life (British Psychological Society Dementia Advisory Group, 2016:5)

While this may be true, there is drug therapy available to reduce and manage symptoms of dementia, but unfortunately there is no cure for dementia. Although the use of drug therapy is an important part of controlling symptoms, one would contend that the focus should remain on its social manifestation and that drug therapy is a different phenomenon.

3.2.2 THE SOCIAL SPHERE

3.2.2.1 DEMENTIA RATING SCALES

The Clinical Dementia Rating scale, known as the CDR scale, is often used to describe the progression of the disease and the manifestation of dementia (Brankaert: 2016:33). According to the CDR scale, dementia is rated from stages one to three: mild dementia, moderate dementia and severe dementia (Brankaert: 2016:33). Within these three dementia stages the Global Deterioration scale, GDR scale, further distinguish dementia in stages; ranging from stage one to seven (Healthline, 2017). The figure provided below is a diagram showing the dementia stages in accordance with the CDR scale as well as the additional stages within the GDR scale.

GDR SCALE	CDR SCALE
Stage One	Mild Dementia
Stage Two	Mild Dementia
Stage Three	Moderate Dementia
Stage Four	Moderate Dementia
Stage Five	Moderate Dementia
Stage Six	Severe Dementia
Stage Seven	Severe Dementia

Figure 08: GDR & CDR Scale

If dementia is attributed to various medical conditions, manifests in a social environment with psychiatric symptoms, but is rated in a clinical manner and varies from person to person; one should question the validity of the diagnostic methodology. With neuropathology and social circumstances as opposing phenomena, neuropathology can be influenced by social circumstances and vice versa. This confirms the notion of dementia as a multidisciplinary problem (Manthorpe and Iliffe, 2016:5). Hendriks et al. (2017:12) state that if one looks at how a person with dementia experiences the present, taking into account the person with dementia's subjective interpretation of the world, with their own behavioural- and meaning-giving rituals, one can begin to understand a person with dementia. Reason being that people with dementia focus on the present as opposed to the future (Wiersma et al., 2014:5).

For the purpose of distinguishing dementia ratings, the social manifestations of dementia will be looked at according to the CDR and GDR scale, and generally described occurrences from various literature with different objectives. Firstly, there is a long road before the first indications of memory problems and advanced dementia (Brankaert: 2016:16). It is seldom experienced alone; the burden of care and worry is likely shared by a spouse or caring family member (Brankaert, 2016: 32). The occurrence of dementia is higher in very elderly people, but not restricted to them (Chappel & Reid, 2000:1). Dementia in younger people is mostly associated with Alzheimer's disease, also defined as younger-onset dementia (Ryder, 2016: 464).

3.2.2.2 SOCIAL ASPECTS OF DEMENTIA ACCORDING TO THE CDR AND GDR SCALE

The social occurrence in stage one is none, the only indication of dementia is that of a family history. In stage two there are signs of memory impairment, but so little that it is categorically associated with normal forgetfulness (Healthline, 2017). Mild dementia, rated on the CDR scale, is associated with forgetfulness, social anxiety and loss of concentration and is very minimal (Brankaert, 2016:44). This very mild cognitive impairment is rarely noticed by family members or a physician (Healthline, 2017).

As mentioned previously, dementia detected in the early stages is quite rare or sometimes inaccurate, as some people can function normally without displaying regular signs of cognitive impairment (Manthorpe and Iliffe, 2016:17). In addition, people with early signs of dementia often hide and disguise these impairments (Brankaert, 2016: 44). Reason being that there is a stigma associated with dementia. Dementia is associated with one losing one's mind and losing one's identity; contributing to the public fear of aging (Manthorpe and Iliffe, 2016: 7). In countries such as South Africa, the understanding and awareness of dementia seem to be absent which can further contribute to the stigma surrounding dementia (Prince et al., 2016:97). For example, there is no term in the Xhosa language for dementia, and the meaning of dementia in different contexts in South Africa needs to form an important part of further studies (Khonje, Milligan, Yako, Mabelane, Borochowitz, & de Jager, 2015:30). This is evident, especially in townships, where dementia is associated with witchcraft or an illness that cannot be treated nor assisted (Prince et al., 2016:97). The public consensus of dementia in general is that of a calamitous occurrence, resulting in fear (Manthorpe and Iliffe, 2016: 7). This fear is so debilitating that it precedes any compassion and empathy for people with dementia (Manthorpe and Iliffe, 2016:7). People with dementia are by risk of reason vulnerable to abuse and harm (Prince et al., 2016:97).

Moderate and severe dementia is associated with a range of social and physical symptoms. Moderate dementia is affiliated with stages three to five of the GDR scale. The social manifestation of dementia is quite progressed as opposed to the previous stages discussed.

In a study, *Dimensions of Care for Dementia Suffers in Long-Term Institutions,* which is concerned with the outcomes of special care units versus non special care units, there are four social features chosen for the measurement of the quality of care (Chappel & Reid, 2000:234). These four social elements are: agitation, independence, mood and cognitive behavioural functioning (Chappel & Reid, 2000:237). The target group of the study is that people with moderate to severe dementia identifying what behaviours are typical of this stage of dementia as per the CDR scale. It is therefore evident that moderate dementia is associated with noticeable deviations from normal social behaviour.

In stage three, cognitive impairment can be noticed by family members, friends and even co-workers (Healthline, 2017). There is a decline in concentration and people also seem to get lost more often (Healthline, 2017). These social occurrences can create further disturbances: a person with moderate dementia is prone to feelings of agitation accompanied by frustration and lost behaviour resulting in wandering (Centre for Excellence in Universal Design, 2015:57). It is also from stage three that research states that there is a time period connected to the onset of the dementia stages, noting that stage three has an average duration of seven years (Healthline, 2017).

In stage four, people with dementia experience that in combination with memory loss, it may become challenging to manage their finances, traveling alone to unfamiliar locations, and difficulty in remembering personal history (Alzheimer Society of Canada, 2019). This stage has an average duration of two years (Healthline, 2017).

Stage five is associated with major cognitive impairment, resulting in severe memory loss. This severe memory loss is different from the previous stages in the sense that it affects daily tasks and routines such as bathing, eating and getting dressed (Healthline, 2017). Equally important, spatial reasoning is also impaired. People with stage five dementia, often need prompting in these daily routine tasks because there is little or no recognition that it is necessary to bath or eat; this is mainly due to memory loss and recognition of neither personal hygiene, nor hunger (Alzheimer Society of Canada, 2019).

Evidently people with moderate dementia find it difficult to orientate themselves, especially with external environments, causing confusion and disorientation (Centre for Excellence in Universal Design, 2015:31). Disorientation is measured by means of independence, as well as cognitive and behavioural functioning in the mentioned study; this is done by looking at a person's movement between locations and the measurement through the use of the MASR concentrating on two scales (Chappel & Reid, 2000:237). The two scales consist of eleven items each where the first focuses on early memory and the second on orientation (Chappel & Reid, 2000:237).

The relationship between social and physical activities become interrelated for people with dementia, this notion combined with the loss of short-term memory makes it difficult for people with dementia to understand their *place*. This results in their inability to navigate their physical environment and is associated with emotional distress and spatial disorientation. In combination with other age-related diseases, stress levels might increase. Loud and constant noise may lead to more emotional anxiety and disorientation, sometimes even aggression (Centre for Excellence in Universal Design, 2015:32). Aggression manifests in two categories, physical and verbal. The reactions of individuals with dementia manifests differently, in relation to verbal or physical aggression, disorientation, fear and anxiety .

Stage six dementia is associated with severe dementia. It is during this stage that the impact of dementia in a person's social environment and capabilities become detrimental. Throughout this stage a person with dementia only recognises close family and friends, has limited communication skills, and undergoes a major personality change. Major personality changes are associated with delusions, compulsions such as repetition, and complete disorientation (Healthline, 2017). Incontinence is also characteristic of stage six dementia; creating a further social disconnection due to embarrassment and inability to be in public spaces (Alzheimer

Society of Canada, 2019). People remain in stage six for approximately two and a half years (Healthline, 2017).

A person with stage seven dementia has essentially no ability to speak or to communicate (Healthline, 2017). Apart from social incapabilities, a person with this final stage of dementia is incapable of performing any daily routines and activities independently; therefore being totally dependent on others for care (Healthline, 2017). Finally, people in stage seven dementia may also lose their ability to walk and swallow. The average duration of this final stage is also two and a half years (Healthline, 2017).

In the severe stage of dementia, where informal caregivers no longer have the capacity to take care of a person with dementia, the institutional stage sets in (Brankaert, 2016:35). This progressed state of dementia, as discussed in stage six and seven, is associated with the inability of performing routine tasks, is disorientated and experience limited bodily functions (Brankaert, 2016:16). The degree of dependence is considerable during the severe and final stages of dementia. Hence, the stress of homecare by informal caregivers, especially if they are working and have other children living at home, is essentially impossible.

3.2.2.3 CARING FOR DEMENTIA AND THE SOCIAL IMPACT

Caregivers are a further extension of the social manifestation of dementia. As mentioned, dementia is seldom experienced alone. The effect of dementia, especially on informal or unpaid caregivers, is that of emotional burdens that often result in mental and physical deterioration (Brankaert, 2016:32). Informal caregivers are highly recommended by local authorities as they enable people with dementia to remain in their community for longer, and preserve their self-worth (Manthorpe and Iliffe, 2016:21). Although, this enables people with dementia to remain in their own homes, the social impacts on caregivers are dramatic. Perhaps the notion of home care is idealised. Ninety-eight percent of informal caregivers suffer from mental and physical health problems due to taking care of a loved one with dementia (Brankaert, 2016:35). Understandably, the side-effects of depression and physical exhaustion are detrimental, but further harm is introduced when informal caregivers are accused of being harmful or negligent due the immense burden of taking care of people with dementia (Manthorpe and Iliffe, 2016: 21). Ironically, informal caregivers reported that the biggest challenge they face is dealing with and watching the behavioural change of their loved ones with dementia (Brankaert, 2016: 35).

The social occurence for people with dementia is highly individual, and also country and culture specific. Various countries have their own care systems, being pharmaceutical or socially orientated (Brankaert, 2016:36). In addition, these interventions can also manifest differently in various cultures (Brankaert, 2016:36).

3.2.3 THE POLITICAL SPHERE

Caring for people with dementia encompasses a diverse range of skills, resources, emotional endurance and support. All of these factors have a financial implication and is sometimes used to gain political favour. Jill Manthorpe and Steve Iliffe (2016:12) describe this notion as the medicalisation of dementia; it is used to mobilise and to be mobilised within a political argument. In other words, the immense stress and focus on the expertise of the medical field becomes a way in which a government strategise political self-interest; be it financial, social, or both. It suggests the manifestation of the Machiavellian school of thought; also described by Jill Manthorpe and Steve Iliffe (2016:12) as Biopower. The Machiavellian school of thought is concentrated on how one is portrayed in a certain light in order to gain power; in this instance using the medicalisation of dementia (Henaff & Strong, 2001:15). Biopower focuses on staying alive and policies for governing life; therefore, people with dementia become the object of political strategies (Manthorpe and Iliffe, 2016:12).

In addition, people with dementia are mostly cared for by family and friends; well-known as the informal care phase of dementia (Brankaert, 2016:36). The informal care phase, where some people with dementia remain the burden of cost and limited support, is the responsibility of the informal caregivers. In many cases informal caregivers have to quit their jobs in order to fulfil the demanding task of caring for a loved one with dementia; yet the focus of the political sphere remains on medicalisation (Manthorpe and Iliffe, 2016:22). This is especially evident in England where significant resources are made available for early diagnostic measures, keeping in mind how difficult it is to diagnose dementia, as opposed to the support and financial assistance of informal care (Manthorpe and Iliffe, 2016:22).

People with dementia should not be used as objects of political favour; however the literature shows political interest in the medical realm as opposed to fields such as architecture. Perhaps the focus of governments, especially in the South African context, should look at how to better design for people living with dementia. This can improve the quality of life for people with dementia while also encouraging growth in the sector of the built environment. It is important to note that the development of specialised facilities combined with medical care, especially with the majority of the population relying on under-resourced healthcare, would be a very difficult task.

3.3 THE INTERRELATION OF THE BIOMEDICAL, SOCIAL AND POLITICAL SPHERE AS A MEANS FOR DEVELOPING A TEMPLATE FOR DEMENTIA PERSONAS

In reviewing the various spheres underpinning the development of the persona template for dementia, it became evident that the spheres and nature of dementia are completely entangled. The manifestation of dementia in a specific sphere, such as the social sphere, is also intertwined with the biomedical and political sphere. An example of such an overlap is the issue of a dementia diagnosis. A diagnosis, according to the literature discussed, is a medical practice but is made by considering social and cognitive displays. Being a social manifestation, a dementia diagnosis is difficult to establish, because it is based on memory and the ability of a person to engage in problem-solving. The means of making diagnoses is in return funded and supported by a political structure. This is done in order to improve a country's social development and simultaneously gain power by promoting dementia for political support. Furthermore, political and governmental structures control the development and progression of a country, being responsible for the opportunities available for education and development in the country. It has been noted that people with better education and social development are at a lesser risk to develop dementia.

The development of the personas occurred as a process of various workshops; described in the paper as Iteration one to three. The development of the dementia personas posed various challenges; iterative amendments had to be made to make the personas relevant and concrete enough to be used as an effective design tool. All iterations are discussed below; demonstrating the development and outcomes of each iteration as the development of the final personas Annie and Susan.

3.3.1 ITERATION ONE

A workshop was held with my study leaders and me for the development of dementia personas. The objective of the workshop was to create the outline of a dementia persona template, resulting in further development and ultimately a persona. This was to be based on the theories discussed previously, and which had been done in detail. The literature content was divided into the various spheres covering dementia symptoms, dementia types, diagnoses, care facilities, caregivers, political support, treatment, and therapy. The literature was summarised highlighting all the important and key concepts as discussed in the three spheres. A twenty-one page summary was compiled by studying each source individually and listing the possible underlying characteristics of dementia. Each page was divided into two compartments; one listing the possible underlying characteristics of dementia, and the other referring to the various stages of dementia. The purpose of this is to apply certain characteristics of dementia during various

stages, in order to highlight these characteristics to observe when creating a dementia person template for stages four to seven.

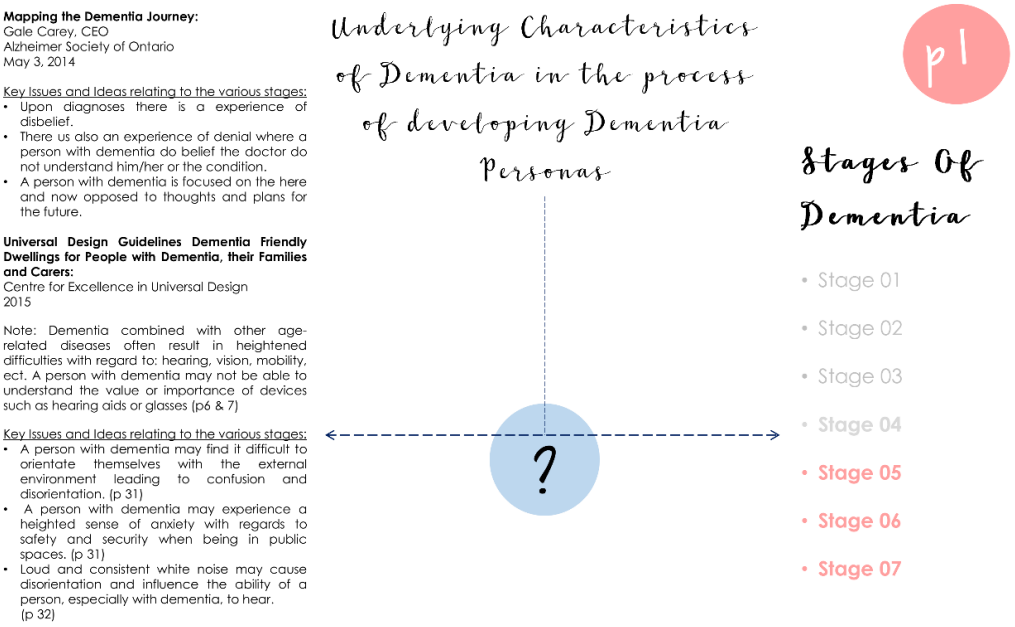


Figure 09: Extract of Literature Summary for Dementia Persona Workshop - Page 01

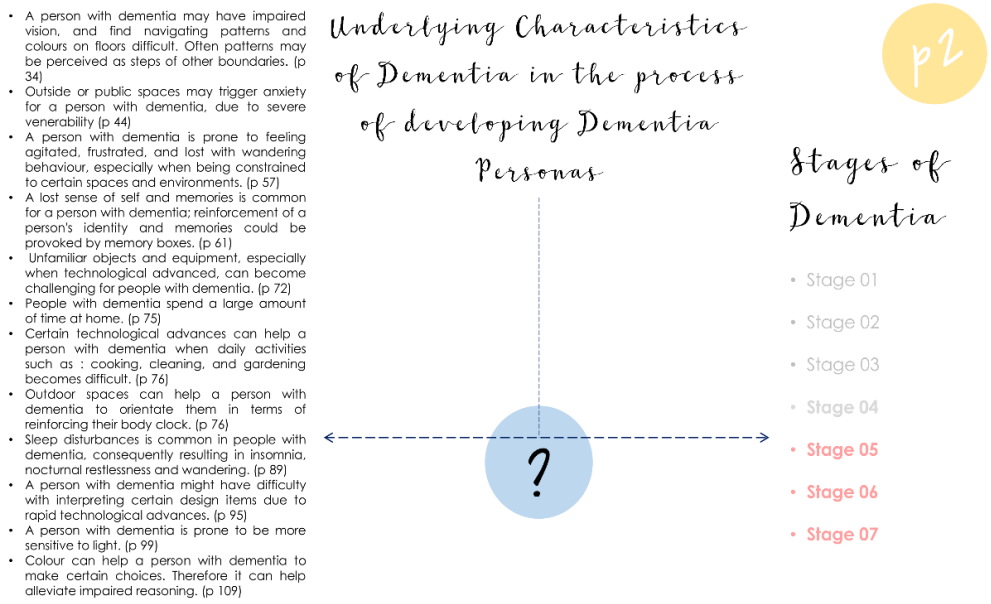


Figure 10: Extract of Literature Summary for Dementia Persona Workshop – Page 02

The workshop commenced by establishing that the goal was to have a draft dementia persona template that could be used to develop into a final template, and ultimately a persona. The final template was given to experts to establish criteria for the development of dementia personas for stages four to seven. The twenty-one page literature summary was divided among all workshop participants with a set of sticky notes. Each participant reviewed seven pages of the literature summary and wrote down important characteristics, possible characteristic headings and characteristic domains. The individual reviewing process by each participant lasted about forty minutes.

After the review process each participant was asked to discuss her notes and collaboratively identify possible headings. All headings were written on a circular shape note in order to distinguish it from other notes. All participants were asked to place their notes under relevant headings, and if there was not a suitable heading one had to be created by the participant. The figure provided below was the first outcome in the process of the development of a persona template outline.

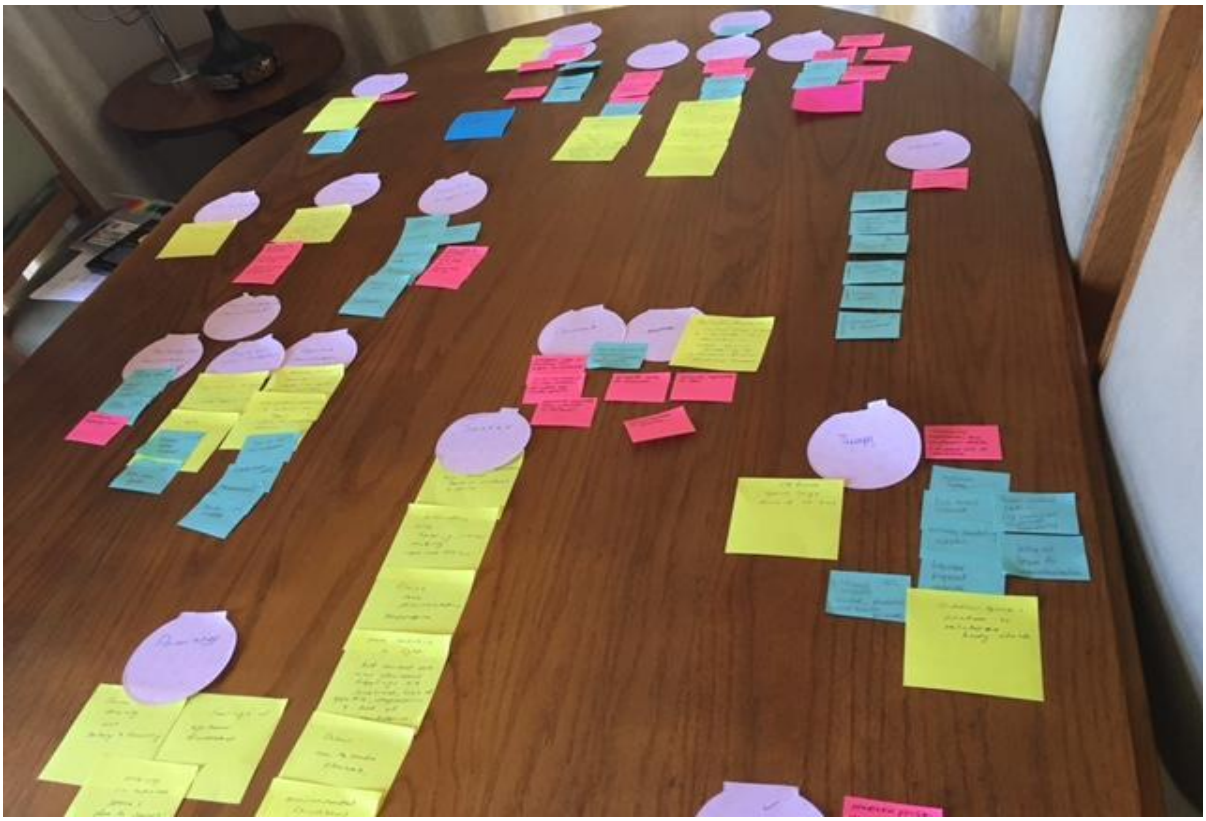


Figure 11: Photograph of Information Categorised Under Headings during Dementia Persona Workshop

During the process of organising ideas, and characteristics in accordance with a certain heading, theme or domain, it became clear that the characteristics overlapped in various sections. Consequently, a second layer of information was added in order to establish how these headings, themes and domains could be distinguished and how they could be identified according to the placial- as well as the person-environment-occupation model.

The placial and person-environment-occupation model was outlined and added to the information by identifying what section of the model best describes a specific heading. The placial model was used for identifying the specific heading or domain considering the material dimension of place, the mental dimension of place and the lived dimension of place. The person-environment-occupation model was used by identifying person, place and occupation.

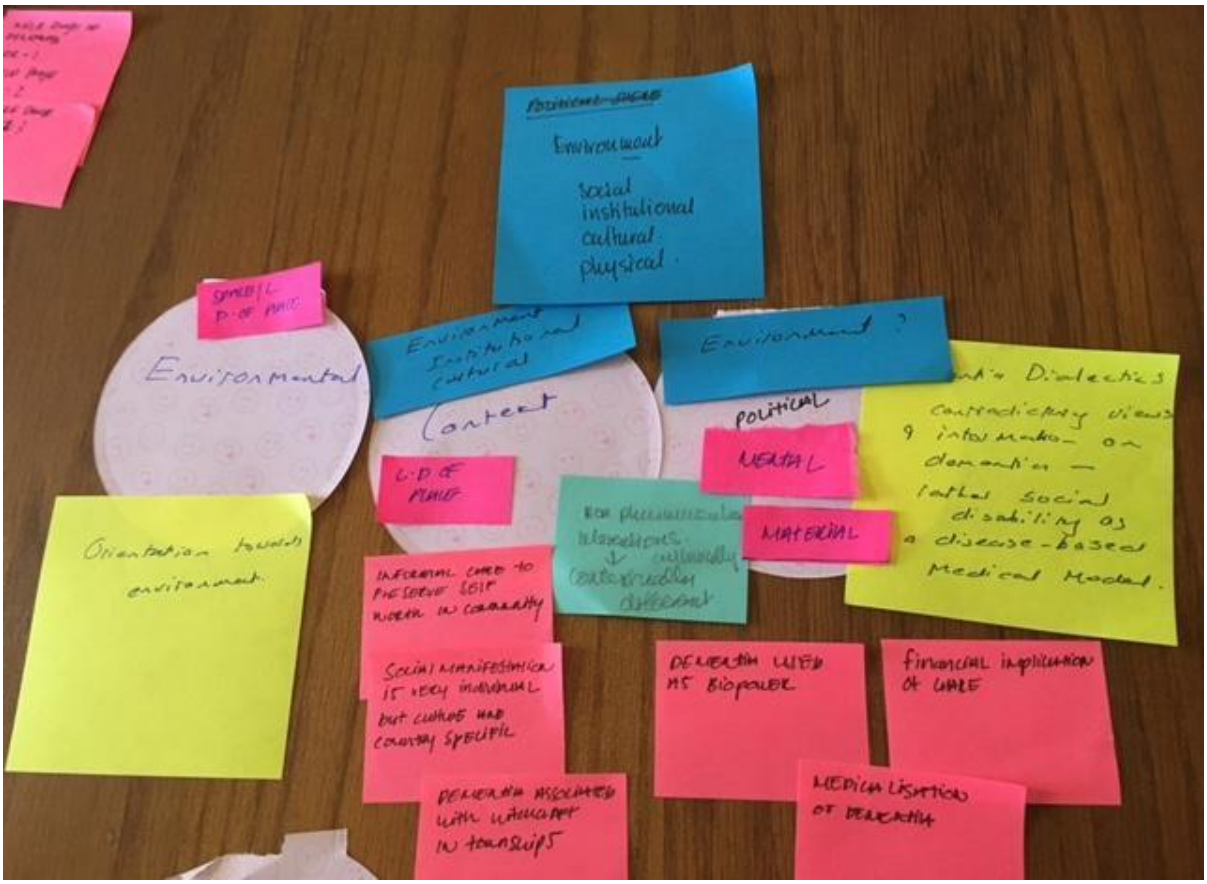


Figure 12: Photograph of Information Categorised Under Headings with Placial- & PEO Model Headings during Dementia Persona Workshop

With all the information gathered from the workshop a draft persona template was developed. The persona identified spatial envelopes and certain domains or themes that will be encompassed in this spatial envelope. The persona template must be set-up in such a way that it will be relevant to the research anticipated. The following draft template was derived from the workshop with the help of a formal diagram summarising all the information gathered from the workshop.

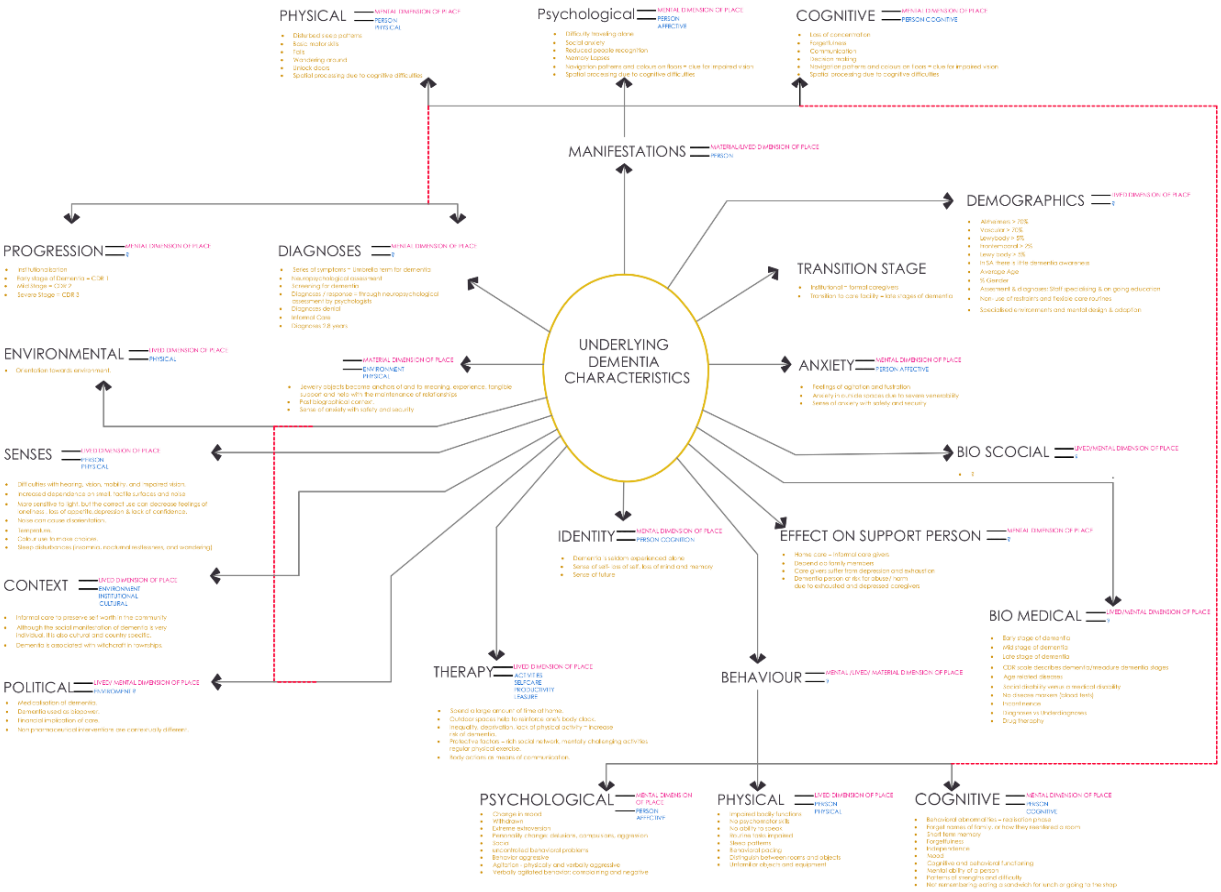


Figure 13: Formalised Diagram of all Information Gathered

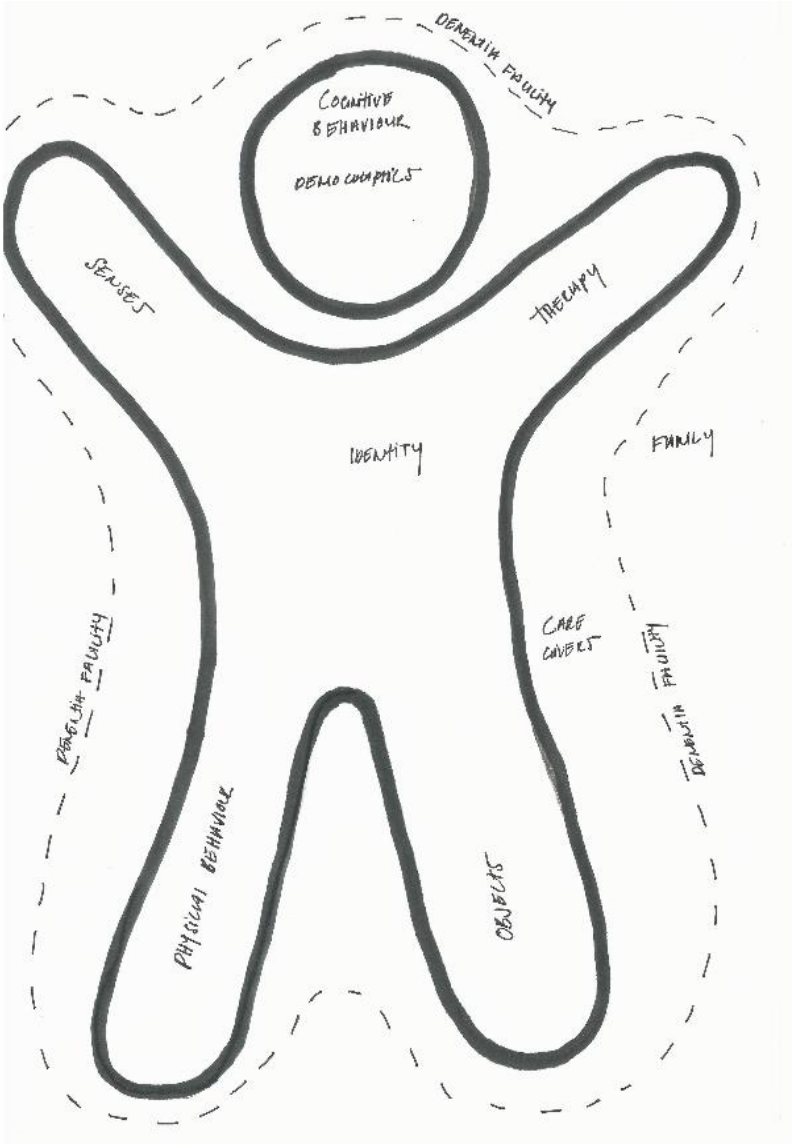


Figure 14: First Persona Template

The draft template for the personas was sent for review to my study leaders. Upon reviewing the personas, and after consultation with students doing research in the same field, both study leaders and I realised that the persona template should rather be based on the CDR scale as opposed to the GDR scale. The reason for this is that the CDR scale, divides dementia into stages one to seven, has overlapping symptoms and distinguishes the severity of these symptoms according to the various stages which is complex, especially if it is done by a designer, and not a dementia specialist. Another reason for using the CDR scale is that it is more efficient for data collection, as it ensures accurate research information for the specialist reasons mentioned above. As a result, the persona template was developed according to the CDR scale, focusing on moderate and severe dementia.

3.3.2 ITERATION TWO

Another workshop was hosted once the dementia persona template had been reworked. At the workshop, valuable expert input on the developed persona template was shared. An expert in health care service design provided insight into the dementia personas by discussing how they could be used in procuring data for design purposes. The insight process started with an explanation on how the dementia template was developed using literature and the two theoretical models, placial triad and PEO model, as analytical lenses to ensure that the moderate and severe persona templates are in line with the aim of the research.

After the discussion, the health care design expert presented research done in residential health care. The expert mentioned how they involved stakeholders through the building of miniatures. Miniatures are objects built at a smaller scale usually using inexpensive, easy to find and pliable materials such as cardboard, plastics, all sorts of recycled materials and even diagrams of maps on paper. The mentioned research methodologies presented by the health care service design expert, especially the use of miniatures, was then brainstormed as means of collecting data for the purpose of this research.

The dementia personas will be used as probes for the building of dementia environment miniatures by stakeholders. During the building of the miniatures, stakeholders are requested to make notes about the building of the miniature aligned with the specific characteristics of the persona. Once the miniatures, with accompanying notes were completed, the stakeholders participate in a group discussion, from where data will be categorically organised. Organisation of the notes can be done by writing down information on sticky notes and organising them on a big table, displayed against the wall, in accordance with certain themes or concepts. The health care service design expert discussed headings that were used in the case presented by her; these are ultimately design informant themes, such as: tasks, actions, touch points, stakeholders, pain points, challenges, dreams and needs.

The insight into the dementia persona template came as a direct result of the discussions around the design informant themes. I noticed that the themes refer to the two models chosen for the analysis of literature and data. Firstly, touch points were referring to both the material – and lived dimensions of place. Whereas dreams and needs made reference to the mental dimension of place. In addition, tasks and challenges were linked to the PEO model making reference to the occupation and the environment the person is in.

Further discussion with regards to dementia persona information and its visual attributes delivered the following outcomes that were used for further development. Firstly, race, gender and cultural background were still vague in terms of the demographic background of the persona template. It became evident that expert input was needed as the demographics of a person with dementia were not clear from the literature reviewed. The figure in the persona

template was also gender and race nonspecific; the focus was to present a moderate or severe dementia persona irrespective of race and gender. Theerfore, it was suggested that two different dementia caricatures must be drawn for the respective persona templates. Additionally, the characteristics identified must also be populated before sending the template out for further expert input. The persona template was adjusted and sent to the study leaders of this paper.

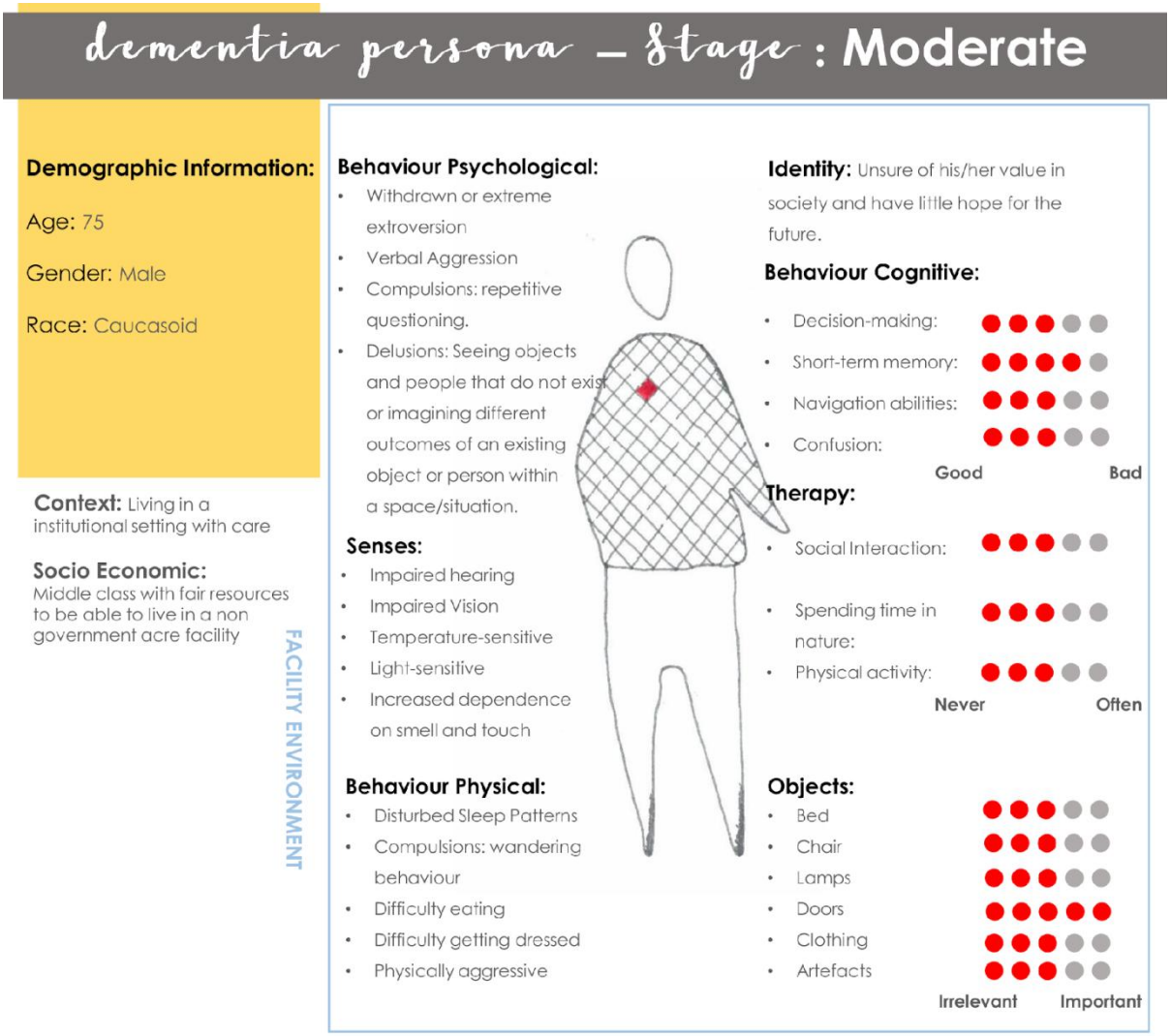


Figure 15: Moderate Dementia Persona with Caricature Developed Post Workshop 02

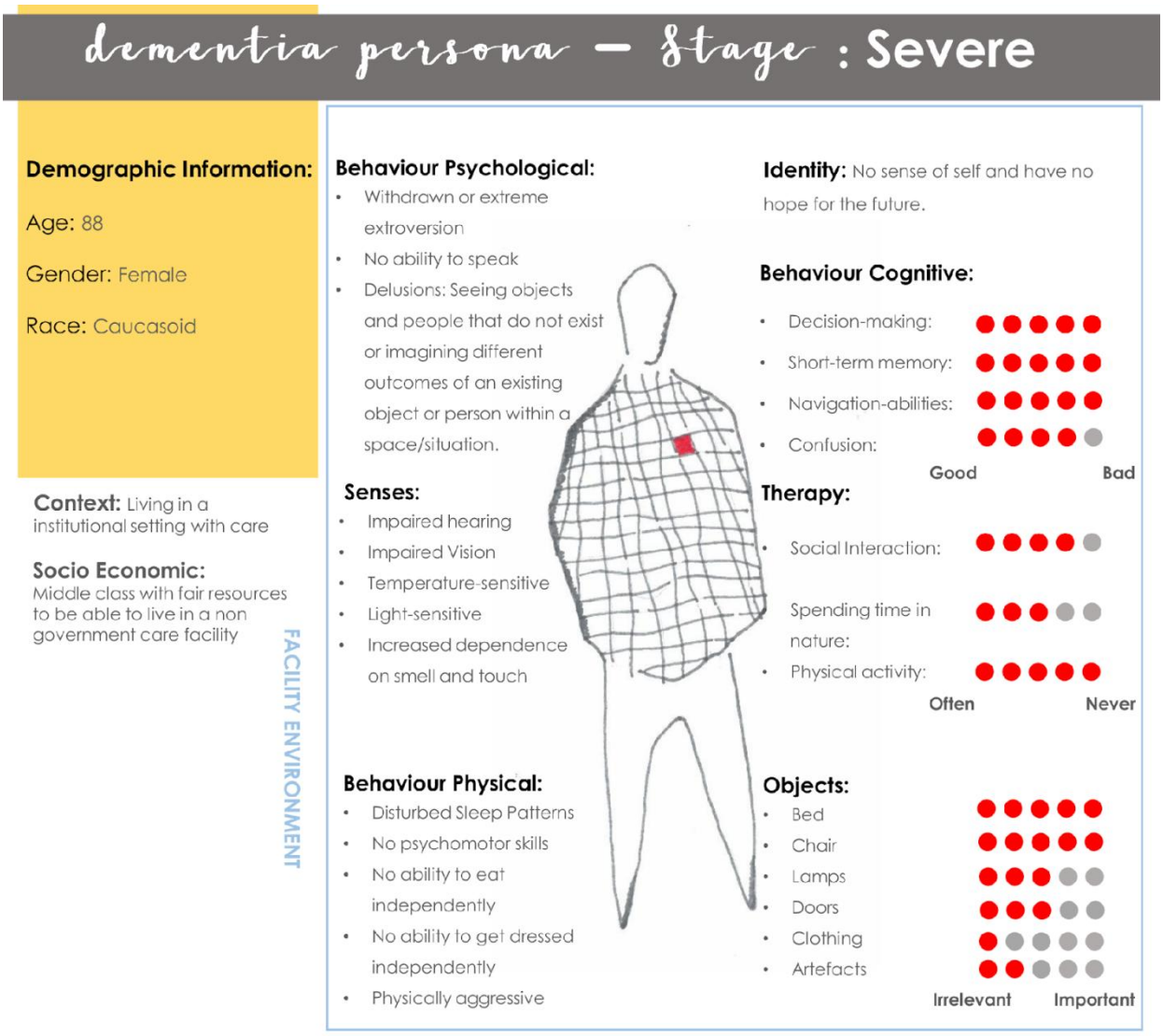


Figure 16: Severe Dementia Persona with Caricature Developed Post Workshop 02

3.3.3 ITERATION THREE

After sending the reworked template for comment, the persona template was again shared with experts. The expert input was obtained from an international health care service design practitioner, a local professional nurse and PhD candidate, teaching and working with dementia patients, an international PhD student researching dementia care with a visual communication perspective, and taking care of persons with dementia in the UK in his spare time and an international professor specialising in human activity and product design focusing on the elderly. A third workshop was arranged where the revised dementia persona templates and development thereof were presented to the experts mentioned. The workshop was attended by the same panel of experts, except for the expert in health care service design, due to other obligations.

After presenting the personas the following expert inputs and suggestions were given on how the template should change in order to develop two dementia personas. Firstly, the persona template consisted of a vast amount of text and was very dense. Secondly the demographic information was not completely correct, and experts provided the gender and ages that are prevalent for moderate and severe stages of dementia experienced by people living in South Africa. The cultural background of the personas is important and must be in line with people living in the facility where the data collection will be conducted. Although important, the cultural background, for the purpose of this research, was not researched and analysed in detail.

The characteristics of the persona templates were found to be correct but needed to be described in a manner that was engaging. The engaging dynamic is also missing in the means of how the template is visually presented; it was felt that the dementia caricatures were too abstract and did not provide a sincere connection, especially when the personas would ultimately be utilised as probes. All experts agreed that the persona template needed to be relatable, so it was proposed to use real people for the imaging and to improve the graphic design of the personas.

As a result of the expert input received the dementia templates were developed into two personas. The first persona is an elderly female living with CDR scale-rated moderate dementia; the persona is known as Annie. The second dementia persona is also an elderly female, living with CDR scale-rated severe dementia; this persona is known as Susan. The two personas were sent for review to my study leaders for final approval in order to start the data collection process. The personas below are the final personas developed to be utilised as probes in the data collection process. Please note that consent was given by both individuals for the use of their photographs as part of the persona identities.

Annie

"I do not have dementia, and there is nothing abnormal about my behaviour"

Age: 75

Cultural Background:
English-speaking, widowed, tertiary educated mom of three children. She enjoy watching rugby, cooking and hosting.

Socio Economic Status:
Middle class with pension and medical aid.

Therapy
Annie enjoys walks in the garden and doing her own shopping.

Objects
Annie is very fond of her kitchen equipment; although she struggles to use them she often refers to certain items that can be used to improve a cooking process.

Senses
Annie struggles with her eye sight and is dependent on her glasses. She also struggles with her hearing and has to wear a hearing device. In addition she is sensitive to slight temperature variations.

Behaviour Psychological
Family members have noticed that Annie seems to struggle when she goes to the shops alone. When engaging in conversation she often repeats topics that have already been discussed. She is easily overcome by emotions. She is very irritable.

Behaviour Cognitive
Annie can be very indecisive, resulting in difficulty in making even minor decisions. She has issues with spatial processing; consequently finding herself in spaces that are not aligned with her actions. Annie struggles with her memory forgetting words and names.

Behaviour Physical
Annie uses a walking stick for support. Family member's are concerned for her safety as Annie is prone to wandering, unlocking doors, especially at night in dark environments. In addition she struggles with finer motor skills when using eating utensils; resulting in spillage and mess. Annie has a short concentration span.

Figure 17: Susan - Severe Dementia Persona

Susan

Age: 88

Cultural Background:

Afrikaans-speaking widowed mom of four children. She enjoys cooking, knitting and talking about world politics.

Susan was in denial about her dementia at first, but now she is completely oblivious to her dementia as she is unable to comprehend what it is.

Socio Economic Status:

Middle class with pension and medical aid provided by her children.

Therapy

Susan enjoys people sitting with her, looking at the garden and listening to music.

Objects

Susan is dependent on her wheelchair and lounge chair . She is fond of her embroidered chair pillows, flower vase and pictures hanging on the wall.

Senses

Susan struggles with her eyesight and hearing. She becomes distressed by loud noises. Susan is prone to smelling and touching everything. She is afraid of the dark and likes being in natural sunlight.

Behaviour Psychological

Susan is unable to communicate cohesively; she will utter words, but verbal communication is very limited. She is prone to aggressive outbursts and constant moaning. Occasionally she will push and throw objects at carers. She is withdrawn and refuses to eat in a large dining room setting. Susan suffers from delusions.

Behaviour Cognitive

Susan has no ability to make decisions for herself; all decision-making must be done for her by a family member and carers. She is unable to recognise family members and friends. She has no special processing abilities and is constantly confused with her environment.

Behaviour Physical

Susan is only able to walk very short distances with assistance and walking aids, for any other mobility she is dependent on a wheelchair. She is unable to feed herself and has difficulty swallowing. Susan also suffers from incontinence.

Figure 18: Susan - Severe Dementia Persona

Chapter Four

DISCOVERING DEMENTIA – DATA COLLECTION AND FINDINGS

4.1 DATA COLLECTION AND FINDINGS OUTLINE

The data collected is from an anonymous NGO facility housing elderly people as well as elderly people living with dementia. The village consists of free-standing houses, apartments, apartments with assisted care twice a day and the frail care facility with twenty-four-hour assistance. Dementia patients are housed in a specific ward of the frail care facility. It is important to note that the entire facility is gated and that the frail care section is situated on the periphery of the site. The frail care facility is integrated into the larger urban context, bordering the club house and dining room, where other non-dementia residents outside the frail care facility live. The following image is a free-hand sketch of the entire village with the frail care section indicated in red, as well as a floor plan of the frail care unit with the dementia ward indicated in yellow. A colour coded floor plan identifying the different areas in the dementia ward and frail care unit is also included.

Figure 19: Nolli Map of Retirement Village

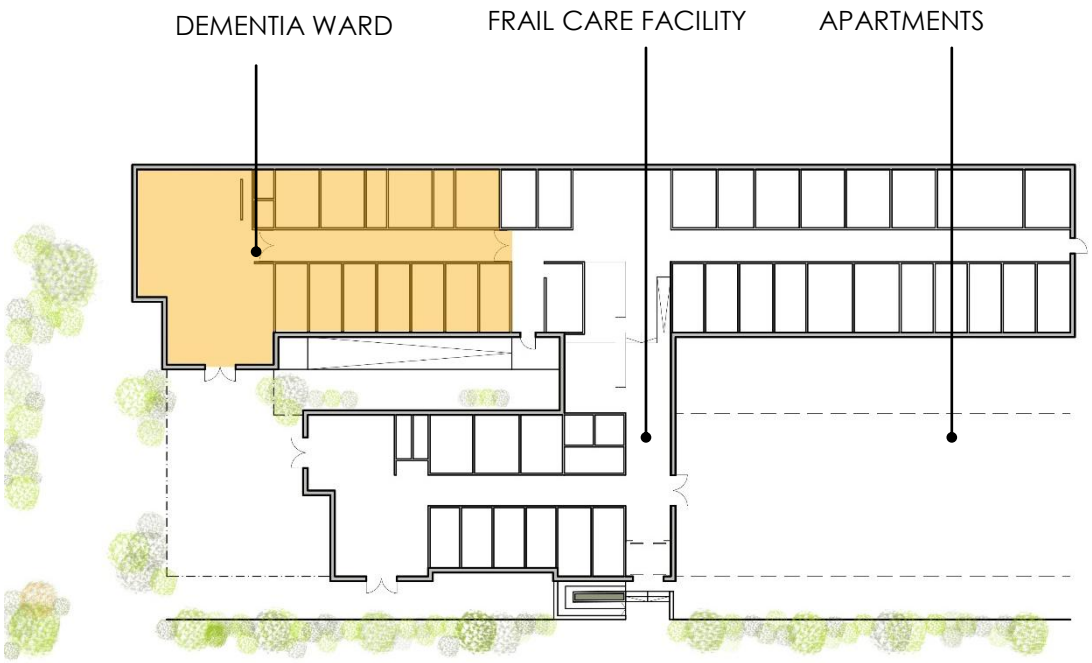


Figure 20: Frail Care Facility with Dementia Ward

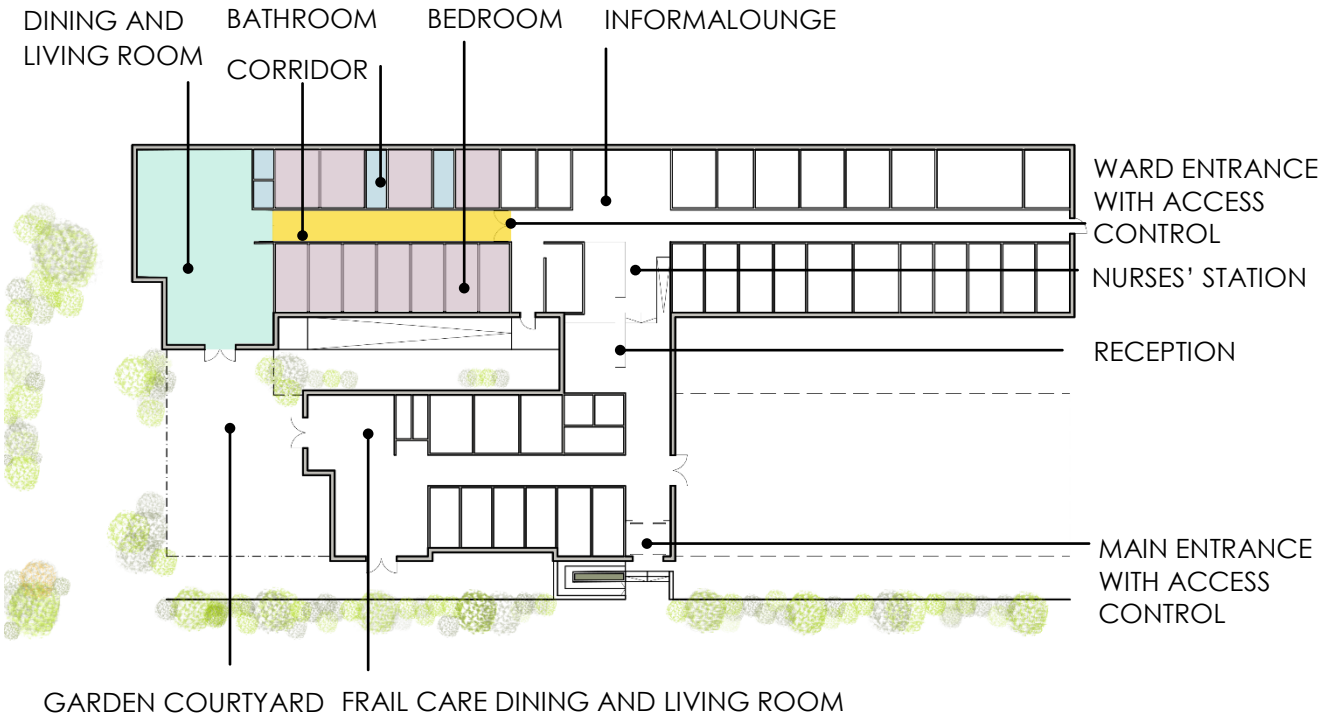


Figure 21: Dementia Ward Layout

The calendar image below gives a holistic view of the dates used to collect data; the dates were chosen purely on my availability of study leave and the availability of staff members to

participate in activities. In addition, the later dates procured were due to additional time and information needed as the information was documented. The later dates are also subject to the availability of my study leave, as well as the availability of participants and the facility. Notes have been made on the calendar to indicate what information was gathered on each date. The data saturation dates are also indicated on the calendar.

September 2018

01	02	03	04	05	06 Observation
07 Observation	08	09	10	11	12
13	14	15	16	17	18
19	20	21	22	23	24
25	26	27 Observation	28 Observation & Informal Interview	29	30

October 2018

01	02	03	04	05	06
07	08	09	10 Observation	11 Affinity session one	12
13	14	15	16	17	18
19	20	21	22	23 Affinity session two	24 Observation
25	26	27	28	29	30
31					

January 2019

01	02	03 Observation (data saturation)	04	05	06
07	08	09	10	11	12
13	14	15	16	17	18
19	20	21	22	23	24
25	26	27	28	29	30
31					

The data collected engages with various underlying and subjective qualities of people's experiences within spaces and meanings associated with it. As Du Plooy-Cilliers *et al.* (2014: 173) notes, it is very difficult if not impossible, to measure and quantify the significance of experiences. It is evident that the methods proposed in the previous chapter align with both the inquiry of the lifeworld. The goal of the research is to obtain and understand dementia in all its peculiarities, full human experiences, and characteristics of individual experiences through the eyes of caregivers, family and friends in context to *place*. In order to analyse and understand the data collected the methods chosen to analyse the data are 'qualitative content analysis' and 'textual analysis'; these are exchangeable and interchangeable terms used depending on the discipline, origin and ultimately theme chosen (Du Plooy-Cilliers *et al.*, 2014:234).

Evidently the methods implemented originate from deductive measures driven by the two analytical frameworks proposed; the Placial Triad and PEO model. These two models provide themes from where the data can be reduced, but not flattened, and fragmented in order to understand the phenomenon of place in context to architectural design considerations for NGO dementia facilities. The fragmentation of the data collected will also help to provide further insight into the sub-questions posed, while supporting the main research question: why architectural elements are important, the current state of dementia care facilities is, and the obstacles indicated from a care perspective, when considering a sense of place.

From the themes, coding was used to understand the themes in relation to one another and potentially bring new ideas and insights to the foreground. The three modes of coding identified the suitability pertaining to the research question, and sub-questions of which the following are: pattern codes, reflective codes and descriptive codes. These codes are generally used in qualitative data analysis as identified by Welman *et al*. (2005:214). Firstly, pattern codes are used to connect different textual analysis in order to uncover a meaningful whole, whereas reflective codes introduce observant, non-verbal and gestural behaviours giving depth to and a deeper understanding of the phenomenon that is not always evident (Welman *et al*., 2005:214). Lastly, descriptive codes were mainly used as they are dependent on a theme and need interpretation (Welman *et al*., 2005:214). Note that qualitative data analysis is subjective analysis of data through a systematic approach, and can be ultimately described as: "*The focus here is on textual content such as stories, written and spoken words as well as visualised narratives*" (Du Plooy-Cilliers *et al.,* 2014: 232).

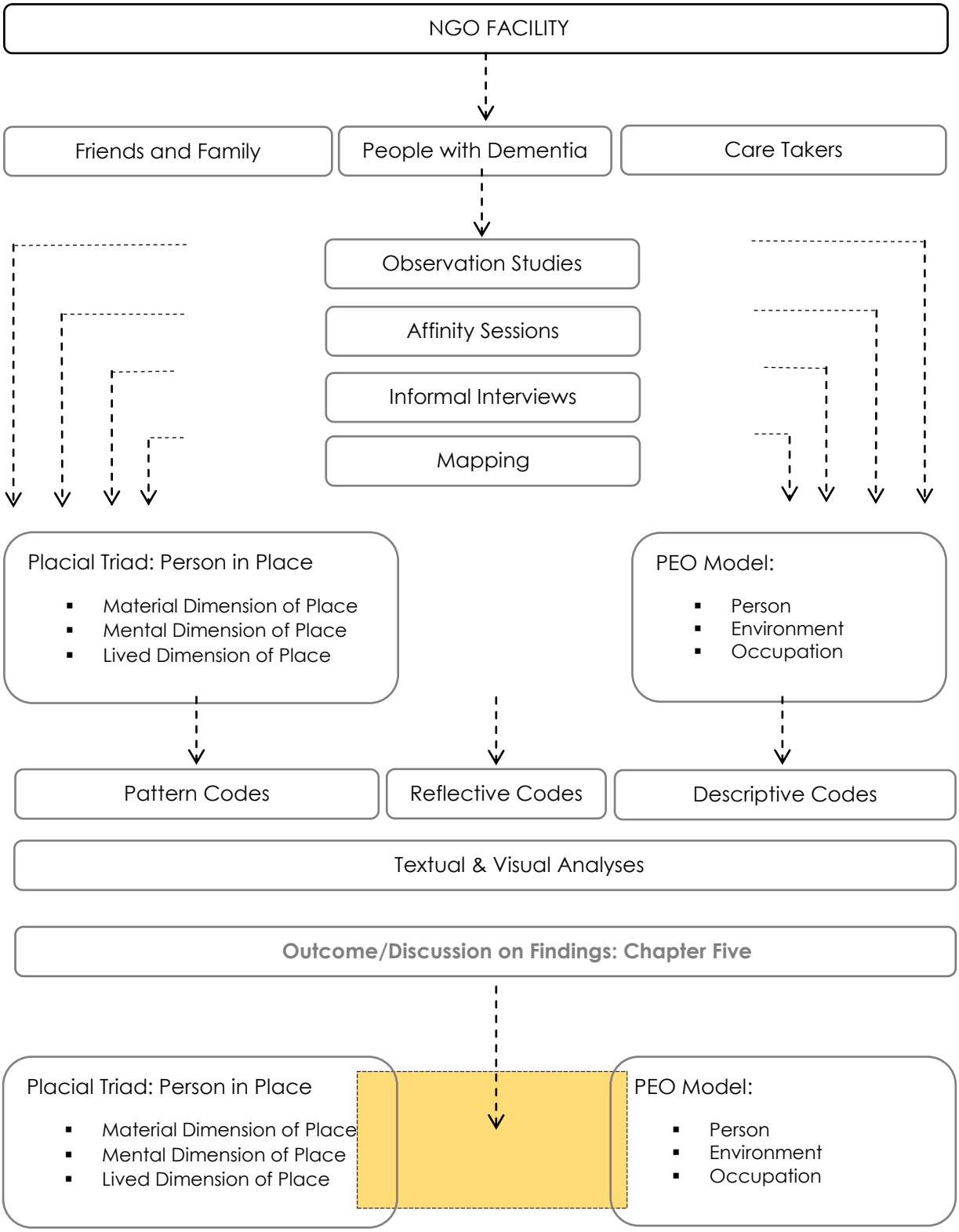


Figure 22: Data Collection and Analysis Diagram

4.2 OBSERVATION STUDIES

Textual analysis, as mentioned in the introduction of the chapter, can be ambiguous and interchangeable; meaning it's both a method for collecting and analysing data (Plooy-Cilliers *et al.* 2014:233). For the purpose of the observation studies, I decided to depict all observations in the method of a diary entry, noting times and routines. Observations are depicted as a narrative diary entry reflecting on all aspects experienced. After each diary entry a short analytical description is given relating to the Placial Triad and PEO Model; referencing key ideas, activities, environments and objects from the observations.

Arrangements for observation studies were done in advance with the matron of the facility via written communication. Two to three days at a time was agreed on, at least a week in advance until data saturation was reached. The matron of the facility briefed staff in advance of my presence for the respective days. I also ensured that the staff knew who I was. After I introduced myself and explained my research objectives. I remained reserved, staying in the background, as I did not want to influence the daily routines and activities. It was important that the daily activities proceeded as normal, with or without my presence. All names used in the diary entries and discussions for either caregivers or for residents with dementia are pseudo names. The names are either picked by caregivers themselves as a part of the consent forms, or given randomly to residents by me.

6 September 2018 – Day One

It is approximately 07:00 and I have just arrived at the NGO facility's frail care unit. I am sitting at the reception while the day staff is being briefed. Once the briefing is done the matron will allow me access to the dementia ward in the frail care facility; yes, there is a specific ward allocated for dementia residents. The briefing is completed, and the matron welcomes me and allows me to set-up in the dining room; it's buzzing and busy as breakfast is almost ready to be served. The dining room has large windows with a view of the gardens.

The dementia ward is isolated from the rest of the frail care unit by means of an access-controlled door. I received the code from the matron to allow me to move through the facility freely. My objective for the day is to orientate myself and get a feeling for the facility and personnel. I am an introvert and it is difficult for me to just start talking and asking questions; however, a few of the staff members are eagerly chatting with me and have agreed to complete the consent forms during their breaks.

It's 09:00 and two hours have passed. It seems as if breakfast is a prolonged process as all residents are not eating simultaneously and at the same speed. I am still based in the dining

room but moved to a different table, surrounded by dementia residents; they are hardly aware of my presence. I am hoping to see the day nurse in charge to help with the completion of consent forms; it's a process of patience…

It's 10:00 and another hour has passed. I am still sitting in the dining room. All residents are now sitting in the front of the dining room in a circle near the television, participating in an occupational therapy class. a Caregiver is sitting opposite me at the table with a stack of clipboards filling out forms. In the corner just behind the nurse, is an old lady covered with blankets in a comfortable chair, fast asleep. Sitting next to her is a younger lady, who I presume, is her daughter giving her some form of companionship by reading and drinking coffee while sitting close to her. The occupational therapy class takes a break.

Another hour has passed and it's now 11:00. I am still in the dining room with all the residents of the dementia ward. The occupational therapy class is over and it seems that the residents are waiting to be taken back to their bedrooms. The mood is light as a few residents are sharing stories and laughing. I am feeling cold and tired for just sitting and watching for 4 hours. I am going to take a break and hope to speak to the nurse soon.

It's 12:00 and I am back in the dementia ward based at my table in the dining room. It's almost lunch time and it seems not much has changed since an hour ago; residents are still sitting in the dining room while others are engaging in conversation. The tables are being set for lunch. The lady keeping her mom company is taking charge and questioning the staff about the positioning of new appliances in the kitchenette that have just been delivered.

It's 12:45 and the residents in the dementia ward are having lunch. Bobotie, peas and potatoes are on the menu. Oh, and some dessert as well! Each resident has a colourful plastic cup with water on the table. Some residents eat while others need to be fed by caregivers. I have noted that there are only two male residents in the dementia ward.

Consent forms for observations are signed by the caregiver. I will be walking through the facility now while residents are still eating. I am wondering if the residents will remain in the dining room after lunch or will they be taken to their rooms for some quiet time.

After a brisk walk down the corridor of the dementia ward I am back in the dining room and it is 13:15. Some residents are still having lunch. There is a lady; let's name her Leigh, sitting in a comfortable chair being fed by one of the caregivers. While being fed she continuously stares towards the ceiling or out of the window next to me. She seems far away from here; only interacting on automatic response. The dining room is starting to clear, with residents retreating to their rooms or being assisted to the bathroom. The dining room TV is on, but little attention is given to it by the remaining residents.

It's 13:45 and I have moved out of the dementia ward. I am sitting close to reception and the nurses' station in an informal lounge area. A lady is also sitting close-by in front of an oil heater that is not plugged in; she is looking at her hands, laughing occasionally. I wonder if she has dementia. The lounge has two two-seater couches with a maple-veneered coffee table in-between them. There are two bookshelves stacked with books, a round table in the corner with a vase of synthetic flowers, a square table with an Aloe in the opposite corner with a TV and two wingback chairs on the edge of the passage. Another lady has just entered the lounge area and is sitting on one of the green couches with her walker at the edge of the couch, due to limited space in-between the couch and coffee table. She is uttering words while observing the nurses' station.

It's 15:00 and I am observing some of the senior staff dealing with calls from family members, as well as family members coming in to deliver medication for residents to the matron for safe storage. I will now break for the day with a total of eight hours of observation.

4.2.1 FINDINGS OF DAY ONE SCHEDULED ACCORDING TO THE PLACIAL TRIAD AND PERSON ENVIRONMENT AND OCCUPATION MODEL:

4.2.1.1 PLACIAL TRIAD: A PERSON'S MATERIAL DIMENSION OF PLACE

The material dimension of place for the day's observation is predominantly focused on the dementia ward dining room with its tables, large windows, curtains, comfort chairs, kitchenette with new appliances, TV and food. In addition, bedrooms are defined as a material entity bordering on the corridor, filled with paintings leading to two sets of doors where the entrance doors are access controlled. The informal lounge area with furniture is also a material entity overlooking the nurses' station with various material objects as well as the reception area. All the material items are listed below:

TABLE 04:

Dining Room	Bedrooms	Corridor	Informal Lounge	Nurses' Station & Reception
Light grey vinyl flooring. Large windows and doors with floral curtains. Tables with white tablecloths and coloured accent cloth. Dining room tables combination of fabric and synthetic leather upholstery.	No internal observations done.	Light grey vinyl flooring. White painted wooden double doors with an opaque glass panel with a black access control keypad. Light pink plastered walls with various paintings donated from residents.	Oil heater Green Couches Maple veneer coffee table Vase with synthetic flowers Square Table Wingback chair Aloe plant TV	Telephone Books Files Fire Panel Bell Keys Desk and Counter

Comfort chairs in light pink fabric Kitchenette with timber melamine finish and black granite counter tops. Flat screen television mounted against the wall above a table with various CD's, documents and electronic equipment. Food: Bobotie, peas, potatoes and dessert		Door numbers on bedroom doors bordering on corridors, sometimes names are also presented on doors.		

4.2.1.2 PLACIAL TRIAD: A PERSON'S LIVED DIMENSION OF PLACE

The lived dimension revolves around the daily morning, afternoon and evening routines. For the purpose of this observation the focus is on morning and afternoon routines. Breakfast and lunch is served in the dining room of the dementia ward, and is a prolonged process where some residents eat by themselves and others are fed. Some residents seem to enjoy eating and others just eat as an automated response. Apart from eating, the morning and afternoon routine includes occupational therapy sessions where some residents participate in activities to the best of their abilities. The lived dimension of place in the dining room is shared with caregivers and nurses performing other activities simultaneously, such as the filling out of paperwork, while keeping an eye over some of the residents. Family and friends are also present reading, drinking coffee and talking to caregivers and residents. A further means of lived dimension is observed; such as the organisation of new appliances in the kitchenette, family members calling and organising medication for their loved ones, outside of the dementia ward, together with the matron and staff nurse. Residents outside the dementia ward are found in the informal lounge area, sitting and talking while observing others during the afternoon.

4.2.1.3 PLACIAL TRIAD: A PERSON'S MENTAL DIMENSION OF PLACE

A person's mental dimension of place is possibly the most difficult to observe. In the dementia ward there is family or a friend keeping their loved one company. The old lady is barely awake, but she is not alone as her family or friend is reading next to her and drinking coffee. In addition, there is a mood or atmosphere felt in the morning which is light and filled with some laughs and conversation among residents. There is a resident, Leigh, being fed in the dining room just staring at the ceiling or out of the window. She is only present on automatic response but seems to be somewhere else in her mind.

4.2.1.4 PEO MODEL: PERSON

The person is mainly referring to residents with moderate and severe dementia., There are also other stakeholders such as caregiver and family members; consequently making the person component of the PEO Model, both a group and institution "person".

4.2.1.5 PEO MODEL: ENVIRONMENT

When looking at the environment there are three distinctions made. The first distinction is the physical environments that consist of the frail care facilities dementia ward. The ward consists of bedrooms, bath rooms, a corridor and a living/dining room with a kitchenette. The second distinction is the environment as a social environment consisting of various dementia residents living together. The last and third distinction is the institutional environment, the dementia ward of the frail care facility; this is a regulated environment with procedures and routines as well as a business with a monetary value. It's important to note that there are environments closely associated with the dementia ward, although not situated in the ward, such as the nurses' station and reception as well as an informal lounge area.

4.2.1.6 PEO MODEL: OCCUPATION

The occupation of the dementia ward is concerned with self-care, leisure and productivity. Eating breakfast and dinner is associated with self-care even though most of it is done by caregivers, such as feeding. Occupational therapy activities can be seen as part of all three mentioned occupations as the activities are focused on health, social interaction as well as making and doing things in a group.

7 September 2018 – Day Two

I have just arrived at the facility and its 7:30. It's a cold and rainy morning; and it seems that everything is moving more slowly than the day before. The staff is in the dining room, busy setting the tables for breakfast; they seem relaxed. I am drained from yesterday's observations. Today I feel a bit out of place and in the way as the caregivers need to constantly engage with residents and I keep myself out of the way by sitting in the corner. It is important for me as the researcher to note my feelings as a part of my observation as it will impact the way I observe and interpret a situation. However, I acknowledge my feelings and undertake to remain as objective as possible.

Breakfast is served. Two lady residents had an altercation about a specific seat at the breakfast table. Staff leave the two residents to it for a minute before calmly guiding one of them to another table. Breakfast is served; some residents are fed by caregivers and others are managing on their own. I am interrupted for the signing of more consent forms.

It's 9:30 and two hours have passed since my arrival. The occupational therapy class is about to start; all the residents are moved to sit in a circle, in the front of the dining room while the TV is on with music playing. Suddenly the TV is switched off and a lady starts playing Afrikaans folk songs on the piano. There is an upright piano situated in a corner of the dining room and is played by an "outside" resident living in one of the free-standing homes in the retirement village. The residents seem happy and some are participating with the music. After a while of music playing and some singing, tea and marshmallows are served. One resident exclaims: "it's wonderful!" After tea is done the occupational therapy class continues and becomes more formal. The class starts with a formal greeting establishing the time and date. Some informal conversations are also part of the introduction and are prompted by asking questions. Physical, very low intensity, exercise/movement commences; flicking of fingers, touching one's head etc.

The old lady in the corner is present again, sleeping through it all. The lady keeping her company, perhaps a family member or friend, is also at her side. Another lady in a wheelchair was just brought in to the dining room; the caregiver explains she had difficulty getting up this morning. She is completely unable to help herself and I presume she has severe dementia. She is sitting with her hands crossed sleeping in her wheelchair. She receives an Ensure supplement as she is having difficulty eating the porridge the caregiver is feeding her. She finishes her Ensure supplement and is just sitting, with the caregiver holding her hand. The caregiver often rubs her hand when she falls asleep. I can't help but feel despair. I experience this feeling of despair perhaps as a result of my own experience with my grandmother's dementia.

Opposite me a student nurse and caregiver is having a conversation with a resident situated between them. The lady sits in an almost school desk setup; as it prevents her from standing up. She is a high risk for falling. With all this in the background occupational therapy is still continuing; it's time in occupational therapy class for some thinking activities. Questions are asked to the residents reflecting on their younger days and what hobbies they used to have. There is a lot of laughter happening. Its's11:30 and I will now break until lunch is served.

It's 12:30 and lunch is served. Everybody is sitting at the exact same seat around their respective tables as this morning. Here and there I spot a few residents that were not in the dining room for breakfast this morning. I presume they had breakfast in their bedrooms, I just realised that I am constantly referring to this space as the dining room, but in fact it is serving as both a dining, living and TV room simultaneously. Most residents are almost done eating lunch; the hairdresser has also arrived and is fetching residents one by one from the dining room.

There is a young, but very frail patient, sitting in a comfortable chair in the corner of the dining room near the TV. One of the caregivers is having a conversation with her, let's call her Mindy, who is not having any of it and is sleeping. Nevertheless the caregiver continues with the conversation. Opposite Mindy towards the entrance of the dining room is Leigh, also sitting in a

comfortable chair, being fed by one of the caregivers. It's the same as yesterday; she is far away staring at the ceiling or fiddling with her hands only engaging in an automated way.

Ultimately one of the caregivers asks who wants to go to their rooms in order to be assisted. I am not sure if anybody still in the dining room is able to answer or even heard, but there is no response. Evidently the frailest residents remain in the dining room. One of the residents who had her hair done walks into the dining room, very proud of her hair, and feels the need to hand a book to Leigh. Leigh is not interested in the book and sweeps the book to the side to continue looking at the ceiling and fiddling with her hands.

With all the frailest residents in the dining room, with the exception of the lady resident showing off her hair, some caregivers are also present. I ask one of the caregivers about the history of the lady with the hair, okay she must also get a name, so let's call her Sarah, in order to grasp a better understanding. The caregiver explains that Sarah used to be a teacher. Mindy seems to be coming around and is now awake wanting to engage in some conversation; she is not able to speak but is uttering sounds. The caregivers close by explaining that she can form words if you listen carefully.

Another frail resident, let's call her Lilly, is sitting in her school desk laughing and fiddling with her hands and a newspaper. She is helped out of her chair, walking to the dining room ablution, with the assistance of a caregiver. It's 15:00 and I am breaking for today with a total of 7.5 hours of observation.

4.2.2 FINDINGS OF DAY TWO SCHEDULED IN ACCORDANCE TO THE PLACIAL TRIAD AND PERSON ENVIRONMENT AND OCCUPATION MODEL:

4.2.2.1 PLACIAL TRIAD: A PERSON'S MATERIAL DIMENSION OF PLACE

The material dimension of place for the day's observation is predominantly focused on the dementia ward dining- and living room with its tables, large windows, curtains, comfort chairs, kitchenette with new appliances, TV and food. Bedrooms are also defined as a material entity bordering on the corridor filled with paintings leading to two sets of doors whereof the entrance doors are accessed-controlled. Breakfast is also served in the bedroom of residents; this is evident as new residents are in the dining room as opposed to the previous day.

In addition, the piano in the dining/living room is also a vital object that is used to entertain and stimulate residents. All the material items are listed below:

TABLE 05:

Dining Room	Bedrooms	Corridor	Dining Room Ablution	Hair Salon
Light grey vinyl flooring. Large windows and doors with floral curtains. Tables with white tablecloths and coloured accent cloth. Dining room table combination of fabric and synthetic leather upholstery. Comfort chairs in light pink fabric and synthetic leather. Kitchenette with timber melamine finish and black granite counter tops. Flat screen television mounted against the wall above a table with various CD's, documents and electronic equipment. School-type desk. Food- such as porridge and ensure supplements Newspaper Books Piano	No internal observations done.	Light grey vinyl flooring. White painted wooden double doors with an opaque glass panel with a black access control keypad. Light pink plastered walls with various paintings donated by residents. Door numbers on bedroom doors bordering on corridors, sometimes names are also presented on doors.	WC Pan Basin Mirror Bin Toilet roll holder	Hair -wash basin and chair. Mirror Styling equipment Glass shop front with blinds.

4.2.2.2 PLACIAL TRIAD: A PERSON'S LIVED DIMENSION OF PLACE

The lived dimension revolves around the daily morning, afternoon and evening routines. For the purpose of this observation the focus is on morning and afternoon routines. The serving of breakfast and lunch is done in the dining room of the dementia ward and is a prolonged process, where some residents eat by themselves and others are fed; there was a resident who ate breakfast seemingly later than other residents. New residents are present who were fed or ate in their rooms the previous day. The occupational therapy session is not the same as the previous day as an "outside" resident was playing folk songs on the piano and the formal occupational therapy session commenced after tea had been served. The occupational therapy activities were different. New activities, such as hairdressing, were introduced with some

residents having their hair done outside the dementia ward close to the nurses' station. Assisted walking and imposed restriction on certain residents are quite evident; the restriction is imposed on residents in the dementia ward.

4.2.2.3 PLACIAL TRIAD: A PERSON'S MENTAL DIMENSION OF PLACE

The mental dimension is quite dynamic as it is intertwined with other dimensions such as the rubbing of a hand while feeding a resident that falls asleep; it's an emotional affectionate response. The playing of Afrikaans folk music on the piano seems to also have an effect on residents perhaps reminding or keeping a memory and identity alive. A resident positively exclaimed her delight and joy that the music and tea made her feel happy. During the formal occupational therapy session residents are prompted to talk about their younger days and hobbies. In addition activities such as doing hair had an emotional response with a resident, Sarah, who was portraying confidence and pride in her appearance. Mindy also has a need to communicate and be understood. There is also Leigh who always seems somewhere else and also rejecting objects inferred by other residents, displaying an emotional response of refusal.

4.2.2.4 PEO MODEL: PERSON

The person is mainly referring to residents with moderate and severe dementia. There are also other stakeholders such as caregivers and family members; consequently making the person-component of the PEO Model both a group and institution "person". In this observation individuals are specifically focused on with specific names and characteristics; they are Sarah, Mindy, Leigh and Lilly. Lilly, Leigh and Mindy have severe dementia, whereas Sarah has moderate dementia. The focus of these residents is specifically on their emotional, physical interaction and response to objects, activities and other residents.

4.2.2.5 PEO MODEL: ENVIRONMENT

The three distinctions of the previous observation are also made for this observation. The first distinction is the physical environment that consists of the frail care facility's dementia ward. The ward consists of bedrooms, bathrooms, a corridor and a living/dining room with a kitchenette. The second distinction is the environment as a social environment consisting of various dementia residents living together. The last and third distinction is the institutional environment, the dementia ward and the frail care facility; this is a regulated environment with procedures and routines as well as a business with a monetary value. The environment promotes certain arrangements, such as circular or u-shaped seating configuration for occupational therapy sessions. The hair salon, a room, situated outside the dementia ward is also an important "external" environment where residents have their hair done.

4.2.2.6 PEO MODEL: OCCUPATION

The occupation of the dementia ward is concerned with self-care, leisure and productivity. Eating breakfast and lunch is associated with self-care even though much of it is done by caregivers, such as feeding. Occupational therapy activities can be seen as part of all three mentioned occupations as the activities are focused on health, social interaction as well as making and doing things in a group. In this observation, music and reminiscing is much focused, as well as self-care activities such as doing hair. The listening and singing along with the piano music can be seen as a leisure activity. Nevertheless, there is also the restriction of activities such as walking. Lilly has a risk of falling and needs assistance to walk; unfortunately, she will get up without warning and as a result, she is restricted by having her sit at a school desk setup which makes it impossible for her to stand up and walk on her own.

27 September 2018 – Day Three

It's 16:00 and I am observing the evening shift tonight. I have just arrived and have gone straight to the dementia ward in the frail care facility. Upon entering the dining room, or shall I say the multipurpose room, I find most of the residents sitting and playing with bubble wrap as part of their afternoon occupational therapy session that was just finished. My focus is immediately on the residents and care staff; consequently, I only noted in hindsight that the space is decorated with paper flowers stuck against the walls accompanied by the words: "Happy elderly week".

There is some conversation among the residents. Most of the care staff is preoccupied with residents. One of the few male residents is insisting on having breakfast, while Lilly sitting in her school desk is constantly uttering sounds and attempting to communicate while trying to get out of the chair/desk configuration. Lilly is constantly stroking the surface of the table.

It's 16:47 and the residents have started with dinner; soup and croissants are on the menu. The male resident, let's call him Frank, is on a mission to go home. He is wearing a black hat and is desperately trying to open the door leading to the garden. He is becoming more aggressive and has managed to open the door and is now walking in the garden. The garden is enclosed and is quite small. It's not too long before he is back in the dining room, now on his way to his bedroom. He re-enters the dining room with his hat, some books and a photo frame on his way to the garden again. Upon returning to the dining room again, the lady who is keeping her mom company, shows him to his room and upon greeting everybody and says she is off for the weekend.

It's 17:30 and some of the residents have gone to their rooms after finishing dinner. One of the residents, one not too familiar, has received a visitor and seems to know and recognises the visitor; even deciding on where to continue their visit. Meanwhile Sarah, still present in the dining

room, is reminiscing about one of the other resident's surname; noting that it is the same as her maiden name which makes her feel she is in the right place. Sarah is quite active and asking for a newspaper and cloth in order to help the staff clean the dining room.

It's 19:00 and the day staff have just left. The night staff is settling in and being briefed. There is a moment of no-care staff in the dining room and I am completely alone surrounded by eight of the lady residents residing in the dining room. The mood has changed completely; Lilly is seemingly sad and another lady, let's call her Sandy, crying loudly. After crying Sandy is lying on her arms at one of the tables and after a while gets up, seeking comfort from the other residents present. I am ethically not allowed to be in contact with any of the residents; hoping the night staff will soon take control of the situation. I am again in complete despair, although I am familiar with such behaviour.

Awaiting the presence of a caregiver I note that Mindy has been sitting in the dining room since my arrival; she seems very unhappy now and is uttering sounds of discomfort and frustration. Thankfully a caregiver has just checked in and is aware of my observations tonight. The matron has arranged and briefed the evening nurse on duty about my research with the necessary consent forms.

It's 19:20 and all residents have now returned to their bedrooms with the assistance of caregivers. Not long after and Lilly returns to the dining room with the assistance of a caregiver; the caregiver say she is restless and wants to move up and down constantly.

It's now 19:35 and medicine is being administered by the staff nurse; some residents like Lilly have returned to the living/dining room since leaving earlier. There is a total of five residents in the dining room just sitting around and taking their medication. Mindy is one of the residents in the dining room and needs to have her medication powdered in some food as she is not able to swallow tablets. Sandy is also walking around asking questions about the medication being administered.

Milo is being served to residents and it's now 20:15. The night staff is actively engaging in conversation and enjoying it very much. Lilly is drinking her Milo with assistance and having a slice of bread; her mood has lightened, and she is thoroughly enjoying the Milo. Sarah, who is present in the dining room, now excused herself and goes to bed.

It's 20:45 and a lady resident, let's call her Allison, is fast asleep, sitting in a chair. The caregiver notices and wakes her up to assist her to her room. Meanwhile Sandy is also encouraged to go to bed by one of the caregivers; she is not willing to cooperate. She is walking around with a handbag, constantly opening it to check what is inside. Lilly is now once again determined to get up and is getting very frustrated. At 21:00 Lilly is assisted to her room and she seems content with the decision.

It's now 22:00 and all residents are in their rooms; some asleep, others watching TV or just lying in bed. It is almost time for me to leave, but before I leave, I feel compelled to ask one of the caregivers if there is a lot of wandering by residents in the early morning hours. One of the caregivers responds to my question, noting that it happens but not very often. After six hours' observing I am done for the day.

4.2.3 FINDINGS OF DAY THREE SCHEDULED ACCORDING TO THE PLACIAL TRIAD AND PERSON ENVIRONMENT AND OCCUPATION MODEL:

4.2.3.1 PLACIAL TRIAD: A PERSON'S MATERIAL DIMENSION OF PLACE

The material dimension of place for the evening's observation is predominantly focused on the dementia ward dining- and living room with its tables, large windows, curtains, comfort chairs, kitchenette, TV and food. Bedrooms are also seen as a material entity bordering on the corridor filled with paintings leading to two sets of doors whereof the entrance doors are accessed-controlled. The bedrooms are noted as a space where residents return to for the evening to sleep. In addition, there are certain objects such as paper flowers, the surface of a table and desk, newspaper, a school desk configuration, cloth and comfort food such as Milo is very evident in this evening observation. All the material items are listed below:

TABLE 06:

Dining Room	Bedrooms	Corridor	Garden
Light grey vinyl flooring. Large windows and doors with floral curtains. Tables with white tablecloths and coloured accent cloth. Dining room tables combination of fabric and synthetic leather upholstery. Comfort chairs in light pink fabric and synthetic leather. Kitchenette with timber melamine finish and black granite counter tops. Flat screen television mounted against the wall above a table with various CD's, documents and electronic equipment. School-type desk and chair configuration. Food and comfort food such as Milo and croissants. Newspaper. Man with his hat and books.	Bed. Cupboard. Curtains. Basin with mirror. No loose carpets. Personal belongings such as photographs, paintings. Clothes and personal care items. Curtains.	Light grey vinyl flooring. White painted wooden double doors with an opaque glass panel with a black access control keypad. Light pink plastered walls with various paintings donated by residents. Door numbers on Bedroom doors bordering on corridors, sometimes names are also presented on doors.	Small enclosed garden with paving, grass and plants. The garden is enclosed with wall and palisade fencing and bordered by two sets of double doors; one leading to the frail care facility dining and living room, the other leading to the dementia ward dining and living room.

4.2.3.2 PLACIAL TRIAD: A PERSON'S LIVED DIMENSION OF PLACE

The lived dimension revolves very much around the daily routines such as morning, afternoon and evening routines. For the purpose of this observation the focus is on the evening routines. The evening routines are preceded by the afternoon occupational therapy session. Dinner is served around 17:00 pm in the dining/living room of the dementia ward within the frail care facility. Day and night staff exchange their shifts just after dinner; leaving some residents to go to their bedrooms and others remain in the dining area. There is a period where residents, in these observations, the frailest ones, are completely alone. During this period there is a need for walking, to be comforted and to be spoken to. Later the evening medication and a snack are served; some medication needs to be grounded for residents to swallow it. Some residents fell asleep in the dining room while others stayed in their rooms sleeping or watching TV. Around 22:00 all residents were in their bedrooms, with confirmation from one of the caregivers that there are some wandering occasionally during the late evening and mornings, but it doesn't happen very often.

4.2.3.3 PLACIAL TRIAD: A PERSON'S MENTAL DIMENSION OF PLACE

The mental dimension is quite different from morning and afternoon routine observations. It's evening and a resident is insisting on having breakfast and then to return home. The resident, a male, is aggressive and is forcefully trying to open the doors with all his belongings. After a walk in the garden, he returns to his home: his bedroom within the dementia ward. There is a lot of frustration from Lilly and severe sadness from Sandy. The sadness seems increased without the presence of caregivers. Later the evening the sadness diminishes with the serving of comfort food and drinks such as Milo. There is a back and forth uneasiness for Lilly deciding if she wants to be in her bedroom or in the dining/living room.

4.2.3.4 PEO MODEL: PERSON

The person is mainly referring to residents with moderate and severe dementia. Nevertheless, there are also other stakeholders such as evening staff; consequently making the person component of the PEO Model both a group and institution "person." In this observation individuals are specifically focused on with specific names and characteristics; they are Lilly, Sandy, Mindy, and a male resident. All of the mentioned residents have severe dementia.

4.2.3.5 PEO MODEL: ENVIRONMENT

The three distinctions of the previous observation are also made for the evening observation. The first distinction is the physical environment that consists of the frail care facility dementia ward. The ward consists of bedrooms, bathrooms, a corridor and a living/dining room with a kitchenette. The second distinction is the environment as a social environment consisting of various dementia residents living together. The last and third distinction is the institutional

environment, the dementia ward and the frail care facility; this is a regulated environment with procedures and routines. The institutional environment in this observation uses a shift system for caregivers; and as a result, there is a shift change from day to evening staff. Thus residents momentarily reside alone in either their bedrooms or the dining/living room. The garden is also an important environment in this observation as it allows residents to escape but not leave the facility; the question of home is evident in the environment of the male resident.

4.2.3.6 PEO MODEL: OCCUPATION

The occupation of the dementia ward is concerned with self-care, leisure and productivity. Eating dinner is associated with self-care even though much of it, such as feeding, is done by caregiver. The evening mainly consists of eating, getting ready for bed and taking medication. A snack is served with a comfort drink, Milo, which can be seen as a leisure activity as residents, such as Lilly, really enjoyed it. Other residents, if not kept occupied by OT or other stimulating activities, become sad in the evening, crying when alone and seeking comfort from other residents. There also seems to be restlessness among residents seeking to escape or just giving up and sleeping where they are situated. Restriction is once again a very large component in the evening observation as Lilly must be restricted during her time left alone between shift exchange to ensure she will not try to walk alone and fall.

28 September 2018 – Day Four

It's 07:30 and I just checked in at the dementia ward of the frail care facility. There is some excitement as the residents are getting a special treat today. The opposite dining room in the frail care facility is set for a special breakfast and all the residents will have a farmhouse breakfast. Tables are decorated with flower arrangements and all is quite festive and pretty. All residents are assisted to move across to the other dining room. This dining room is a bit different from the dining room in the dementia ward. It's a bit smaller and consists of a small living room space with carpet flooring.

After breakfast all residents return to the dementia ward via the garden, the two dining rooms face each other and their escape doors lead to the garden, and the morning continues as normal with an occupational therapy session and residents having tea in-between.

Its 13:00 and lunch is served in the same dining room as this morning; all residents are assisted to the dining room via the garden again. Upon lunch being served one of the resident's family members is present and is curious about my presence. I explain to her that I am doing my research at the facility from an architectural point of view am interested in the placial understanding of dementia patients. I ask if she will be willing to have a short informal discussion about her mother living in the dementia ward of the care facility. She agrees and speaks about

being unable to care for her mom although she wishes she can still be her primary caregiver. Her mom slowly but surely stopped interacting, becoming confused; where one day she completely stopped speaking and walking. She also mentions that her mother is completely aware of her surroundings but is not able to interact with the environment as a result of dementia.

During lunch I also have an informal interview with the day staff nurse in charge sitting in the lounge area in the dining room; this conversation will also be depicted under informal interviews in this chapter. After lunch the residents are assisted back to the dementia dining room again and the afternoon proceeds as normal with tea and OT activities.

Its 15:00 and I break for the day with a total of 7.5 hours of observation.

4.2.4 FINDINGS OF DAY FOUR SCHEDULED ACCORDING TO THE PLACIAL TRIAD AND PERSON ENVIRONMENT AND OCCUPATION MODEL

4.2.4.1 PLACIAL TRIAD: A PERSON'S MATERIAL DIMENSION OF PLACE

The material dimension of place for the day's observation is predominantly focused on another dining room, the frail care facility dining room, and is separated from the dementia ward dining/living room directly by means of a garden. The frail care facility dining/living room is situated in the same space but there is a distinction between the two. The dining room has grey vinyl flooring with dining tables and chairs whereas the living areas have carpet tile flooring with couches and wingback chairs. In addition, this dining room is decorated for a special treat for all residents. A kitchenette with the same finishes as that of the dementia ward is also found in this space close to the living room area. All the material items are listed below:

TABLE 07:

Dementia Ward Dining Room	Frail Care Dining Room	Garden
Light grey vinyl flooring. Large windows and doors with floral curtains. Tables with white tablecloths and coloured accent cloth. Dining room tables combination of fabric and synthetic leather upholstery. Comfort chairs in light pink fabric and synthetic leather. Kitchenette with timber melamine finish and black granite counter tops.	Light grey vinyl flooring. Large windows and doors with floral curtains. Tables with white tablecloths and coloured accent cloth. Dining room tables combination of fabric and synthetic leather upholstery. Kitchenette with timber melamine finish and black granite counter tops. Blue carpet tile flooring. Green couch and wingback chairs.	Small enclosed garden with paving, grass and plants. The garden is enclosed with wall and palisade fencing and bordered by two sets of double doors; one leading to the frail care facility dining and living room, the other leading to the dementia ward dining and living room.

Flat screen television mounted against the wall above a table with various CD's, documents and electronic equipment. School-type desk and chair configuration.	Flower arrangements on dining tables. Maple veneered coffee table.	

4.2.4.2 PLACIAL TRIAD: A PERSON'S LIVED DIMENSION OF PLACE

The lived dimension revolves very much around the daily routines such as morning, afternoon and evening routines. For the purpose of this observation the focus is on the morning and afternoon routines. The routine of the day is somewhat different from the previous observation as breakfast and lunch is served in the frail care facility dining room as a special treat for residents. It's a process where all residents in the dementia ward is taken to the frail care facility dining room via the garden. Stories are shared by a family member and staff nurse that are depicted under informal interviews in this chapter.

4.2.4.3 PLACIAL TRIAD: A PERSON'S MENTAL DIMENSION OF PLACE

The mental dimension is somewhat different from the previous morning and afternoon routine observations. Firstly, the mood for breakfast and lunch is different; it's very energetic and vibrant with all residents moving to another dining room that is decorated and served with luxury meals such as a farmhouse breakfast; it's out of the ordinary for residents.

4.2.4.4 PEO MODEL: PERSON

The person is mainly referring to residents with moderate and severe dementia. Nevertheless there are also other stakeholders such as evening staff; consequently making the person component of the PEO Model both a group and institution "person." There is also a family members present.

4.2.4.5 PEO MODEL: ENVIRONMENT

The three distinctions of the previous observation are also made for the morning and afternoon observation. The first distinction is the physical environments that consist of the frail care facility's dementia ward as well as the frail care facility's dining/living room and the garden. The second distinction is the environment as a social environment consisting of various dementia residents living together, but also family members contributing and visiting residents. The last and third distinction is the institutional environment, the dementia ward and the frail care facility; this is a regulated environment with procedures and routines. In this observation there is a shift between the dementia ward living/dining room and the frail care facility dining room via means of a transitional environment: the garden.

4.2.4.6 PEO MODEL: OCCUPATION

The occupation of dementia ward is concerned with self-care, leisure and productivity. Eating breakfast and lunch as well as doing occupational therapy sessions can be associated with self-care, but due to the nature of the day's breakfast and lunch it can be associated with both self-care and leisure. The key occupation for the day is the eating of breakfast and lunch as it is done out of the norm. The daily occupations of Dora and Allison will also be discussed under informal interviews in this chapter.

10 October 2018 – Day Five

It's 7:30 and I have just checked into the dementia ward at the frail care facility. Breakfast is about to be served. Mindy is sitting at one of the tables in her wheelchair fast asleep. Leigh is sitting in her comfort chair staring at the ceiling and touching her face. Lilly is sitting in her desk chair near the window with some lovely morning sun. The caregivers are busy cleaning bedrooms and others preparing for breakfast.

The season has officially changed, and I can see the staff is looking very happy and positive. Another resident forgot her teeth in the bedroom and is asking one of the caregivers to assist; everybody shares a laugh about the situation.

It's 09:00 and breakfast is still in progress and it seems that all is moving quite slowly. This could be due to the fact that all the floors are being stripped and sealed meaning all residents must stay in the dining room for four hours as it's not allowed to walk on the floors. The carpets from the passage leading to the frail care dining room must be taken out as it was noted from a health and safety audit that no carpets are allowed in the passage or rooms in the frail care facility. I wonder if the confinement in this dining room will have any impact on the daily routines of the dementia ward.

Upon looking around, the result of this confinement is already evident; there is a male resident from the dementia ward I have never seen before. He is sitting in his wheelchair at the table, having breakfast. He seems extremely frustrated and does not want any help eating; nevertheless, he is really struggling. He is slamming the table with his hands, uttering noises of anger and frustration. Apart from having difficulty to manage the eating utensils and being upset, he is falling in and out of sleep with his head almost dropping into his porridge.

It's 10:00 am and occupational therapy is about to begin; apart from a few residents being frustrated to be confined to the dining room, nothing is out of the ordinary.

It's 11:30 and the occupational therapy session is still in progress; today everybody is prompted to remember and share important daily activities via means of questions directed like: "Name

one thing you do every day". Residents are participating as well as they can, with some help from the occupational therapy facilitator.

It's 12:00 and it is announced that the floors are ready for traffic. Some of the frustrated residents leave the dining room. The dining room is now being prepared and lunch is served at 12:30. Lunch and the afternoon commence with no new or out-of-the ordinary routines or incidents.

It's 15:00 and I break for the day, with a total of 7.5 hours of observation.

4.2.5 FINDINGS OF DAY FIVE SCHEDULED ACCORDING TO THE PLACIAL TRIAD AND PERSON ENVIRONMENT AND OCCUPATION MODEL

4.2.5.1 PLACIAL TRIAD: A PERSON'S MATERIAL DIMENSION OF PLACE

The material dimension of place for the day's observation is predominantly focused on the dining/living room of the dementia ward. The floors of the corridor leading to the bedrooms are being stripped and sealed whereas the carpets of the corridor leading to the frail care dining/living room are being removed and replaced with vinyl flooring. Other material objects being prominent in the day's observation are a resident's artificial teeth, Mindy's wheelchair, eating utensils, as well as porridge. All the material items are listed below:

TABLE 08:

Dining Room	Dementia Ward Corridor	Frail Care Corridor
Light grey vinyl flooring. Large windows and doors with floral curtains. Tables with white tablecloths and coloured accent cloth. Dining room tables combination of fabric and synthetic leather upholstery. Comfort chairs in light pink fabric and synthetic leather. Kitchenette with timber melamine finish and black granite counter tops. Flat screen television mounted against the wall above a table with various CD's, documents and electronic equipment.	Light grey vinyl flooring. White painted wooden double doors with an opaque glass panel with a black access control keypad. Skylights. Light pink plastered walls with various paintings donated by residents. Door numbers on bedroom doors bordering on corridors, sometimes names are also presented on doors.	Blue carpet tiles White painted wooden double doors with an opaque glass panel with no access control keypad. Skylights. Light pink plastered walls with various paintings donated from residents. Door numbers on bedroom doors bordering corridors, sometimes names are also presented on door Notice Board with weather, date, season etc. Notice Board with dementia information, poems and prayers. Panel Heater.

Wheelchair A resident's artificial teeth. School-type desk and chair configuration.		

4.2.5.2 PLACIAL TRIAD: A PERSON'S LIVED DIMENSION OF PLACE

The lived dimension revolves very much around the daily routines such as morning, afternoon and evening routines. For the purpose of this observation the focus is on the morning and afternoon routines. The routine of the day is somewhat different as all residents must reside in the dining room due to floors being stripped and sealed. There is a new male resident in the dining/living room having breakfast and he is eating by himself; while eating he is falling in and out of sleep with his head dropping down. Another resident forgot to put in her teeth before breakfast. During the occupational therapy session residents are prompted to remember and identify activities they do every day.

4.2.5.3 PLACIAL TRIAD: A PERSON'S MENTAL DIMENSION OF PLACE

The mental dimension has a few new additions from previous morning and afternoon observations. The mood of the staff is light and there is a definite change in season. A female resident forgot her artificial teeth and the table is sharing a laugh with her about the incident. In contrast a male resident, who is not usually there, is present in the dining/living having breakfast with immense discomfort and frustration; the dining table is being slammed while refusing to be assisted.

4.2.5.4 PEO MODEL: PERSON

The person is mainly referring to residents with moderate and severe dementia. Nevertheless, there are also other stakeholders such as staff, family and external service providers; consequently making the person component of the PEO Model both a group and institution "person." In this observation specific individuals are focused on such as the male resident who is not usually present in the dining room as well as the institutional person being the staff and external service providers working on the floors.

4.2.5.5 PEO MODEL: ENVIRONMENT

The three distinctions of the previous observation are also made for this morning and afternoon observation. The first distinction is the physical environment that consists of the frail care facility's dementia ward dining/living room, the corridor as well as the frail care corridor leading to its dining/living room. The second distinction is the environment as a social environment consisting of various dementia residents living together, but also staff and external service providers. The

last and third distinction is the institutional environment, the dementia ward and the frail care facility; this is a regulated environment with procedures and routines. In this observation residents and staff are confined to the living/dining room of the dementia ward due to the restriction of access to the corridor; and consequently, the bedrooms and the rest of the frail care facility, as service and maintenance are in progress on the floor finishes.

4.2.5.6 PEO MODEL: OCCUPATION

The occupation of the dementia ward is concerned with self-care, leisure and productivity. Eating breakfast and lunch as well as doing occupational therapy sessions can be associated with self-care, but the occupation of this observation is different due to confinement. The male resident is eating with extreme frustration, anger and difficulty but it might be due to him trying to preserve his self-worth. Mindy is sleeping through breakfast and it's not associated with self-care. Apart from breakfast and lunch, occupational therapy sessions are as per normal and can be associated with self-care, self-worth and productivity.

03 January 2019 – Day Six

It's 16:40 and I have checked in for the evening. Residents are in the dining room having dinner. Soup is on the menu. Leigh is not in her comfort chair; she is sitting at the table with her eyes closed. Mindy is in her comfort chair near the TV, also fast asleep. Lilly is already in her pyjamas sitting in her desk chair being fed by one of the caregivers.

One of the resident's family members quickly came in and she seems annoyed with the caregivers. The TV is on and Jan Braai is on. Allison is present and is sitting in her wheelchair at the dining table. Leigh is now being fed by a caregiver and she is just staring in front of her with the ever-automatic response to the routine. Other caregivers are taking meals to bedrooms as not all the residents are eating in the dining/living room tonight. Medicine is already being administered at 17:00.

Leigh has a new haircut and Sarah is very impressed with it. The caregiver feeding Leigh is mentioning to the lady sitting next to her that all leftover food must be discarded, but should residents have leftovers they wish to eat later it can be kept in the fridge for them. Chicken, veggies and beans are now served after soup.

The access-doors to the ward are completely open to the rest of the frail care facility tonight. The doors to the garden are also open. Lilly, sitting close to the garden doors with a caregiver still feeding her, seems very happy.

It's 17:30 and Allison is still eating; she is a very slow eater. Another resident brought her own cookies along, Iced Zoo biscuits, and she is sharing them with another resident. They marvel at

how pretty the cookies are. Allison is still eating and is now counting relentlessly, in-between having bites of food. The counting is not completely consecutive. She starts at one-hundred-and-one and when at one hundred and ninety nine she struggles to transition to the two hundred series. She randomly starts with another series being six-hundred-or -three- hundred series.

Sitting close to Allison a caregiver is filling out the nursing care plan. One of the caregivers mentioned that she received a warning for smoking, and she is only allowed to smoke twice a day during a shift. Caregivers share a laugh about the smoking policy and the amount of stress they have in comparison with how much smoking is allowed. It's 17:43 and Allison is still counting and eating.

17:53 Allison is interrupted and must be taken to have wound care. The remaining residents are now completely alone in the dining/living room watching 7de Laan on TV. Meanwhile Lilly is confined to her desk chair, stroking the table. Allison is back and is starting to count again.

It's 19:00 and night staff has checked in. Residents are still watching TV in the dining room. More medicine is now being administered. Half an hour has passed and Milo with a slice of bread is now being served as an evening snack. Leigh's husband is visiting her.

It's now 20:00; Lilly and Mindy are taken to their rooms. Sarah is cleaning the dining room and Allison is fiddling and folding the table cloth at the table she is sitting. A few minutes later a caregiver interrupts Allison's folding and takes her to her room. One by one more residents are taken to their rooms.

There are only two residents left. The nursing care plans are just left in the dining room lying on the window sill and on some of the dining tables- it seems a bit careless. It's now 09:00 and all residents are in their rooms. One of the caregivers confirms that there is little wandering in the early morning hours as some residents use sleeping medication and others are not very mobile; nevertheless, it does happen. Rounds are done every two hours by caregivers checking diapers and turning residents who are not able to move themselves.

At 9:30 a resident comes down the corridor asking where her parents' room is as she is very unsure where they are. The caregiver shows her to her room.

All caregivers remain at the nurse's desk next to reception, with the access-doors remaining open. The nurses' station looks on to the access doors with the switchboard at the station, indicating bells ringing for assistance.

It's 00:30 and I am checking out with 7.5 hours of observation.

4.2.6 FINDINGS OF DAY SIX SCHEDULED ACCORDING TO THE PLACIAL TRIAD AND PERSON ENVIRONMENT AND OCCUPATION MODEL

4.2.6.1 PLACIAL TRIAD: A PERSON'S MATERIAL DIMENSION OF PLACE

The material dimension of place for the evening observation is predominantly focused on food, cookies, doors leading to the garden and the rest of the frail care facility, Lilly's desk chair, diapers and nursing care plans. All the material items are listed below:

TABLE 09:

Dining Room	Dementia Ward Corridor	Nurse's Station
Light grey vinyl flooring. Large windows and doors with floral curtains. Tables with white tablecloths and coloured accent cloth. Dining room tables combination of fabric and synthetic leather upholstery. Comfort chairs in light pink fabric and synthetic leather. Kitchenette with timber melamine finish and black granite counter tops. Flat screen television mounted against the wall above a table with various CD's, documents and electronic equipment. School-type desk and chair configuration. Food - such as soup, chicken, vegetables, Milo and bread. Eating Utensils Wheelchair A resident's artificial teeth. Nursing care plans on clipboards.	Light grey vinyl flooring. White painted wooden double doors with an opaque glass panel with a black access control keypad. In this observation the doors remain open. Skylights. Light pink plastered walls with various paintings donated by residents. Door numbers on bedroom doors bordering on corridors, sometimes names are also presented on doors.	Station desk Switchboard indicating bells ringing. Telephone Files

4.2.6.2 PLACIAL TRIAD: A PERSON'S LIVED DIMENSION OF PLACE

The lived dimension revolves much around the daily routines such as morning, afternoon and evening routines. For the purpose of this observation the focus is on the late afternoon and evening routines. The lived dimension of place for this observation seems to be a normal routine for staff and residents. it is as if most residents decided to remain in their rooms with only a

handful of residents, mostly with severe dementia, being in the dining room. The doors being open with limited restricted access were new and were not done in the previous evening observation. In addition, objects such as pretty decorated cookies entice conversation and a specific type of reminiscence with two lady residents. Further reminiscence is practiced by Sarah; Sarah participates in cleaning activities after dinner. Alison fiddles and folds the tablecloth until she is taken to her room. Residents are checked on every two hours for hygienic reasons or helped to be physically more comfortable.

4.2.6.3 PLACIAL TRIAD: A PERSON'S MENTAL DIMENSION OF PLACE

A person's mental dimension of place focuses on stressful and repetitive behaviour. The caregivers teasingly discuss the amount of stress they have in comparison to the amount of times they are allowed to smoke on a shift. In addition, Allison constantly counts while she is eating; struggling to always count cohesively and not being able to transition to the next numerical series, being it from one-hundred to two-hundred series higher or lower. Lastly a lady resident walking down the passage is looking for her parents' room in the dementia ward of the frail care facility.

4.2.6.4 PEO MODEL: PERSON

The person is mainly referring to residents with moderate and severe dementia. Nevertheless, there are also other stakeholders; consequently making the person component of the PEO Model both a group and institution "person." In this observation specific individuals are focused on, such as Sarah, Allison and Lilly as well as the institution.

4.2.6.5 PEO MODEL: ENVIRONMENT

The three distinctions of the previous observations are also made this evening. The first distinction is the physical environment that consists of the frail care facility's dementia ward's dining/living room, its corridor, the nurses' station with the informal living room opposite the station. The second distinction is the environment as a social environment consisting of various dementia residents living together, but also staff and family members. The last and third distinction is the institutional environment, the dementia ward and the frail care facility; this is a regulated environment with procedures and routines. In this observation the doors of the dementia ward towards the garden are completely open as well as the doors to the rest of the frail care facility usually regulated with the keypad for access control.

4.2.6.6 PEO MODEL: OCCUPATION

The occupation of the dementia ward is concerned with self-care, leisure and productivity. As the observation is an evening observation, occupation is mostly centred on self-care and leisure. Eating dinner, taking medicine, having wound care and being taken to bed can all be

associated with self-care. Whereas having Milo and sharing cookies is associated with leisure being objects and practices of relaxation and pander.

4.2.7 SUMMARY OF OBSERVATION FINDINGS

TABLE 10:

KEY FINDINGS							
DAY		**ONE**	**TWO**	**THREE**	**FOUR**	**FIVE**	**SIX**
	MATERIAL	Dementia ward's dining room with access controlled doors and a long corridor.	Dementia ward dining room. Hair salon just outside dementia ward.	Dementia ward dining room. Restrictive furniture. Paper flower decorations.	Dining room outside of dementia ward with different material characteristics. Garden in-between two dining rooms. Dementia ward dining room.	Dementia ward dining room. Objects that provoke conversation such as dentures. Objects that draw attention to obstacles such as eating utensils.	Dementia ward dining room. Dementia ward access control doors being completely open. Doors leading to garden open. Comfort food items such as cookies.
	LIVED	Eating breakfast and lunch. Occupational therapy.	Eating breakfast and lunch. Listening to music and singing along to folk music. Hairdressing. Restrictive movement.	Residents remain alone in bedrooms and dementia ward dining room for a long period of time when there is a staff change over.	Special breakfast and lunch; served in a space outside of the dementia ward. The dining room outside the dementia ward is accessed via the garden. Occupational therapy.	Eating breakfast and lunch. Residents are restricted to the dining room due to floor servicing in corridor leading to bedrooms. Occupational therapy.	Eating dinner. Residents remain alone in bedrooms and dementia ward dining room for a long period of time when there is a staff change over.
	MENTAL	A light morning atmosphere filled with laughter and conversation.	Sombre and slow morning atmosphere during breakfast. Delight and nostalgia during the music session	Aggression is displayed by a male resident trying to escape. Sadness and consoling among residents.	Mood is energetic and vibrant. Excitement and delight.	Jokes and conversations are made around a resident's dentures; sharing empathy and understanding. Discomfort and frustration for some residents as a result of being confined to the dining room.	Admiration and love shared over cookies. Stressed and repetitive behaviour while eating dinner. Wandering; a resident is looking for her parents' bedroom.

				Uncertainty; a resident is unsure of where she wants or should be in the evening.		Discomfort progress from frustration and discomfort to aggression.	
PEO MODEL	PERSON	Residents living with moderate and severe dementia. Caregivers. The person as a group and as an institution. Family and friends not living in the facility.	Residents living with moderate and severe dementia. Caregivers. The person as a group and as an institution. Resident of the retirement village not living in the dementia ward.	Residents living with severe dementia. Caregivers. The person as a group and as an institution. Different caregivers on evening shift.	Residents living with moderate and severe dementia. Caregivers. The person as a group and as an institution. Family members.	Occupational therapy. Caregivers. The person as a group and as an institution. Service providers. Family members.	Residents living with severe dementia. Caregivers. The person as a group and as an institution.
	ENVIRONMENT	Dining room in dementia ward. Institutional environment.	Dining room in dementia ward. Institutional environment. Hair Salon.	Dining room in dementia ward. Bedrooms in dementia ward. Institutional environment.	Dining room outside of dementia ward. Dementia ward dining room. Institutional environment.	Dining room in dementia ward. Institutional environment.	Dining room in dementia ward. Open dementia ward corridor.
	OCCUPATION	Eating breakfast and lunch-associated with self-care. Occupational therapy associated with health and leisure.	Eating breakfast and lunch-associated with self-care. Music session associated with leisure. Hairdressing associated with self-care and leisure.	Eating dinner associated with self-care. Escaping. Restriction.	A special occasion breakfast and lunch associated with self-care and leisure. Occupational therapy associated with health and leisure.	Eating breakfast and lunch-associated with self-care. Occupational therapy associated with health and leisure.	Eating dinner associated with self-care. Eating comfort food associated with leisure. Stressed repetitive behaviour through constant counting. Wandering.

4.3 AFFINITY SESSIONS

4.3.1 AFFINITY SESSION ONE

The first affinity session was held on 11 October 2018. Prior to the session consent forms were given and it was explained that all participants are at any stage welcome to withdraw from the session, should they wish to for any reason. There was no icebreaker, due to the staff being familiar with me, as the first three days of my research was mostly observation studies with the aim to get the staff to be comfortable with my presence, and for me to be amenable to them. The session comprised of five caregivers. The caregivers were briefed on the two personas developed, Annie and Susan, and what their respective dementia stages, characteristics and personalities are like. It was further explained to the caregiver that the personas are meant as prompts in order to relate to patients consisting of similar characteristics and personalities. All caregivers were informed that this was not a test in any way, and that there were no right and wrong answers. The task given for the session was structured in line with the Placial Triad and PEO Model in order to gain data that is in line with the models and evidently the understanding of place. The task given for the session was: Identify and write down an object, activity/place and story/emotion that are prominent in the morning and afternoon routines of Annie and Susan. The object, activity and story must be related to each other. The findings of this session are tabulated below with the images of the raw data collected during the session. The tabulated findings are related to the two models mentioned with the findings that will be discussed in chapter five. In addition, I made a point to going through all the data gathered and doing a short discussion with the participants should they wish to share additional information. These discussions were recorded on video and transcribed into the notes section under the morning and afternoon routines relating to the relevant participant. Each participant's findings were tabulated individually according to the Placial Triad and PEO Model.

Figure 23: The Commencement of the Affinity Session with Caregivers

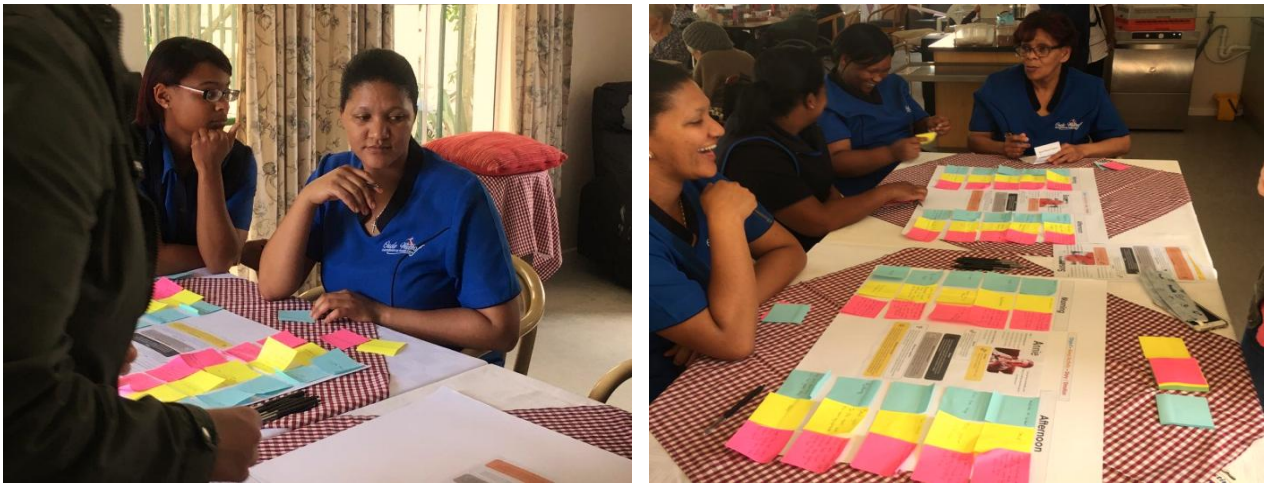


Figure 24: The Final Stages of the Affinity Session with Caregivers

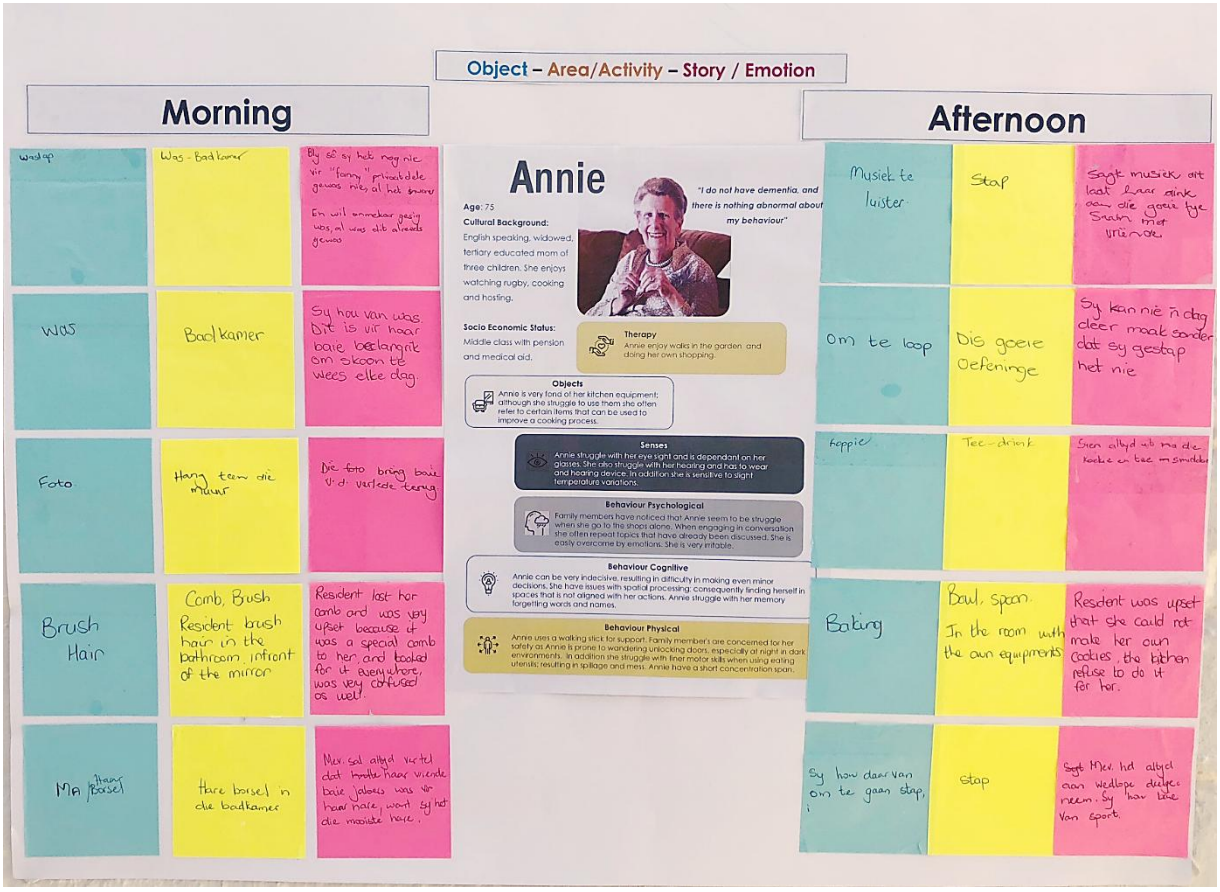


Figure 25: Raw Data Collected of Annie's Morning and Afternoon Routines

4.3.1.1 FINDINGS: ANNIE'S MORNING ROUTINE

TABLE 11:

PLACIAL TRIAD			
PARTICIPANT	**MATERIAL DIMENSION**	**LIVED DIMENSION**	**MENTAL DIMENSION**
01	Face Cloth	Washing in bathroom.	She keeps saying that she has not washed her private parts although the resident had.
02	Washing	Bathroom	She likes to wash; it is very important for her to be clean every day.
03	Photo	Photo hangs against the wall in bedroom.	The photo brings back a lot about the past.
04	Comb/Brush	Resident combs her hair in front of the mirror in the bathroom.	The resident lost her comb and was very upset because it was a special comb to her, and she took it everywhere- she was very confused about it.
05	Brush	Brushing hair in the bathroom.	Mrs would always tell how jealous her friends were of her hair as she had the most beautiful hair.

TABLE 12:

PEO MODEL			
PARTICIPANT	**PERSON**	**ENVIRONMENT**	**OCCUPATION**
01	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Built environment, shared ablution facilities, but only occupied by one resident at a time and shared with one or two caregivers assisting. The ablution facilities are accessed from the passage.	Washing is something that the person, Annie, is not able to do without the assistance of a caregiver. She is also concerned with washing specific areas to maintain her self-worth in order to be comfortable.
02	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Built environment, shared ablution facilities, but only occupied by one resident at a time and shared with one or two caregivers assisting. The ablution facilities are accessed from the passage.	Washing is something that the persona, Annie, is not able to do without the assistance of a caregiver. It is also an occupation that is of importance to the persona Annie to practise self-care.
03	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Built environment, Annie's bedroom, is only shared at certain times when caregivers or family assist with tasks.	Reminiscing about the past gives Annie joy and give her a sense of self-worth.
04	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Built environment, Annie's bedroom, is only shared at certain times when caregivers or family assist with tasks. Note that there is a mirror and basin in bedroom but not shower or toilet facilities. If brushing is done in bathroom then the built environment is a shared ablution facility, but only occupied by one resident at a time shared with one or two caregivers assisting. The ablution facilities are accessed from the passage.	Brushing and maintaining a neat appearance is important to Annie for maintaining self-worth.
05	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Built environment, Annie's bedroom, is only shared at certain times when caregivers or family assist with tasks. Note that there is a mirror and basin in bedroom but not shower or toilet facilities.	Brushing and maintaining a neat appearance is important to Annie for maintaining self-worth

FIELD NOTES FROM ACTIVITY AND RECORDINGS:

During the session participants seemed to enjoy the exercise and were comfortable working with Annie's persona. It was easily relatable although some participants were seemingly referencing the same residents. It was necessary to explain the identification of objects associated with activities and stories a few times as there was uncertainty about whether they had to be correlated. For myself as the researcher and facilitator of the session it was quite hard not to impose my ideas and understandings on the participants and I needed to step back and not give lead examples, as I felt that the results could be influenced in that manner. The session was done in the dining/living room facility of the dementia ward in the frail care unit; this might have helped participants identify specific residents relating to Annie's persona. It must also be noted that the morning information from participants 01, 02, 03 and 05 were translated from Afrikaans into English, but the original text is identified in the raw data collection image. The information below is additional information gained from a short discussion reflecting on the morning routines. Not all discussions are included below; only discussions that contained additional information is included, containing information not captured in the writings of participants.

Participant 01 Discussion:

Izoné McCracken: *Ok let's start with Annie's morning routine from the top down. Tell me about your morning routine story.*

Participant 01: *The object is the face cloth.*

Izoné McCracken: *Is the object important to her?*

Participant 01: *Washing, she is fond of washing. She gets washed in the bathroom. And she will always say we haven't washed "fanny" yet- her private parts. And her face; she is anxious about her face and "fanny". She likes to be clean (laughing).*

Participant 03 Discussion:

Izoné McCracken: *Who wrote about the photo?*

Participant 03: *O-okay so every morning she looks at a specific photo that hangs on the wall.*

Izoné McCracken: *What is the story behind the photo?*

Participant 03: *It maybe brings her back to her younger days; it's a photo of her in her younger days with her family. She talks a lot about her family in that photo.*

4.3.1.2 FINDINGS: ANNIE'S AFTERNOON ROUTINE

TABLE 13:

PEO MODEL			
PARTICIPANT	**PERSON**	**ENVIRONMENT**	**OCCUPATION**
01	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Environment is not specifically described, but from observation of the facility walking often occurs in the long corridor and garden space just outside the dining/living room. Listening to music, from observation, can either occur in Annie's bedroom or the dining/living room that is then part of a group activity.	Reminiscing and remembering or re-living the past brings joy and self-worth to Annie.
02	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Environment is not specifically described, but from observation of the facility walking often occurs in the long corridor and garden space just outside the dining/living room.	Walking can be associated with a leisure activity, although it can also contribute to self-care and self-worth for Annie.
03	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Environment is not specifically described, but tea and coffee is mostly served to residents in the dining room or in their bedrooms depending on their mood and preference to be in a communal space	Drinking tea and having cookies can be associated with self-care, self-worth as well as a leisure activity.
04	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	The environment is specifically described on two occasions as Annie's bedroom as well as the kitchen. From observation the kitchen refers to either the kitchenette in the dining/living room facility or the master kitchen in the clubhouse. Annie's spoon and bowl is described to be located within her bedroom.	Baking can be associated with a leisure activity as well as self-worth activity for Annie.
05	Annie is living with other residents in the dementia ward in a care facility. There is occasionally interaction with non-dementia residents as well.	Environment is not specifically described, but from observation of the facility walking often occurs in the long corridor and garden space just outside the dining/living room.	The walking can be associated with leisure and self-worth and self-care.

TABLE 14:

PLACIAL TRIAD			
PARTICIPANT	**MATERIAL DIMENSION**	**LIVED DIMENSION**	**MENTAL DIMENSION**
01	None identified.	Walking	Listening to soft music as it reminds her of times with her friends.
02	None identified.	Walking	She cannot make it through the day if she has not walked a bit- it is good exercise.
03	Cup	Drinking tea.	Having tea and a cookie is something she looks forward to every day.
04	Bowl and Spoon.	Bowl and spoon is in Annie's room; she likes to bake.	The resident was upset that she could not make her own cookies; the kitchen refused to do it for her.
05	None identified.	Walking	She really likes to go walking; she used to participate in marathons and is very fond of sport.

FIELD NOTES FROM ACTIVITY AND RECORDINGS:

During the session all participants were relaxed and enjoyed the exercise. Although the afternoon routine was done after the morning routine some uncertainties crept in; the information collected from participant 01 was not correlated and there was some confusion as to colour coding the information on post-it tags by participant 04. This was realised by some of the participants after the session. No additional information is added for afternoon routines, apart from mentioning that participants realised that some of the information did not correlate, as no information was shared containing additional understandings other than the written information received

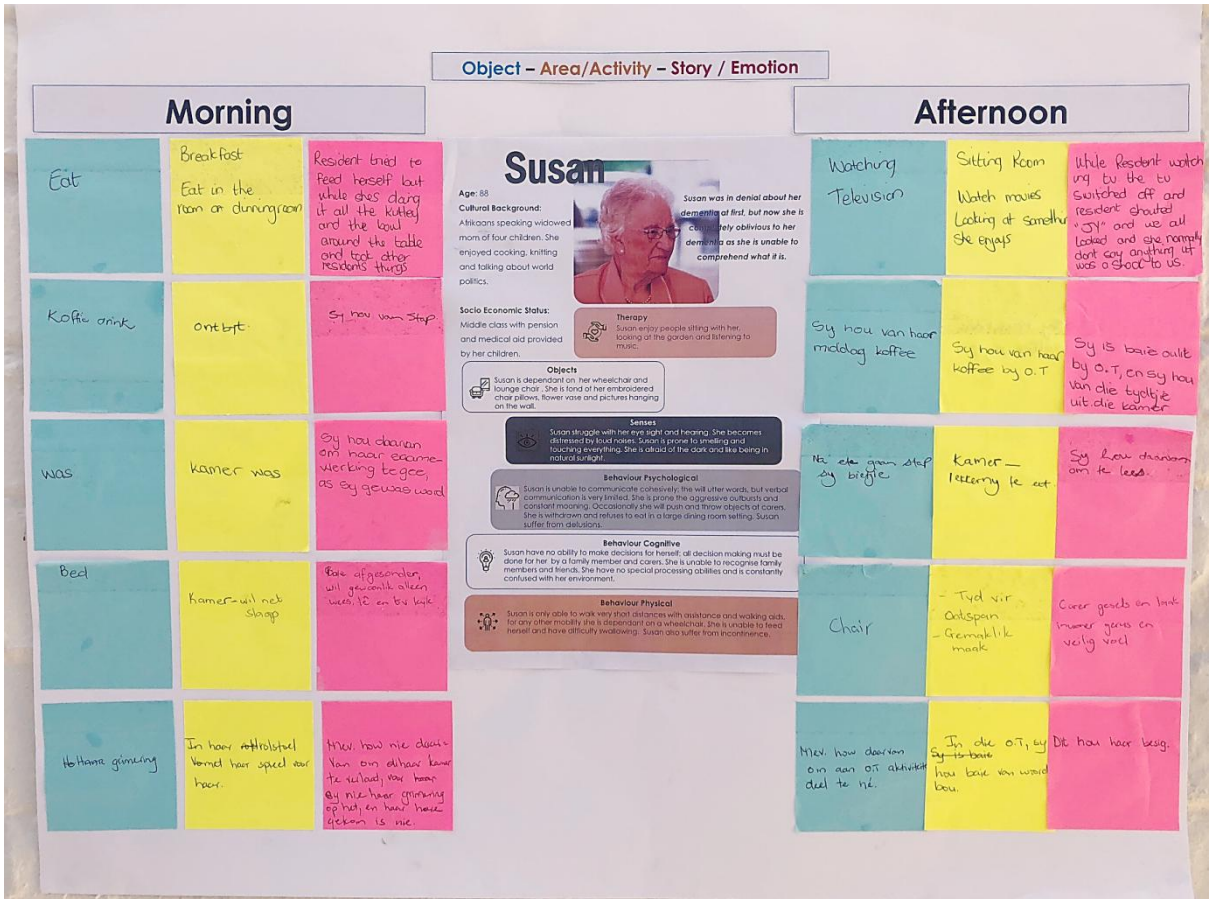


Figure 26: Raw Data Collected of Susan's Morning and Afternoon Routines

4.3.1.3 FINDINGS: SUSAN'S MORNING ROUTINE

TABLE 15:

PLACIAL TRIAD			
Participant	**Material Dimension**	**Lived Dimension**	**Mental Dimension**
01	No object specifically identified, but rather the activity of eating.	Eating breakfast in the dining/living room.	The resident tried to feed herself, but while she was eating, all the cutlery and the bowl fell down around the table and she took other residents' utensils and food in the process.
02	No object specifically identified, but rather the activity of drinking coffee.	No specific area is identified, but the activity of eating breakfast is identified. From observation breakfast is usually served in the dining/living room.	No story is identified nor a concept that is correlated with breakfast or drinking coffee. It is noted that she likes walking.
03	No object specifically identified, but rather the activity of washing/bathing.	Washing in her bedroom.	She likes to give her cooperation when she is being washed.

04	Bed	She wants to be in her room, and she just wants to sleep.	She is very isolated and usually just wants to be alone, lying down while watching TV.
05	Makeup	Sitting in her wheelchair with a mirror in front of her.	Mrs does not like to leave her room if her makeup is not done and her hair is not brushed.

TABLE 16:

PEO MODEL			
Participant	**Person**	**Environment**	**Occupation**
01	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of various tables with table cloths, upholstered chairs and a kitchenette facility. The room is large with many windows, curtains, and an ablution facility. The room is decorated with information posters. The space is shared with other residents.	Eating as an activity can be associated with self-care; even though Susan needs assistance with eating.
02	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of various tables with table cloths, upholstered chairs and a kitchenette facility. The room is large with many windows, curtains, and an ablution facility. The room is decorated with information posters. The space is shared with other residents.	Eating and walking can be associated with self-care and leisure.
03	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of basin and mirror, but no toilet or bathing facilities. It is shared at times with caregivers and family for assistance with tasks.	Washing and hygiene are associated with self-care and self-worth.
04	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of basin with mirror, bed, window and closet. The room is furnished with own furniture on vinyl flooring as no carpeting is allowed as a part of H&S requirements.	Sleeping in this sense is not necessarily associated with self-care; Annie is withdrawn and is not really participating. Watching TV can be associated with leisure but the question begs whether she is really watching or if the TV is on.
05	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of basin with mirror, bed, window and closet. The room is furnished with own furniture on vinyl flooring as no carpeting is allowed as a part of H&S requirements.	Grooming can be associated with self-worth and self-care.

FIELD NOTES FROM ACTIVITY AND RECORDINGS:

Susan's persona for morning activities was done after Annie's in the session. It seemed as if the immediate shift into another persona caused some confusion with the participants as Annie's persona was still very recent in their thought processes. No additional information that was not in the written context was shared upon discussion.

4.3.1.4 FINDINGS: SUSAN'S AFTERNOON ROUTINE

TABLE 17:

PLACIAL TRIAD			
PARTICIPANT	**MATERIAL DIMENSION**	**LIVED DIMENSION**	**MENTAL DIMENSION**
01	Television	Watching movies or something she likes in the dining/living room.	While the resident was watching TV the device was switched off and the resident shouted: "hey." We all looked and were shocked as she normally doesn't say anything.
02	No object specifically identified, but rather the activity of enjoying her afternoon coffee.	She likes her coffee while doing OT. From observation OT is usually done in the living/dining room.	She is really "oulik" in occupational therapy; participating and enjoys time out of her room.
03	No object specifically identified, but rather the activity of enjoying reading.	She likes eating something sweet in her room.	After lunch she likes walking.
04	She is fond of her chair.	She likes to relax and be comfortable.	When a caregiver talks to her it makes her feel safe.
05	She likes participating in occupational therapy.	She likes word building in occupational therapy.	Occupational therapy keeps her occupied.

TABLE 18:

PEO MODEL			
PARTICIPANT	**PERSON**	**ENVIRONMENT**	**OCCUPATION**
01	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of various tables with table cloths, upholstered chairs and a kitchenette facility. The room is large with many windows, curtains, and an ablution facility. The room is decorated with information posters. The space is shared with other residents.	Watching TV can be associated with a leisure activity as Susan only spoke when she was denied access to watching TV.

02	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of various tables with table cloths, upholstered chairs and a kitchenette facility. The room is large with many windows, curtains, and an ablution facility. The room is decorated with information posters. The space is shared with other residents.	The participation in OT and drinking of coffee while practicing activities can be associated with leisure activities as well as self-worth.
03	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of basin with mirror, bed, window and closet. The room is furnished with own furniture on vinyl flooring as no carpeting is allowed as a part of H&S requirements.	Eating, walking and reading can be associated as follows: Reading- leisure activity. Eating: self-care. Walking: leisure activity as well as self-care.
04	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of basin with mirror, bed, window and closet. The room is furnished with own furniture on vinyl flooring as no carpeting is allowed as a part of H&S requirements.	Being talked to and being in a place of comfort could be associated with self-worth and self-care as well as a leisure activity. She needs to be comfortable and someone to take care of her.
05	Susan is living with other residents in the dementia/Alzheimer's ward in a care facility. There is occasionally interaction with non-dementia residents as well.	From observation the built environment/room consists of various tables with table cloths, upholstered chairs and a kitchenette facility. The room is large with many windows, curtains, and an ablution facility. The room is decorated with information posters. The space is shared with other residents.	Participating in cognitive challenging activities in occupational therapy can be associated with a leisure activity, self-worth and productivity as being part of the group.

FIELD NOTES FROM ACTIVITY AND RECORDINGS:

Although Susan's morning routine was done in the session before the afternoon routines; it was as if the persona was not fully related to the information being written. As previously mentioned, I at the time of the session thought it might be due to Annie's persona being very recent in the thoughts of participants. Upon discussing the Susan's afternoon routines participant 03 and 05

commented that the activities and stories described may not be for a severe dementia patient. No additional information that was not in the written context was shared upon discussion as I noted that the caretaker participants were needed elsewhere, and they were aware of their time constraint in discussing any additional matters.

4.3.1.5 AFFINITY SESSION 01 FINDINGS SUMMARY:

TABLE 19:

KEY FINDINGS					
	DIMENSION	**Annie**		**Susan**	
		Morning	**Afternoon**	**Morning**	**Afternoon**
PLACIAL TRIAD	**Material**	Face cloth and photographs.	Bowl, spoon and cup.	Bed and wheelchair. Make-up	Television. Chair.
	Lived	Washing and reminiscing.	Walking and drinking coffee and tea with baked treats.	Sleeping. Applying make-up. Walking.	Watching television (or being aware of it) Participating in occupational therapy sessions.
	Mental	Practising self-care and self-worth. Need to feel wanted and admired.	Looking forward to receiving sweet treats. Keeping memories and practices alive through walking opposed to running in the past.	Isolation- wanting to sleep and be alone. The need for wanting to look pretty by applying make-up.	Being aware of surroundings when a television is switched off; motivating Susan to engage. A need for feeling safe.
PEO MODEL	**Person**	Annie with moderate dementia. Caregivers. Remembering family and friends.	Annie with moderate dementia. Kitchen staff. Caregivers.	Susan with severe dementia. Caregivers.	Susan with severe dementia. Caregivers.
	Environment	Bedroom(s) of Annie in the dementia ward. Institutional facility.	Dining room of the dementia ward. Garden(s) of the retirement village. Institutional facility	Bedroom(s) of Susan in the dementia ward. Institutional facility	Dining room of the dementia ward. Institutional facility
	Occupation	Washing and reminiscing.	Walking and wanting to bake.	Sleeping. Grooming.	Watching television. Participating in occupational therapy session. Eating and drinking.

4.3.2 AFFINITY SESSION TW0

The second affinity session was held on 28 October 2018. Consent forms were given prior to the session as I asked willing staff to participate prior to the session. I thanked all for their participation and also stated that they may ask questions any time and is allowed to leave at any stage should they wish to. The session comprised of six caregivers. Before the session started, I introduced the two personas to the group explaining their respective attributes. It was also explained that the personas were merely prompts to help caregivers to think of someone with the same attributes in order to answer the questions from experience. For the session various questions were posed where half of the group would answer them based on the Annie persona and the other half on the Susan persona. The questions could be answered by drawing, writing or even by imitating dialogue through speech bubbles. The questions for the session were structured in line with the Placial Triad and PEO Model in order to gain data that is in line with the models and evidently the understanding of place. Six questions were posed to the group and are listed below:

a. What is the physical behaviour of a person with dementia?

b. What is the psychological behaviour of a person with dementia?

c. How is a relationship maintained between family members and a person with dementia?

d. What difficulties do you as the caregiver experience physically and emotionally?

e. How is an environment maintained by a person with dementia?

The findings are captured below by means of a condensed summary of the information gathered for each question posed and by the various ways in which the question was represented and evidently answered. The questions were answered by writing snapshot observations by caregivers or dialogue heard, interacted and repeated by caregivers. The data was compared to the Placial Triad as well as the PEO Model. For this session the focus was not on individual participants as the session was hosted as a group activity. The data was accompanied by images of the raw data collected during the session, as well as photos of the session itself.

4.3.2.1 PHYSICAL BEHAVIOUR

Persona Annie

SNAPSHOT OBSERVATIONS

"She walks around and enters other people's rooms. She sleeps a lot and suffers from incontinence. Eats and forgets that she has eaten. Does not like drinking water. Talks incoherently."

"In the beginning of Annie's dementia, she just wanted to walk out. Annie also opens other people's bedroom doors. When she sits at the dining table, she tends to repeatedly slam her hands on the table."

"Annie sometimes talks consistently; and everybody in the surrounds was hanging on her lips. She was usually very quiet, and we were not used to Annie talking so much."

PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

In the snapshots given by caregivers looking at the physical behaviour of a person with dementia, the most evident aspect relating to the material dimension of place is the spaces consisting of doors and tables, more specifically bedrooms of other people or residents. In addition there is a component of food interrelated with eating and routine.

A Person's Lived Dimension of Place:

The lived dimension predominantly features the action of walking out, escaping or entering private spaces of other people or residents. In addition, various habitual practices are not considered to be normal, such as incontinence and eating.

A Person's Mental Dimension of Place:

A change in personality is evident where a quiet reserved person is suddenly outspoken. Incoherent speech is also an indication of restrained mental capabilities. Apart from being outspoken, aggression also manifests in eating routines through bodily gestures such as slamming the table. There is also a need for escape from a space or environment.

PEO MODEL TRAITS

Person: The focus from the snapshots given by caregivers is mainly focused on Annie as a person suffering from moderate dementia and only entering the spaces of other people.

Environment: The environments described mostly focus on spaces of eating and bedrooms of other people.

Occupation: The activities related to occupation mainly revolve around self-care and self-worth. This is attributed to eating, talking gregariously as well as displaying emotions of frustration and anger.

Persona Susan

SNAPSHOT OBSERVATIONS

"They throw things around, seek the nearest exit, and are assured that their vehicle is around the corner in the garage. They are forever on their way somewhere."

"Talk about things that happened years ago. Walking up and down as there is always something that must be attended to."

"Walk up and down. Wet them. Knock on doors and push and pull on doors. Chase the caregiver. They don't want to wash. Eat and just leave. They eat healthy. Pack their bags and look for their mother. Look through other residents' rooms and belongings. Take belongings and eat other residents' food in their bedrooms."

"Very aggressive. Walk up and down opening doors. Everybody is not always calm and doesn't want to wash. They pack their clothes and just want to go home. Take other people's belongings."

"Very positive and likes reading books; even if it is the same book repeatedly. Likes to tell stories that happened years ago. Sometimes very nasty to people"

DIALOGUE

"My mom is coming to fetch me; we are going to do groceries"

PLACIAL TRIAD TRAITS

Material dimension of Place: There is a lot of reference to material object-related to spaces. Firstly doors, either exit doors or doors leading to private spaces of others. Secondly a vehicle in a garage somewhere around a corner. In addition the packing in of personal items such as clothing is important, but the taking of other residents' belongings and food is also apparent.

Lived dimension of place: There is a focus on escaping, neglect of daily routines such as washing, and eating.

Mental dimension of Place: There is a focus on escape; not just physical but also mental. Reliving the past is crucial through the telling of stories, by wanting to go home as well as longing for care

by a mother. The taking of belongings is crucial; it is as if there is no distinction between wrong and right or having a conscience that stealing is not acceptable.

PEO MODEL TRAITS

Person: It is almost as if Susan as persona is referring to a few people living with severe dementia. The caregivers are using words like "they" and "everyone".

Environment: The environment is almost abstract; there is reference to spatial qualities such as walking up and down, perhaps a corridor, and going "somewhere" as well as "home".

Occupation: It seems as if there is no real sensible occupational output, except from the one caregiver mentioning that there is a love for reading even though it is the same book repeatedly. There is a lack in wanting to maintain personal hygiene as wells as a lack of care with eating and manners associated with communal eating and living.

4.3.2.2 PSYCHOLOGICAL BEHAVIOUR

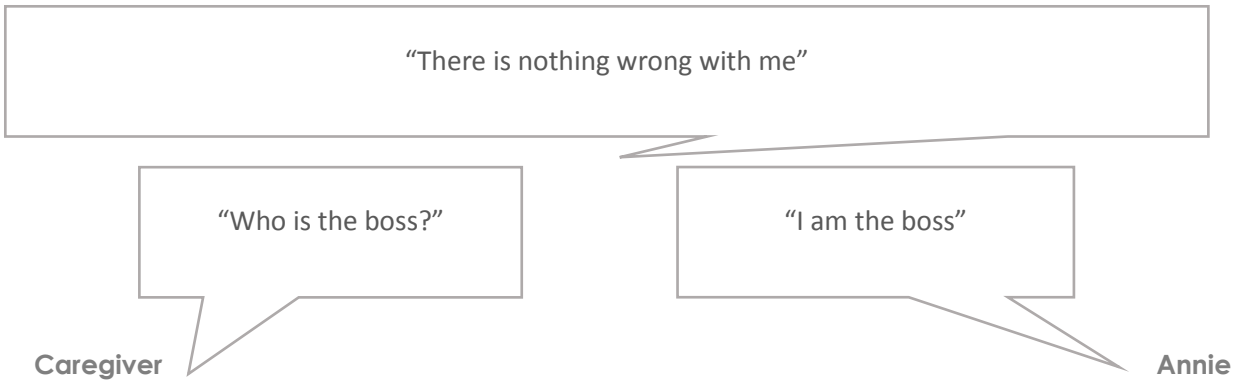
Persona Annie

SNAPSHOT OBSERVATIONS

"Annie can have a conversation, but she gets irritated quickly. She does not like it if you tell her that she is repeating herself."

"Annie can have a conversation. She gets scared sometimes. She wants to be left alone."

DIALOGUE



PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

The question posed directly links to the mental dimension of place. It is mentioned that Annie prefers her own company and not to interact with other residents or caregivers in her environment.

A Person's Lived Dimension of Place:

The lived dimension concerns everything happening to and in spaces, evidently places. In the snapshots little is mentioned, but having conversations with people in spaces can emulate a possible lived dimension.

A Person's Mental Dimension of Place:

Irritation, fear and withdrawal are quite evident in the snapshots of Annie, nevertheless it is noted that she is psychologically able to have conversations.

PEO MODEL TRAITS

Person: The focus from the snapshots given by caregivers are mainly focused on Annie as a person living with moderate dementia and being insistent and agitated. This is very evident in the dialogue.

Environment: There is no mention of the environment.

Occupation: Annie is able to have conversations, although she prefers not to.

Persona Susan

SNAPSHOT OBSERVATIONS

"Difficulty with acceptance. Withdrawn. She gets very angry except if she forgets what to say in order to complete the sentence."

"Sometimes very aggressive. One should not firmly address the patient. Easily become emotional and does not want to accept help."

"If you approach them you must talk to them with dearness. They become anxious and confused. They become emotional when alone and throw things around."

PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

The only material items mentioned in the snapshots are the throwing of things, presumably any objects within their vicinity.

A Person's Lived Dimension of Place:

The lived dimension concerns everything happening to and in spaces, evidently places. In the snapshots there is not much mentioned to constitute the lived dimension.

A Person's Mental Dimension of Place:

Aggression, being emotional and a loss of words are powerful mental constructs mentioned in the snapshots. Being very angry is stopped abruptly due to a loss of words to complete the sentence.

PEO MODEL TRAITS

Person: In the snapshots Susan is referred to as a person suffering from severe dementia, but the snapshots also mention "they" as numerous people suffering from severe dementia.

Environment: There is no mention of the environment.

Occupation: The physiological effect of being angry is hindered by the ability of comprehending words to express anger. Consequently, the occupation of becoming angry and expressing feelings are very difficult. The throwing of objects can be interpreted as a means of expressing anger as an alternative to verbal communication.

4.3.2.3 RELATIONSHIPS

Persona Annie

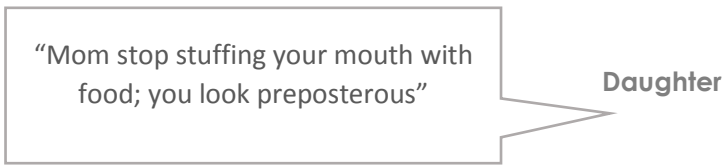
SNAPSHOT OBSERVATIONS

"Annie's daughter visited her often. But Annie began to talk less and less over time. Later Annie did not recognise her family anymore. Annie's' daughter kept on coming, trying to have some conversations. She always brought a treat for Annie to eat. Annie loved eating her treats."

"Family comes to visit often. Sometimes the family just want things to be the same. Many can't accept it. Family take their mom out for coffee without knowing the impact of their actions afterwards."

DIALOGUE

Annie's mouth is filled with food.



PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

There is a lot of emphasis on food being a means of caring as well as spoiling loved ones. Apart from bringing food, patients are sometimes taken on an outing to drink coffee or eat at a restaurant. Food is also associated with unacceptable behaviour as noted under the dialogue section.

A Person's Lived Dimension of Place:

Family visit patients at the facility or take them out for coffee. There are also families that feel things should remain the same; not related to their routines, but how their loved ones behave despite living with dementia. Interesting that the normality and the disturbance thereof for people living with dementia is something that is not accepted by family, and that their loved ones, despite living with dementia in a dementia facility should not change. Ironically it is the families who decide on specialised care for their loved ones as they are not able to deal with the manifestation of the dementia syndrome.

A Person's Mental Dimension of Place:

There is avoidance to accept the situation by the family as well as the patient. In addition, there is love and care but also misunderstanding and traits of being unkind to people with dementia. It is very hard and difficult displaying a mixture of mental and emotional dynamics.

PEO MODEL TRAITS

Person: The patient and family are both important; the patient is Annie in the snapshots referred to as a person living with moderate dementia.

Environment: The facilities, as well as external environments are referenced such as coffee shops.

Occupation: The occupation is both the emotional and physical relationship that needs to be maintained between family members and the dementia patient.

Persona Susan

SNAPSHOT OBSERVATIONS

"The family sometimes don't have a lot of patience with a patient as they constantly have to repeat themselves. If the family doesn't visit often the patient will likely forget who they are. Sometimes the family gets upset if the patient does something, and often things are taken away from patients."

"Some families do not have the patience while others make an effort to take them to church. Family also becomes upset and angry because they are not remembered by their loved ones."

"Photos they bring along on their phones or photo albums. Family get people to come to the facility and play music for the patient. Bring treats to eat or take the patient out for a walk in the garden."

"When it's a difficult and emotional day for a family member, we as caregivers tell family about good things that happened during the day in order to help the family not to be so sad or depressed.

"Give a gift such as a tie to his/her father if the father used to like wearing ties."

"We as caregivers are the people spending the most time with patients therefore, we make an effort to make things more pleasant for families and patients."

DIALOGUE:

"No, she is not my daughter. I know her; we used to go to school together."

PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

Family members bring treats and gifts for patients. The treats and gifts that are brought are items such as clothing items that they were very fond of, and sometimes still are, prior to developing dementia. In addition, digital media becomes a martial item where photos of family members are shown to loved ones. Physical printed albums are also used as a means of communication and a tool of interaction and remembrance.

A Person's Lived Dimension of Place:

Family members take their loved ones to church or for a walk in the garden. Others play music to their loved ones at the facility.

A Person's Mental Dimension of Place:

Care for loved ones with dementia are displayed in various manners, although it's clear there is hardship. Some family members don't have the patience to take a family member with dementia out and others are consumed by the gravity of the situation and become emotional. Here caregivers play an important role and remind the family members of positive occurrences which happened earlier the day. Caregivers are an emotional and physical connection to the patient for many family members.

PEO MODEL TRAITS

Person: In the snapshots Susan is referred to as a person suffering from severe dementia, but the snapshots also mention family members and caregivers. The caregivers are both a physical and emotional connection for family members and patients.

Environment: The facility as well as external environments such as a coffee shop, church or the garden is mentioned.

Occupation: The occupation is both the emotional and the physical relationship that needs to be maintained between family members and the dementia patient. Family members of the patient with dementia find it hard to maintain a relationship and become emotional and frustrated.

4.3.2.4 DIFFICULTIES

Persona Annie

SNAPSHOT OBSERVATIONS

"*Annie is a difficult patient. She is sometimes aggressive. One day she confronted two caregivers in her room. She wanted to hit them with a small table, but both caregivers were able to leave the room. They were very scared. When Annie was calmer the caregiver givers returned and told her what she had done. She could not believe it and she laughed*."

"*At times I become scared of Annie. I will leave her alone for a while or try another way to calm her. When Annie looks like she is feeling better I will continue with care*."

PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

There is a strong reference to Annie's room as well as other rooms as a means of refuge for the caregivers when Annie becomes aggressive.

A Person's Lived Dimension of Place:

The lived dimension here is concerned with care practices in the facility; being it in a room or communal area. It is about the physical and emotional struggle of caregivers in spaces.

A Person's Mental Dimension of Place:

Care for moderate dementia patients such as Annie is emotionally challenging. Caregivers need to stay calm and calm down Annie in order to take care of her.

PEO MODEL TRAITS

Person: In the snapshots Annie is referred to as a person living with moderate dementia.

Environment: The facility as well as rooms is mentioned as spaces where care is given.

Occupation: The occupation is concerned with the reaction and interaction in the care taking process of a resident with moderate dementia, Annie, but specifically the physical and emotional impact on caregivers.

Persona Susan

SNAPSHOT OBSERVATIONS

"*Remain calm and try to calm Susan. When she is calm, I will try again. Sometimes I become very emotional and will then talk to someone to calm down or ask for advice. It helps to talk to someone*."

"*I was once chased into another room. I closed the door behind me; although she tried to push the door open. Later when she calmed down she moved away from the door and I left. When I saw her later she was laughing at me. I always try to keep her calm as she can become very aggressive. I will also try to change her mind-set*."

"*I always try and keep the patients calm. I handle them with a lot of care. I will wait until the patient is calm and approach them differently*."

PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

Caring for people with severe dementia by caregivers can be physically demanding. At times patients become highly aggressive forcing caregivers to remove themselves from the area. There is little mentioned about the material dimension apart from a room and its physical attributes, especially the door.

A Person's Lived Dimension of Place:

Much is said about care within the facility. Mostly it is the struggle of taking care of Susan when she becomes difficult or aggressive.

A Person's Mental Dimension of Place:

Caring for people with severe dementia is emotionally challenging. Caregivers informally share their experiences with each other and develop a knowledge base to draw from for future encounters. Caregivers expressed that they often feel humiliated or unappreciated by the reactions of residents in their care.

PEO MODEL TRAITS

Person: In the snapshots Susan is referred to as a person living with severe dementia. Her caregivers are also referenced.

Environment: The facility as well as rooms is mentioned as spaces where care is given as well as being spaces of refuge.

Occupation: The occupation is concerned with the reaction and interaction in the care taking process of a severe dementia patient, Susan, but more so the impact of the care physically and emotionally on caregivers.

4.3.2.5 ENVIRONMENT

Persona Annie

SNAPSHOT OBSERVATIONS

"*Annie is calm in her room. She enjoys watching occupational therapy in the dining room and likes to walk out into the garden. She can differentiate between various types of flowers*."

"The *room must have a bed, a cupboard and not loose carpets. The bathroom must not have any loose items. The dining room must have tables and chairs that are not close to any stoves or hot equipment. The toilet must also be situated in proximity*."

PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

There are many items mentioned bound up to the material dimension of place, such as a bed, a cupboard, carpets, stoves, tables, etc. Flowers are also mentioned as a material entity.

A Person's Lived Dimension of Place:

The lived dimension of place is concerned mainly with items being an element of caretaking as well as emotional well-being. It is how the material entity items influences Annie's state of calmness in her room and her experiences in the garden.

A Person's Mental Dimension of Place:

Material objects are linked to behaviour such as being calm in a space and encouraging self-worth.

PEO MODEL TRAITS

Person: In the snapshots Annie is referred to as a person living with moderate dementia.

Environment: The environment is predominantly the facility with a focused on the bedroom but also referencing the broader environment like the dining/ living room as well as the garden.

Occupation: The occupation is broad as the question is focus on making sense of and managing the environment; consequently the occupation is concerned with daily routines but mostly the connection of the environment and the person with moderate dementia.

Persona Susan

SNAPSHOT OBSERVATIONS

"*In her room where she lives there must be photographs to remind her of her family. Also, books which she has read before, as well as furniture from her previous home. It creates a wonderful atmosphere*."

"*There must be many photos and books, as well as space to walk or to sit comfortably in a chair. The radio and television are also important*."

"*Listen to the radio while lying in bed or sitting in a chair. Constantly eating sweet things. Going to the toilet*."

PLACIAL TRIAD TRAITS

A Person's Material Dimension of Place:

Material objects mentioned are mainly photographs, books, furniture, especially a bed and a chair. The radio and television are also technological items that are mentioned and found within the bedroom space. Food is also evident, especially sweet items.

A Person's Lived Dimension of Place:

The lived dimension has to do with the with the daily routines taking place within the space of the bedroom, but also just being able to look at photographs, books, television as well as lying down while listening to the radio or sitting comfortably in a chair.

A Person's Mental Dimension of Place:

The objects and setup of the bedroom enable mental and physical connections to the environment. Therefore, the photographs can be reminiscent items as well as books and furniture items. The environments can also have a mental effect by calming and comforting the patient.

PEO MODEL TRAITS

Person: In the snapshots Susan referred to as a person living with severe dementia.

Environment: The environment is predominantly Susan's bedroom with objects of importance like photographs, furniture, books, television and radio.

Occupation: The occupation is broad as the question is focused on making sense of and managing the environment, but in the snapshots the environment is predominantly the bedroom. Consequently, the occupation dealt with is predominantly daily routines but also looking at photographs, listening to the radio, sitting in a chair and watching television.

4.3.2.6 AFFINITY SESSION TWO FINDINGS SUMMARY:

TABLE 20:

KEY FINDINGS			
		Annie	**Susan**
PLACIAL TRIAD	**Physical Behaviour**	Physical behaviour is related to material objects such as doors, as well as other residents' bedrooms. The lived dimension is focused on escaping the facility or entering other residents' private spaces. The mental dimension looks at extroversion as well as aggressive behaviour through physical bodily gestures.	Physical behaviour is related to material objects such as doors, as well as other residents' bedrooms. Imagined vehicles and garages are also mentioned as material objects linked with escaping. The lived dimension is focused on escaping as well as the entering of other residents' private spaces. Escaping also forms an important part of the mental dimension as there is a need for mental escape as well through longing for life before and parents.
	Psychological Behaviour	Annie wants to be alone; meaning alone in a space physically and mentally. Little is mentioned about the lived dimension. Aggression and withdrawal are the major mental constructs relating to Annie's psychological behaviour.	The material dimension can be linked to the throwing of objects although not specified. No mention is made about the material dimension of place. The mental dimension is concerned with aggression and being emotional accompanied by a loss of words when being angry.
	Relationships	Food is seen as a material object of interaction. Taking a loved one out of the facility environment is a lived dimension construct; going on an outing. The mental dimension intricate where the lack of acceptance and opposite emotions such as love becomes confused.	The material dimension is concerned with gifts and photographs. Going to church with family members and walking in the garden are activities associated with the lived dimension. The mental dimension has opposing emotions such as love and care versus lack of patience as well as grief.
	Difficulties	The material dimension is concerned with Annie's bedroom where care practices occur. The bedroom's mental construct is a refuge space for Annie as well as caregivers.	Not much is mentioned about the material dimension; only the bedroom and door. The lived dimension is concerned with care practices. The mental dimension is centred on the need for caregivers to share their experiences and receive advice.
	Environment	Many material objects within the bedroom space is mentioned; predominantly furniture and small personal items. The mental dimension is concerned with objects associated with a certain emotion or memory.	The material dimension is concerned with Susan's bedroom, but specifically photographs, her bed and chair. The lived dimension is focused on her daily routines occurring in her bedroom. The mental dimension looks at how the objects mentioned help to keep Susan calm in her bedroom while performing daily routines.

PEO MODEL		Physical behaviour of Annie living with moderate dementia related to the environment as the bedrooms of other residents. Occupation and physical behaviour are interlinked through the need of self-care and self-worth, as well as displays of aggression.	The persona Susan almost embodies various people in an abstract environment. There is no sensible output mentioned apart from reading. Other occupational outputs are displays of aggression and need for escaping.
	Psychological Behaviour	Little is mentioned about the environment, but Annie is able to have conversations although she chooses not to.	Susan living with severe dementia is the primary person. There is little mentioned about the environment. The occupation varies as it is concerned with behaviour, but a loss of words while becoming aggressive was prominent. The inability to express emotions verbally.
	Relationships	There are three stakeholders as the person; Annie, family members and caregivers. There is a strong focus on leisure environments such as coffee shops outside of the facility. The occupation is the maintenance of the emotional and physical relationship of residents with their family members.	There are three stakeholders as the person; Annie, family members and caregivers. Environments outside of the facility, specifically the church as well as gardens are mentioned. The occupation is concerned with the maintenance of the relationship between the family members and resident, but caregivers play an important role in the output of this occupation. They console both residents and family members.
	Difficulties	The primary person(s) are Annie and the caregivers. The environment is the dementia ward; specifically bedrooms. The occupation associated with difficulties is the daily care routines.	The primary person(s) are Annie and the caregivers. The environment is the dementia ward; specifically bedrooms. The occupation associated with difficulties is the daily care routines and caring in general.
	Environment	The primary person is Annie. The bedroom is specifically mentioned as the environment, with the daily routines within the bedroom as the occupation.	The primary person is Susan. The environment is her bedroom. The occupation is concerned with daily routines happening within the space of the bedroom.

4.5 INFORMAL INTERVIEW

An informal interview was conducted with a caregiver, Benay, who is mainly responsible for occupational therapy in the dementia ward. The interview was transcribed and coded according to the two theoretical models. Refer to Appendix B for interview transcription. Note that the name of the caregiver as well residents mentioned are pseudo names to protect their identities. The findings of the interview are reported below according to the two theoretical models.

4.5.1 PLACIAL TRIAD

4.5.1.1 A PERSON'S MATERIAL DIMENSION OF PLACE

There are three domains that stand out from the interview with regards to the resident's material dimension of place. The first domain is focused on objects used for occupational therapy

sessions such as skittles, puzzles, board games, etc. The second domain focuses on larger personal objects such as furniture items brought with residents to the facility from their previous residence. The third domain focuses on small personal items; items associated with identity and love. The small personal items are the most interesting as they provide insights of the person's identity such as a Christian man with strong moral values who loves and cares for his family. Another example is Mary, a resident, who has a sculpture of her husband's face in her bedroom.

4.5.1.2 A PERSON'S LIVED DIMENSION OF PLACE

The lived dimension focuses predominantly on activities associated with occupational therapy. Some residents choose to observe opposed to participating in activities. Other residents also practise habitual activities such as trying to help caregivers by fetching and showing other residents to their seats in the dining room as a result of their previous occupations and habits throughout their lives. Negative output such as beating caregivers with objects such as walking aids also occurs due to frustration. The frustration can be the result of not being able to perform certain tasks or due to psychological factors as the manifestation of the dementia syndrome. Lastly eating is also an important aspect of the lived dimension and is connected to morning, afternoon and evening routines.

4.5.1.3 A PERSON'S MENTAL DIMENSION OF PLACE

In the interview positive and negative mental traits are mentioned. Reminiscence is a strong concept that is prompted in occupational therapy, but also something that happens naturally for some residents. In contrast there are residents who choose not to speak about their pasts at all. In correlation with reminiscence; residents long for their homes; home as a place rather than a space. This notion is also evident in the rejection of the institutional facility, specifically the dementia ward, as a new residence. Refusing to accept the facility as a home; perhaps not being able to build a relationship with the environment physically as well as emotionally. Other negative emotional and psychological characteristics mentioned are aggression and a lack of confidence. The rejection of the facility as well as the frustration of not being able to be independent often leads to physical abusive behaviour towards caregivers. One of the residents, Henry, is prone to beating caregivers with his walking stick.

4.5.2 PEO MODEL

4.5.2.1 PERSON

The key stakeholders mentioned in the interview are: residents with serve and moderate dementia, caregivers, family members such as brothers and sisters and spouses. Mention is also made of residents' parents who have passed away, but various residents still think they are alive. Lastly the facility and group of residents' can be seen as a person, as an institution and as a group.

4.5.2.2 ENVIRONMENT

The environment is predominantly concerned with the facility, specifically the dementia ward. The dining room and the need for an additional or separate space for occupational therapy are mentioned. Additionally, remembered environments also feature; reference is made to places where residents grew up or their longing for their homes. Garden spaces are also an important environment where residents can escape to when needed while being protected from harm.

4.5.2.3 OCCUPATION

The occupation is concerned with daily routine activities such as eating breakfast, lunch and dinner as well as occupational therapy activities. These activities can be associated with self-care and self-worth. Additionally, negative outputs such as physical abuse towards caregivers are also noted. Frustration and abuse are the result of not being able to perform certain activities or an occupation such as independently assisting, helping caregivers to assist and move residents who are not able to help themselves.

4.6 PROTOTYPING AND MOCK-UP SESSION: MAPPING

4.6.1 OVERVIEW

A mapping exercise was conducted with two professional architects in a professional architectural office. The purpose of the mapping exercise was for the architects to use the two personas, Annie and Susan, as probes for the design of dwellings for each persona. Note that the findings of the affinity sessions, specifically the lived experience of people with dementia, were not shared with the architects as a part of this session. The reason for not disclosing the findings was to see how architects understand and uses the personas and understands facilities for people living with dementia currently.

Subsequently, two dwellings for each persona was built using Lego blocks, and after building the dwellings each architect had to discuss how they came about their designs. In addition, it was explained to the two professional architects that the aim of the exercise was not to necessarily depict and build pragmatically resolved dwellings, but rather to build conceptual models that capture the essence of each persona. The process and discussion thereof proved to be collaborative. For that reason, the two dwellings for each persona will be discussed simultaneously looking at the placial dimensions and PEO model collaboratively. Each finding will be prompted with photographs of each dwelling as supporting evidence for the discussion.

4.6.2 DWELLINGS FOR PERSONA ANNIE

Figure 27: Participant 01 Lego Mapping – Dwelling for Annie

Figure 28: Participant 01 Lego Mapping Perspectives – Entrance to Annie's Dwelling

Figure 29: Participant 01 Lego Mapping Perspectives – Garden and Reception Area of Annie's Dwelling

Figure 30: Participant 02 Lego Mapping – Dwelling for Annie

4.6.2.1 FINDINGS OF DWELLINGS FOR PERSONA ANNIE

The dwellings constructed for Annie by both participants show a sincere interest in her therapeutic needs as well as her background. The persona, Annie a lady with moderate dementia, was recognised as an individual centre to the dwelling, but there was little regard for other persons as support for Annie's daily activities and routines. For that reason, the lived dimension of place is somewhat disregarded when considering the lifeworld and daily activities associated with it. The lived dimension and occupation of Annie was considered to some degree. Both dwellings focus on providing a garden with a physical and visual connection to the rooms; as well as a dining table as central part of the dwelling as she is fond of entertaining. Participant two also mentioned that yellow Lego blocks represent a low wall with garden bedding to enable Annie to have tactile stimulation and that it will serve as support and a directional barrier. In other words, dictating her movement through supporting her and providing textured surfaces that can be pleasant for her to touch. The garden walls of participant one's dwelling is much higher than that of participant two; serving as a barrier to avoid escaping and getting lost if wandering occurs. Participant one also considered physiological environment factors; temperature variants between internal and external environments and opted to provide a roof structure that can help regulate these variants as it was noted that Annie is sensitive to temperature changes.

4.6.3 DWELLINGS FOR PERSONA SUSAN

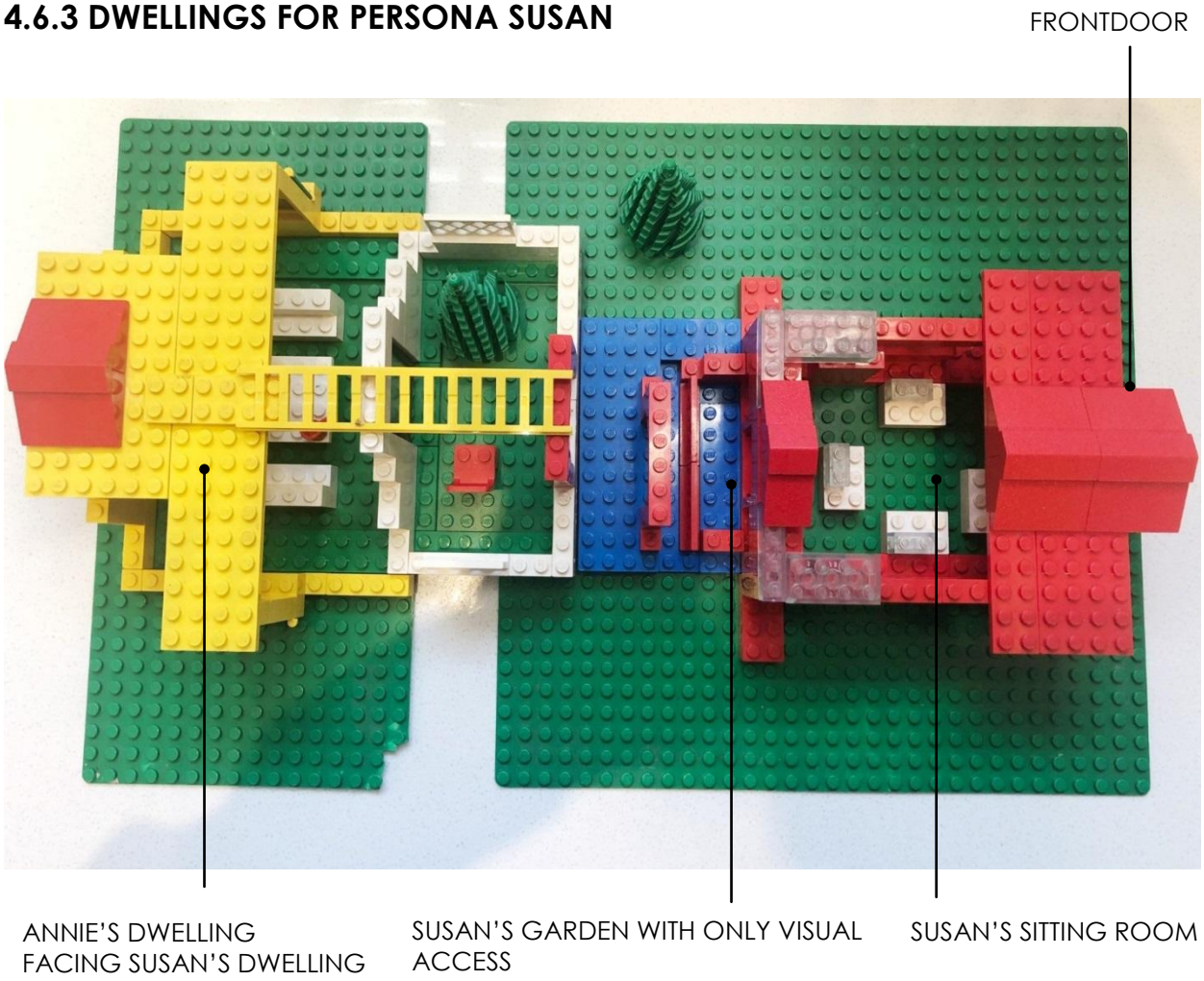


Figure 31: Participant 01 Lego Mapping –Dwelling for Susan

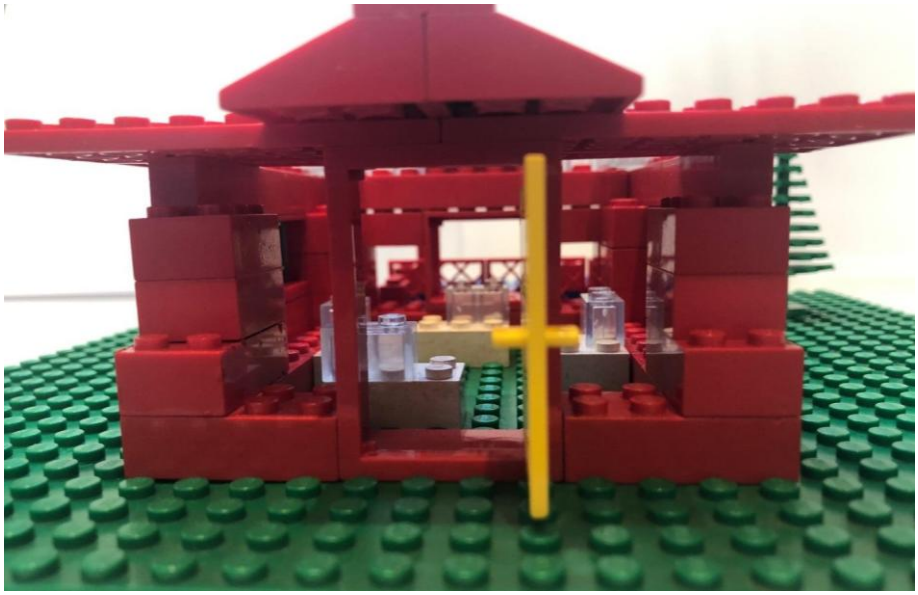


Figure 32: Participant 01 Lego Mapping Perspectives – Entrance to Susan's Dwelling

Figure 33: Participant 01 Lego Mapping Perspectives – Garden and Living Area of Annie's Dwelling

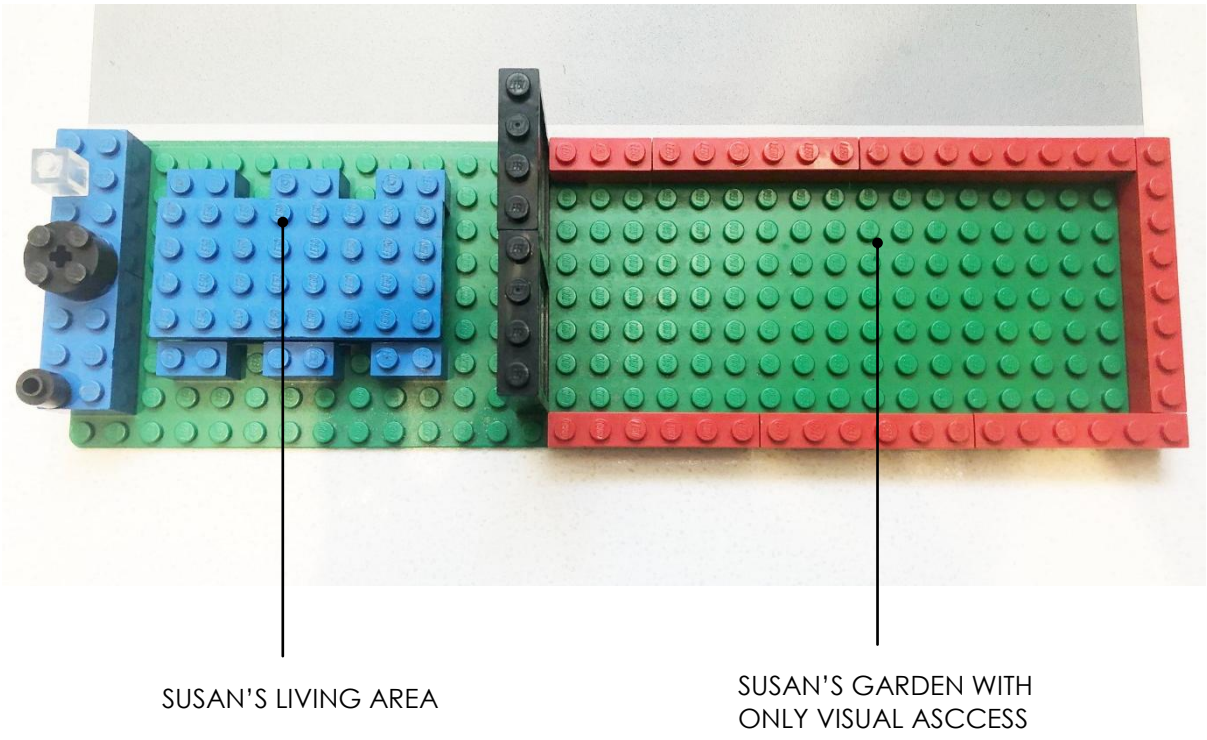


Figure 34: Participant 02 Lego Mapping –Dwelling for Susan

4.6.3.1 FINDINGS OF DWELLINGS FOR PERSONA SUSAN

The dwellings constructed for Susan are very much focused on Susan, a lady with severe dementia, as the primary person's centre to the dwelling, with little and no mention of persons of support or family apart from provision for seating space for people to sit with Susan. The lived dimension of place, especially about daily activities and routines, are also somewhat disregarded as the focus of the dwelling is in a sitting room and with a view to the garden. This indicates that there is a sincere of focus on Susan as the centre to the design, but not necessarily to Susan as a person with dementia situated in the lifeworld. Both dwellings also strongly focus on the restriction of movement to the outside of the dwelling; both have views to the garden but no access to prevent from Susan escaping or getting injured. The views of the garden were incorporated in the design of the participants to establish a calming outcome as linked with the mental dimension of place. Participant one specifically considered a waterfall and view to another resident, without access to it, as a mental stimulation outcome. The environment with regard to the broader context is not considered by participant two as in the case of participant one; participant considered a visual connection to other residents for Susan where participant two only focused on the dwellings as isolated entities. Little to no mention is made of material aspects of the dwelling for Susan.

4.7 METHODS COMPARISON

TABLE 21:

KEY FINDINGS					
		OBSERVATIONS	**AFFINITY METHODS**	**INTERVIEW**	**MAPPING**
PLACIAL TRIAD	**MATERIAL**	Dementia Ward dining room. Dining room outside of dementia ward in frail care facility. Hair Salon. Restrictive furniture to prevent residents' from moving when they are considered a risk. Access control doors of dementia ward. Comfort food items. Eating utensils.	Moderate dementia: personal items Severe dementia: essential furniture items Food as items for maintaining relationships as well as objects of interaction Bedrooms are associated with difficulties for caregivers Bedrooms are the areas where residents need to maintain a relationship with their environment	The material dimension is bound to objects used in occupational therapy sessions such as: skittles dominoes and puzzles. Personal furniture is important items to maintain a relationship with the environment. Personal items such as photos, hats, Bibles etc. help residents keep a sense of who they are and where they come from. A sculpture of a loved one's face is also a prominent personal item. There is a lack of updated posters in the facility to help orientate residents. Insights are given with regards to additional spaces needed; a separate space for occupational therapy would be ideal. The garden is an important space for residents.	The material object is bound to objects of the built environment as well as furniture. They are listed below: Front doors for Annie and Susan. An access door to the garden only for Annie. Dining table for Annie. Plants and garden space for Annie. A built waterfall for Susan. External roof structure to regulate the temperature variants between internal and external environments for Annie
	Mental	Light morning atmosphere on first day of observation. Sombre and slow morning atmosphere on the second day of observation.	Maintaining a relationship with the environment through objects; these objects are associated with an emotion or memory.	Residents reminisce about their past; it is sometimes prompted and at other times it occurs naturally. Objects and activities help with reminiscence.	Annie is fond of entertaining guests. The garden and the view of the garden are calming for both Susan and Annie.

		Energetic vibrant mood when residents are treated to a special breakfast and lunch. Delight and nostalgia during music session. Sadness when residents are left alone for long periods of time. Uncertainty among residents where they should be in the evening. Discomfort and aggression among residents when confined to one space for a period of time. Admiration and love because of food items. Stressed and repetitive behaviour when eating dinner. Wandering in the later part of the evening; longing for parents.	Physical behaviour is predominantly associated with aggression, withdrawal and the need to escape the facility mentally. Emotions and thoughts related to maintaining a relationship between family members and residents seem to have opposing emotions: grief, love, lack of patience and anger.	Some residents do not like to speak about their past. Some residents' lack confidence in participating and answering questions due to a group setting. A lack of acceptance of the facility as their residence. Entitlement as a result of a profession a resident previously pursued or practised. Aggressive behaviour among residents. Possessiveness over personal items, especially with reference to the sculpture of resident's loved one.	The restriction of movement and the lack of considering broader activities and stakeholders may have other impacts mentally on Annie and Susan.
	LIVED	Occupational therapy sessions. Eating breakfast and lunch. Being treated to special breakfasts and lunch in another environment outside of the dementia ward. Restricting movement of residents. Residents, especially residents with severe dementia, left alone in spaces for long periods of time.	Focused on escaping the facility. Crossing boundaries by entering other residents' private spaces. Taking residents outside the facility is an important activity for residents and family members to maintain a relationship. Most difficulties with caregivers and residents are centred on daily routines, such as getting dressed or eating.	Eating breakfast, lunch and dinner. Occupational therapy; physical and mental exercises. Prefer observation opposed to participation. The need of residents to help and assist other residents as a means of previous practices in life. Story telling. Perception Activities.	Annie is fond of entertaining guests. Walking in the garden is important for Annie. People sitting with Susan. Restriction of movement to the outside of the dwelling, preventing Susan from escaping and injuring herself.

PEO MODEL	**PERSON**	Residents living with severe and moderate dementia. Caregivers. Friends and family residing outside the facility. The person as a group and institution.	The key stakeholders are Annie, Susan, Caregivers as well as family members.	Residents living with severe and moderate dementia. Family members such as brothers and sisters. Spouses of residents. Parents of residents as current figures but who passed away.	The persons mentioned are the two personas and people in general being entertained or sitting with Susan as general stakeholders.
	ENVIRONMENT	Dementia ward as an institutional facility. Dining room in dementia ward. Bedrooms of residents in dementia ward. Dining room outside of dementia ward, but still within the retirement village. Open access control doors of dementia ward corridor.	Various environments are mentioned. The facility in general as well as the residents' bedrooms is key spaces. Environments outside of the facility are also mentioned as environments that help to facilitate the relationship between family members and residents such as a coffee shop and church.	Dementia ward as an institutional facility. Dementia ward dining room. A past place; such as a place where a resident grew up. Garden. Dementia Ward corridor.	An abstract dementia facility. Annie's dining area. Annie's reception and garden area. Susan's sitting area, garden and living room.
	OCCUPATION	Eating breakfast and lunch associated with self-care. Occupational therapy associated with health and leisure. Music sessions associated with leisure. Hairdressing associated with self-care and leisure. Escaping Restriction of movement. A special breakfast and lunch associated with leisure. Eating comfort food associated with leisure. Stressed and repetitive behaviour	Occupation is concerned with daily routines, emotional well-being, as well as residents' choice and ability to engage and give expression to their feelings.	Eating in general. Participating in occupational therapy activities. Story telling. Not talking. Observing other residents. Residents assisting other residents. Beating caregivers with objects as a result of the lack of desired occupation.	Entertaining of guests by Annie. Annie walking in the garden. Sitting (Susan). Susan viewing the garden as well as Annie's dwelling. Risk management by restricting movement for escaping purposes. To project Susan from getting Injured.

Chapter Five

CRITICALLY LOOKING AT DEMENTIA AND PLACE – DISCUSSION ON FINDINGS

5.1 APPROACH ON DISCUSSION AND FINDINGS

Discovering dementia and reflecting on the literature dealt with, it is important to start this chapter by reinforcing the research problem, question and sub questions. Thus, this paper has explored numerous degrees of key concepts pertaining to dementia, people living with dementia, phenomenology and place making in architecture. Therefore, it is important to now bring all of these concepts together and discuss them by critically looking at the research problem, questions and sub questions while giving a holistic overview of the concepts dealt with according to the data collected and literature reviewed. In doing so, this chapter aims to uncover what theory in the compilation of concepts and practices can help architects in understanding place for designing NGO dementia facilities. As the concepts discussed in this paper are very elaborate and interlinked, I will start by systematically listing and discussing the findings, uncovering the questions, concepts and data together. Therefore, this chapter will be outlined as follows: the key research question will be delineated followed by the sub questions. The sub questions will be answered first by discussing and answering each question through the data collected and literature reviewed throughout the paper. After answering all the sub questions, the key research question will be answered. Please note that each question will be dealt with separately with sub headings in order to unpack and discuss the information systematically. The questions to be discussed are:

RESEARCH QUESTION: What are the design considerations from an architect's perspective to design person-centred dementia care facilities?

SUB QUESTION 01: What are the post diagnostic facility care options for people with dementia?

SUB QUESTION 02: How could the placial relationships of persons with dementia correlate to architectural elements of dementia facilities?

SUB QUESTION 03: What are the challenges experienced by persons involved in dementia care in a specific place?

5.2 WHAT ARE THE POST DIAGNOSTIC FACILITY CARE OPTIONS FOR PEOPLE WITH DEMENTIA?

5.2.1 CONTEXT AND AWARENESS

The diagnosis of dementia has been discussed as a problematic and difficult task. Dementia is an umbrella term for a set of symptoms and underlying diseases that predominantly occur in the later stages of a person's life and cannot be detected through a blood test but rather through a neuropsychological assessment. Establishing that a diagnosis of dementia is quite difficult; the considerations of post diagnostic care options can be just as intricate and difficult.

Firstly, it is realised that context is very important; the two theoretical models addressed environment, but not necessarily context. Context, as another important construct, is of vital importance to all research subjections as well as the primary question. As a result, South Africa's diverse population and unequal healthcare systems force the majority of the population to rely on under-resourced healthcare services. Only a small percentage of the population have access to private medical health care and usually at a large expense. To put this in perspective: there are about twelve dementia residents at the NGO facility where data collection was done with an average annual cost for residency of around R240 000 per resident. The average annual salary in South Africa currently is R238 300 for the middle- income population (BusinessTech, 2019). The problem is evident for people earning minimum wages who are supporting loved ones with dementia as well as for pensioners living with dementia. It was noted that most of the residents in the facility receive financial support from family members by some means to be able to afford living in an NGO care facility.

Dementia awareness in South Africa is limited; this also limits the number of facilities orientated towards dementia care; making occupation specific architecture quite rare in the case of dementia design (Prince *et al.,* 2016:97). The absence of awareness varies for various socio-economic groups and cultures in South Africa. This is evident where in townships or informal settlements, dementia is seen as witchcraft or a state of madness that cannot be cured (Prince *et al.,* 2016:97). Considering the understanding of dementia among various cultures and income groups, the belief in and understanding of a dementia diagnosis, or rather a neuropsychological assessment proves to be challenging. I will even contend to say that dementia is understated and under accessed even for the smaller percentage of the population with access to private medical healthcare services as the number of specialists is also limited in South Africa. Fewer than ten geriatricians and five old-aged physiatrists (Prince *et al*., 2016:99).

5.2.2 STIGMA

The realisation and formal assessment to establish a possibility of dementia can also be hindered by the stigma associated with it in cultural and socio-economic groups who are aware of dementia. This stigma is due to the association of dementia with losing one's mind; as if it is something that can be controlled or was intentionally induced by a person. Almost as if a person would be at fault if they developed symptoms of the dementia syndrome. Consequently, symptoms of dementia are often hidden for as long as possible by people who have dementia (Brankaert, 2016:44). The stigma associated with dementia also induces a public fear of aging; leaving little empathy and compassion for people living with dementia (Manthorpe & Iliffe, 2016:7).

5.2.3 INFORMAL CARE

People living with dementia are by reason evidently vulnerable to abuse and harm, especially if the caregivers do not thoroughly understand dementia. From observation and from the literature it is evident that families and government institutions encourage that people living with dementia remain in their environments for as long as possible. In other words, informal care is provided by family and friends in order to maintain the relationships of the person living with their environment and community. I would argue that in theory this notion seems to be the ideal, but the literature also indicates the downside of informal caregiving. From observation at the NGO facility, it is evident that care for people living with dementia is all encompassing being emotionally and physically intensive. As stated by Brankaert (2016:35) ninety-eight percent of informal caregivers suffer from some form of mental or physical problems as a result of caring for a loved one with dementia. In affinity session two it was also reported that family members struggle to come to terms with the effect of dementia on their loved ones; not always understanding or being sad themselves when visiting in the NGO facility. This does not mean that informal care is impossible or unsuccessful in maintaining a quality of life for people living with dementia. Van Steenwinkel *et al*. (2014:7) notes that Mary's entire home environment was adapted to enable home-based care. Caregivers were also employed to help take over errands Mary was no longer able to perform in order to help both her and her husband. With Mary's husband being a part of her caregiving and the employment of staff, I would contend that the situation incorporates both informal care and formal care in a less formal or institutional manner.

5.2.4 CARE INSTITUTIONS

On the opposite spectrum of informal care are special care units or facilities. Special care units cater specifically for people living with dementia as opposed to traditional nursing homes; but are also considered a fast-growing business phenomenon. Arguably, as introduced at the beginning of this section, the cost of such specialised care units in South Africa is very expensive and less common as in more developed countries. In the introduction of this paper the Hogewey Village in the Netherlands is noted as one of those specialised care facilities, nothing like facilities in South Africa, where there is a sincere focus on quality of life. Although there are some moral concerns with facilities such as the Hogewey Village in the architectural domain, specifically pertaining to place, the facility itself seems to provide residents with a sincere prospect of a quality life. The observations done at the local NGO facility, I would argue, the -quality of life, considering place, is not bad but is definitely not ideal. The issue pertaining to place and how it manifests in architecture will be further discussed in sub question two, although I would like to touch on facilities described as home-orientated for care as a commercial commodity as per the business phenomenon mentioned above.

Buse *et al*. (2017:1437) notes that health care facilities must attract patients by presenting itself as a hybrid of a hotel and a mall. The aim of this is perhaps really to create fewer institutionalised environments on the surface, but also to appeal to those opting to place their loved ones in a care facility. The question is perhaps where would a family member be comfortable to place a loved one needing care; and to whom is it really appealing? This is arguably a moral individual interpretation thereof, but the commercial aspect is definitely a means of creating revenue. In addition, this consumer-driven aspect of care facilities will also be further discussed in the next sub question as an architectural design element pertaining to place.

5.2.5 CARE OPTIONS

What are the post diagnostic facility care options for people who will have to live or who are already living with dementia? With regards to facilities, there are not many specialised facilities in South Africa. The majority of the facilities are NGO facilities, predominantly considered to be old age homes, with a ward or frail care section devoted to people living with dementia. This type of step is not ideal as it fails to address specific needs and rather focuses on risk avoidance. This is not to say that there aren't any specialised facilities in South Africa; there are facilities that specialise in dementia care, but facilities like these and, that are accessible to the majority of the population are rare considering the rising figure of dementia in South Africa. Although there are institutions providing support for people caring for loved ones living with dementia; people are evidently returning to the notion of informal care. Conclusively, it can be said that there are limited post diagnostic care facilities for people living with dementia in South Africa; forcing informal care as a primary solution. The impact of limited post diagnostic care options is a topic that can be further explored considering both the quality of life of informal caregivers, people living with dementia as well as the broader stakeholders of such an informal care environment.

5.3 HOW COULD THE PLACIAL RELATIONSHIPS OF PERSONS WITH DEMENTIA CORRELATE TO ARCHITECTURAL ELEMENTS OF DEMENTIA FACILITIES?

5.3.1 OVERVIEW

Innes *et al*. (2011:548) notes that occupants often experience facilities, such as dementia facilities, constricting and debilitating if they are not designed properly. Therefore, Maria Lenora Lehman (2010:18) encourages architects to understand how the human brain works in order to establish how occupants think and how their needs inform design practices and the design itself. This paper used the analogy of land and landscape; land and space refer to an environmental setting whereas landscape and place refer to dwelling and the uncovering of the lifeworld. In

order to extricate this notion, the sub questions must be answered in such a way that they unravel what entails dwelling and consequently place.

This sub question will be answered in sub themes relating to the two theoretical models, the placial triad and person-environment-occupation model, as it was already used for data collection and reviewing the literature. In addition, the two models are specifically developed to understand place and output with the person at the centre of the phenomena. The two models will be discussed combined by looking at the three dimensions of place while considering the occupation, environment and person in each of the dimensions. The dimension will be discussed in the following order: a person's lived dimension of place, a person's material dimension of place and a person's mental dimension of place.

5.3.2 A PERSON'S LIVED DIMENSION OF PLACE

5.3.2.1 RESTRICTION

From the observations, affinity sessions and mapping exercise the following was noted with regards to morning, afternoon and evening routines, as well as how architects design or perceive these routines in the lived dimension of a person living with dementia. In the mapping exercises there is strong focus on containment, especially for Susan and to a certain degree for Annie. From observations, similarly the dementia ward is isolated from the rest of the facility by means of an access-door with a code; the code is used by staff and family members to move freely in and through the facility. However, it prohibits occupants from leaving the ward or moving through the rest of the facility. This is done to avoid the risk of residents wandering off and getting hurt or lost. Lilly, a resident living with dementia, is confined to a school-type of desk to restrict her from getting up and walking alone. She is prone to falling and will get up and most probably hurt herself as she is not able to walk without assistance. Therefore, the movement of people living with dementia at the facility is restricted to certain areas. This is important as I will contend that movement is very important in a person's lived dimension of space; how the body inherently remembers a space. In the case of the mentioned facility; movement is uninteresting and passage orientated as the configuration of the ward is very similar to that of a hospital.

Interestingly during the evening, the doors of the ward are completely open to the rest of the facility. Upon asking a caregiver for the reason it was explained that some of the residents do wander in the evenings, but it doesn't happen very often. The doors remain open as caregivers who will be stationed at the nurses' desk will be able to see who is ringing a bell for assistance or if a resident wanders by. In addition, the garden door was also left open during an evening observation, although the garden area is restricted, to allow for better ventilation and indoor and external connection during a hot evening. It seemed that the residents enjoyed the cooler open environment; and the residents that are able or try to walk without assistance did not

wander into the garden. But, when the residents were confined to the dining/living room, a room with dual purpose, for a prolonged time period they became agitated. There were residents in the dining room I had not seen before showcasing severe discomfort as a result of being confined to a space.

5.3.2.2 MORNING AND AFTERNOON ROUTINES

With the focus and the restriction of movement to certain areas of the ward and looking at evening routines; I would now like to discuss some important features I noticed in the morning routine. Waking up, getting dressed and having breakfast is a highly individual process at the facility. As mentioned above, there were residents on the day the floor had to be cleaned in the dining and living room for breakfast whom I had never seen before. I also noticed that the morning routine is quite a prolonged process due to it being highly individual. What I mean with individual is that the various residents have different preferences and needs; caregivers are courteous and attend to these individual needs. In affinity session one it was noted that for the persona Annie, there is an inherent need to be washed every morning; focusing on specific areas. Although some caregivers perceived the manner in how insistent Annie is about this as being demanding, they still understood her need for self-worth through washing every morning. This evidently takes time and requires a caregiver's full occupation and attention.

For the persona Susan it was again noted by one of the caregivers that she only wants to sleep. She doesn't like getting up in the mornings and prefers to be left alone in her room and bed. Another caregiver in affinity session one noted for the persona Susan, breakfast is important; she likes having breakfast but is very insistent on feeding herself. Although she is not able to feed herself, she still tries; even though she drops utensils and was opting to use other resident's utensils, she also ate some of the other residents' food. This was also the case for one of the male residents in observation on day five. The male resident, due to the floors being cleaned, was situated in the dining room for breakfast, struggling to eat with utensils and using the utensils while falling asleep trying to feed himself. His head was dropping into the porridge as he was trying to eat while falling asleep. Another example of an extended morning routine was observed on day two where a lady in a wheelchair was brought into the dining room after having difficulty getting up; a caregiver was trying to feed her but had to give her a supplement due to her not being able to eat. The caregiver was holding her hand while she seemed fast asleep in her chair.

Considering afternoon routines; Sarah loved having her hair done. She was so proud to show her hair off to the other residents after having it washed and styled. The washing and styling of hair is done for the residents once a week. Sarah is a lively resident and seems to be very interested in things happening around her. Upon request a caregiver mentioned that she used to be a teacher and that she can play the piano-based muscle memory, but she will not play if anyone

is in the room. The caregiver also noted how interesting it is that she is very confused and disoriented at times, but she is able to remember how to play the piano. In addition, as a part of a late afternoon moving towards the evening routine, Sarah asked for a newspaper and a cloth to help the caregivers clean the dining room after dinner that was served at 17:00. This very interesting embodied act of remembering and doing is an interrelation of the lifeworld and Seamon's place-ballet (Seamon & Nordin, 1980:35).

It is important to remember that phenomenology is the vantage point of uncovering place for people living with dementia, as it is the theory of understanding, perspectives, perceptions and in the lived dimension of place *experiences*. The lifeworld is the person-world immersion. It is the unnoticed everyday life experienced as normal. Trigg (2012:25) notes that it is only when this normality of life is disturbed that people become very aware of the lifeworld; "a phenomenology of the uncanny". In Sarah's case, also in the lives of other people living with dementia, the normality of being able to clean the dining room and having your hair done is so noticeable in a setting that it is defined by the disruption of being able to live the unnoticed everyday life; doing tasks, routines and chores that once seemed trivial. This is also where the person-environment-occupation model becomes evident by showcasing the disturbance; the person environment with little integration of the occupational circle.

Another part of morning and afternoon routines is occupational therapy. The session is a group activity where all the residents will gather in the dining or living room voluntarily participating in activities to the best of their abilities. The sessions consist of formal activities and questions or informal questions as prompted by the residents. As explained in the observation the occupational therapy session can include questions about time, date, place, hobbies, the singing of songs and playing with bubble wrap. Morning and afternoon tea breaks are also related where residents are served with tea and a treat such as marshmallows or cookies. What was found as an interesting part of the dynamic of the lived dimension, especially when referencing the person-environment-occupation model, is that there are so many things happening within the dementia ward and facility around the residents living with dementia. It was especially during the occupational therapy sessions that this was noticed; while the occupational therapy session was in process other caregivers were filling out forms, family members bringing in and sorting medication and caregivers organising new equipment in the kitchenette area. There is an intricate dynamic of occupation during the occupational therapy session where the residents interact in a group, caregivers operating separately or with a family member. The occupation in the facility is concerned with self-care, leisure and productivity by various persons all at once. Therefore, the lived dimension in the facility is extremely dynamic. This dynamic consideration is certainly missing in the mappings of two professional architects, where the supporting personal and other residents are either not considered or considered in isolation and not as a collective integrating whole.

5.3.2.3 EVENING ROUTINES

I would also like to discuss evening routines as observed; as per the morning routine and eating breakfast, eating dinner is also an individual and somewhat prolonged session. Dinner is from 17:00; where some residents are fed by caregivers and others are able to feed themselves. On day six it was observed that Allison, a very slow eater in general, is counting relentlessly while eating. The counting was not numerically consecutive. The counting was not observed during morning and afternoon routines. During evening routines, when staff shift changes took place, some of the most frail residents living with severe dementia was left alone in die the dining room. Residents like Sandy took it upon herself to console and be consoled by others remaining in the dining room whilst being very sad. As mentioned previously, wandering does not occur often in the evening or early morning hours, however one resident did stroll through the corridor on day six of observation; she was looking for her parents' room where a caregiver then kindly and calmly escorted her back to her own room.

5.3.2.4 MOVEMENT AND SPACE PLANNING

Attempting to unravel how the placial relationships of persons with dementia correlate to architectural elements of dementia facilities, it is important to look at the aspects discussed in each dimension of place correlating to architectural elements within facilities. Key objectives relating to architectural elements, and this might also be closely interwoven with a person's material and mental dimension of place, and a person's lived dimension of place is: movement within the facility, how the facility helps to mediate morning, afternoon and evening routines, as well as the dynamic operations of various person aspects within the facility. In other words, when looking at the PEO model, the person aspect within the facility consists of: individuals living with moderate or severe dementia, caregivers, family and other residents who do not have dementia. For that reason, I will argue that architectural elements of an NGO facility for people living with dementia, related to a person's lived dimension of place are: the layout of the facility including thresholds such as doors and windows contributing to movement through the facility, the layout and configuration of objects such as dining tables and how spaces are distinguished from another, as well how spaces are allocated and integrated for various persons, should be considered.

When the layout and flow of the facility is carefully considered, movement can most probably be less restricting for residents who are able to walk and move without assistance; without feeling confined. Better flow can also alleviate difficulties with morning routines such as offering an alternative space to eat, should maintenance be required in the facility for both caregivers and residents. In addition, the integration of spaces or the location of spaces when staff change-over occurs, and where frail residents reside, should be considered to ensure the

emotional well-being and safety of residents. Although this may also be a logistics matter; architectural planning can help to alleviate such problems.

5.3.3 A PERSON'S MATERIAL DIMENSION OF PLACE

5.3.3.1 OBJECTS OF ROUTINE, TEMPORARY OBJECTS AND PERSONAL OBJECTS

Much has been said about routines and the operations of a facility with reference to a person's lived dimension of place. It is evident that a person's lived dimension of place is closely bound to its physical environment; therefore the physical attributes of a space influence the placial conception interlaced with routines and movement. In addition, material objects hold the ability for people to connect with places or keep a relationship with a loved one living far away or even a passed loved one (Davidson *et al*.,2005:136). Objects and materials also hold the possibility to evoke memories; memories are spatial and engraved in our bodies to be retrieved, or automatically retrieved without being aware that they are there (Trigg, 2012:45). Strangely enough, the material aspects in the mapping exercise were fairly limited; objects were identified but their materiality, apart from a low raised textured wall for Annie, was not mentioned in discussions.

In the case of people living with dementia in an NGO facility, it was evident that physical objects and the materiality of objects are in fact quite important, and that these objects directly or indirectly influence the quality of life for people with dementia. In affinity session one a point was made that caregivers must identify objects that form or play an intricate part in the morning and afternoon routines of people living with dementia; it was also asked that caregivers must identify a story connected to the object and routines. An interesting correlation made between the object and the importance thereof was done by participant 04 for the persona Annie's afternoon routine. The objects identified were a bowl and spoon. The bowl and the spoon's significance come as a result of the PEO model analysis thereof; the significance of the objects to Annie declares a means of her self-worth, independence and leisure associated with it. The facility serves all meals with relevant utensils and cutlery, making the need for items such as bowls and spoons completely unnecessary.

In addition, temporary objects such as food also form an important material dimension for a person living with dementia. It was observed that cookies brought by a resident to the dining hall became an object of interaction and bonding between two female residents. It was further noted that some of the meals served in the facility are also culturally specific, such as Bobotie and croissants. I will argue that specific types of food, especially being culturally specific, enforce a sense of belonging. In affinity session two it was also noted by a caregiver that the bringing of food to residents by loved ones is a means of maintaining the relationship between family and people living with dementia in the facility. Hence, it is apparent that food, which is

also closely bound up with routines, is a very important object and the connections to it, range from self-care, self-worth to leisure and maintaining relationships.

Other objects can also display these types of connections; such as photographs, clothing items, books or objects of information. On day three of observation, one of the male residents tried to escape the facility wanting to go home. The objects he chose to take with him, and I presume with no intention to return, was his black hat, a book and photographs. These are most likely the items he cherishes and associates with as part of his understanding of being-in-the-world. Another example is a photograph mentioned in affinity session one; where the photograph of the resident with her family reminded her of her younger days, perhaps days filled with various routines, and objects relating to other spaces and, evidently places. This notion will be further discussed under a person's mental dimension of place.

5.3.3.2 OBJECTS OF RESTRICTION

In contrast, objects can also play a restricting role in the quality of life for a person living with dementia. As mentioned in the introduction of this paper, that in *Mary's Little Worlds,* many of the objects and material aspects of her home were changed to alleviate some of the dementia syndrome manifestations, and to help Mary better cope with her environment. An example is where Mary's living room was painted in order to be lighter and some of the furniture was discarded and others rearranged to make the space more manageable (Van Steenwinkel *et al*., 2014:6). Objects used as restriction devices are the school-type desk configuration at the facility; it is used as seating for Lilly by ensuring that she stays seated and doesn't walk on her own. The desk works in such a manner that Lilly is not able to operate it while the desk part of the seating is over her lap; preventing her from standing up and consequently walking. This restriction is used for risk avoidance as caregivers are able to leave Lilly alone for a while when other residents need attention. The same notion of restriction was depicted in the mapping exercise where the architects allowed for Annie to wander the garden to a certain extent, and Susan to have no access to the garden; only visually.

Other restriction objects are doors, windows as well as certain material finishes such as carpets. The facility had to make a few changes as a result of a Health and Safety audit; therefore, no loose carpeting is allowed, or carpeting in passageways. Additionally, the doors are used as restriction devices; such as the entrance doors to the ward that consist of access control, as well as room doors that are used by residents to block caregivers when they are upset and acting on it, as mentioned in affinity session two. It was also noted that the doors leading out into the garden to the other dining halls, consist of doors that are operable on the dementia ward side, but the doors leading into the other dining hall is not operable form the dementia ward garden's side. This ensures that residents living with dementia are not able to escape the facility. Doors also provide residents with privacy and security when considering access control and bedroom

doors; therefore, they restrict unwanted guests in certain spaces. Nevertheless, it does happen, as noted in affinity session two, that residents do wander into each other's room taking belongings and eating food in another's room.

5.3.3.3THE COMPILATION OF MATERIALS AS A MEANS FOR PLACE

What is evident and intricate of a person's material dimension of place, is the ability of physical objects to concretise a routine, feeling, memory, emotion and sense of being. The material dimension is bound to all the senses; sight, smell, touch, sound and even taste. This also reinforces the idea of place as being a concept that bleeds and seeps into other dimensions and as a result places. What is interesting and phenomenological about this very obvious material aspect that constitutes a space, and also most relevant and obvious in architecture, is the fact that the material dimension of place is something experienced as a collective whole. It is not just about the lack of a carpet or the access control panel at the entrance doors that make a facility feel like an institution as opposed to a home; it's rather the collective existential experience of its materiality that evokes such an interpretation. Therefore, materials will always be perceived and experienced in context to another and to a larger reference system.

5.3.4 A PERSON'S MENTAL DIMENSION OF PLACE

5.3.4.1 FEELINGS, MEMORY AND ARCHITECTURE

Memory is inherently spatial and also bound to place; the one endorses the other. This is evident in how one's memory of childhood is bound to a specific place, or how a life-changing event is remembered by where a person was when the event occurred. It's these memories, thoughts and ideas that shape our constructs of the lifeworld and influence how the lifeworld is perceived. Thus our memories are not separated from our present; it's a continuation of past memories to the present (Davidson *et al*., 2005:206).

For people living with dementia, memories, or as described in scientific terms- mild cognitive impairment, can be quite problematic. Magnusson (2014) describes this notion so perfectly in the title of her book: *Where Memories Go*. The intent of the book was to capture the emotions, feelings and memories of Sally Magnusson's mom as a person living with dementia before all her mom's memories diminished, and I will also contend Sally's own memories of her mom. As a result, there are also many of her own emotions and perspectives; capturing how her mom's relationship and her own evolve within the lifeworld; noted on the cover of the book as a sweltering declaration for social change. Evidently emotions and feelings relates to our thoughts and memories; being learned responses to both a person's lived dimension of place as well as a person's material dimension of place.

When considering how people living with dementia's placial interpretation correlate with architectural elements, while considering a person's mental dimension of place, it is evident that

Pallasmaa understands the intangible role of architecture. In other words, the intangibility and emotions of architectural materiality. Buildings facilitate deep understandings of place, time and culture (Pallasmaa, 2012:20). In addition, he also notes that responsible architecture is rooted in time and place, underwriting a sense of belonging as a cultural breadth as opposed to contemporary architecture, that is used up by self-centredness and a flattened sense of time and history (Pallasmaa, 2012:20).

To practically demonstrate this notion from the observations and affinity sessions in collaboration with the literature, I will use the vantage point of narrative. All observations are written as a diary entry capturing the perceived emotions of people living with dementia, caregivers, family members and other stakeholders. Many of the affinity sessions are comprised of stories, attached to objects and routines, and were also discussed as a part of the sessions in order to shed more light on the understanding thereof. Davidson et al., (2005: 206) notes that narrative has the potential to convey meaning and emotion without extensive analysis. In addition, it is through emotions and memory bound to concrete environments that establish emotional geographies; therefore it is extremely important to uncover a person living with dementia's mental dimension of place.

On day one of observation Leigh, a female resident with severe dementia, was only staring out of a window or towards the ceiling, being somewhere far from the present. She only interacts with caregivers on automatic response; opening her mouth to be fed but always staring elsewhere with no eye contact. The only interaction or display of emotion ever observed from Leigh is when she swept a book to the side that Sarah offered her one afternoon; appearing not to be impressed by the gesture at all. Although Leigh is visited by her husband occasionally, she does not seem happy, present or being interested in her environment. Her only interpretation and connection with her environment is through constantly touching her chair, face and fiddling with her hands. She shows very little emotion.

Lilly, also a female resident with severe dementia also tends to fiddle with her hands constantly stroking her school-desk setup. She is very different from Leigh. She connects with caregivers and residents by making eye contact. She utters sounds, desperately trying to communicate and displays emotions while interacting with caregivers and residents when seemingly alone. She smiles and has a soft gaze when given food that she enjoys such as Milo. She cries when left alone for a long period of time without caregivers in the vicinity; being trapped in her seat. She interacts relentlessly; being present no matter what emotions she is experiencing. She wears her heart on her sleeve.

These are two very different phenomena of a person living with severe dementia's emotional capacity and feelings. The one is interested in her environment, people and surfaces she is exposed to, where the other is only surviving, but being somewhere else far from where she

physically is. Leigh is seemingly unhappy, where with Lilly it is clear when she is unhappy or very happy. In addition, the one person's emotions are also influencing the emotions and mood of other residents; when Lilly was left alone sad in the dining room one evening, all the residents who were present in the dining room became distraught. In this instance, Sally was crying and seeking comfort and support from the other residents present.

For other residents who are mobile, such as the mentioned male resident who takes his hats, books and photographs, there is a need for escape; constantly trying to go home or waiting on a loved one to come and fetch them. In some instances, wandering the corridor looking for parents; for their emotional security. I will argue that it's both a physical and mental escape of the environment, and the emotional connection or non-connection to it. There is a need for going home; where good times or feelings are associated with concrete environments, escaping to a sense of familiarity and security.

5.3.4.2 QUALITY OF LIFE AND FAMILY

People with dementia are focused on the present and do not really focus or plan for the future (Wieserma *et al*., 2014:5). Happiness, an emotion and essence of a quality life, is also found in the present. This is not to say that reminiscing about past events or looking forward to something is not happiness, but it is not a guarantee for the present. A person living with dementia's mental dimension of place, is essentially about the present and how architectural elements can facilitate happiness and a quality of life condition for the present.

In affinity session two, the question was asked how people with dementia maintain a relationship with their environments as well as with their family. Tapping into deep emotional connections, the following scenarios stood out. Firstly, the anger and frustration from the families' side, with loved ones being unable to eat or just be in the lifeworld in a way that is different from how they previously experienced it. Apart from the anger and frustration there is also embarrassment and sadness. A daughter being embarrassed about how her mom is behaving and eating in public, but also trying to maintain a relationship by taking her mom out of the facility to go and have a coffee and something to eat; a gesture of love. Another example is a family member being very upset while visiting their loved one with dementia at the facility; needing love and comfort from caregivers and being dependent on caregivers to help maintain a relationship with their loved one. Caregivers help maintain the relationship through reminding family of positive and happy events that happened during the day or time when they were not able to be with their person living with dementia.

The mental dynamics of place and architectural elements reported in how people living with dementia maintain a connection with their environment, recorded in affinity session two, is somewhat thin. There is a strong emphasis on items, material objects, and their respective role in the care-taking activities. Evidently, this is from a caregiver's perspective. For the persona Annie,

it is noted how her environment needs to be organised in according to health and safety standards, but also from a care perspective as some items need to be placed in proximity to Annie. Critical items identified are a bed, toilet and cupboards etc. The caregiver also mentioned that Annie is able to recall the names of flowers which makes Annie feel calm. As for the persona, Susan, the mental connection and maintenance of her environment also came as the result of physical objects such as photographs, books and furniture pieces that used to be in her home. These objects allow her to have a personalised space, her room, which is hers and filled with her items. The familiar objects help her to reminisce over her life and memories. Although this is a positive attribute, I still think that the environment must do more than just facilitate an environment of memories; it must be an environment for present being-in-the world as a contributing happy being. An environment that can stimulate emotional consciousness and contentment for both the person living with dementia as well as their family and caregivers.

5.3.4.3 INTENTIONALITY AND WELL-BEING

Perhaps peace of mind is so much considered for the functional aspect of design that little attention is given by designers as to how good intentions can lead to emotional turmoil. In the mapping session with the two professional architects it was evident that the best intentions were used to consider the safety and mental well-being of the personas Annie and Susan. Although both the architects' dwellings, constructed from Lego, predominantly focused on the two personas' likes and personal preferences as they were almost interpreted as abstract beings. The dwellings focused on entertainment, gardening and all the aspects of importance for the respective personas, but the dwellings also had a very strong focus on restriction, especially on movement beyond the dwelling. The building placed importance on ensuring Susan and Annie were not able to escape or move too freely to avoid risk and harm to them; giving peace of mind for loved ones and caregivers. It can be said that the mental and psychological well-being of the personas in the dwellings will only reach a certain level of satisfaction; what happens if Susan and Annie's needs go beyond the primary activity or point of importance? Can they still find some means of establishing a sincere connection emotionally to their environment, and how sustainable the environment is in facilitating these emotions and inevitably connections?

5.4 WHAT ARE THE CHALLENGES EXPERIENCED BY PERSONS INVOLVED IN DEMENTIA CARE IN A SPECIFIC PLACE?

5.4.1 CARE IN CONTEXT

There is little awareness of dementia in South Africa, therefore there are not many facilities that are designed specifically for people living with dementia; resulting in limited services and caregiving orientated towards dementia. As mentioned, many people with dementia receive

informal care and the few that can afford private and more specialised care do not necessarily receive optimal care, due to the lack of knowledge and formal training. This does not mean that caregivers don't provide care with a sincere objective to help, but rather that caregivers are not given the background, understanding and training to always fully grasp the complexity of a situation, especially in a country such as South Africa, with diverse culture groups and dynamics. Consequently, both caregivers and facilities are not fully equipped or always in a position to provide care with a focus on occupant-centred care aid through design.

Dementia is something that is not experienced alone; the impact of dementia on caregivers and family members are tremendous. It is in the moderate and severe stages of dementia that family members usually seek help as they no longer have the capacity to take care of a loved one; also known as the institutional phase of dementia. This is where a person living with dementia, living with very difficult and severe changes to his/her being, are moved to a new environment dependent on strangers in a very precarious time of their lives. This is inevitably not just very hard for people living with dementia, but also for caregivers within a facility that is not essentially designed to support caregivers with their care routines and tasks. In addition, the care dynamics become personal for caregivers, also having a very big impact on their physical and emotional well-being.

5.4.2 CHALLENGES OF CAREGIVING AND THE CONCRETE ENVIRONMENT

In affinity session two caregivers were asked what physical and emotional problems they encounter caring for people with dementia. The ultimate focus was on the emotional reactions of people living with dementia towards them as caregivers; some caregivers reported being sincerely afraid of getting hurt. A resident tried to throw a small table at a caregiver, while another resident was chasing the caregiver, where the caregiver locked herself in a room while the resident was trying to push the door open. The caregivers all insisted that they always try to keep residents with dementia calm, or will try to change their mood or wait until the resident is calmer before approaching them. This also puts emotional strain on caregivers where they feel the need to talk to someone that can understand or give them advice on what to do in a situation where aggressive behaviour becomes threatening towards a caregiver.

While the affinity session mostly gave insight on the emotional aspect, the observations however do give insight on the problems within the facility, concrete environment, dealt with regards to caring. Starting with administrative functions, things that seem trivial, in my perspective have an influence on the dynamics of a space, how a space is used and feels. From observation, many administrative functions such as the filling out of patient information was done in the dining and living room while activities such as occupational therapy was presented. On one particular evening the files were left on the window of the room overnight; it seemed careless but is also understandable to some degree. Caregivers are fully occupied with the care of residents, while

having to monitor and conduct administrative duties simultaneously. When the time comes to go home or to take a break, the files are left behind. The shift change procedure and briefing area is situated far from where residents with dementia are situated; therefore leaving them alone and vulnerable for certain periods of time. This was evident one evening when the frailest of residents with dementia sat alone in the dining and living room crying and being distraught.

With regards to routines, it was also evident that morning and evening routines take various lengths of time for different residents. Depending on the day, the same resident might react differently with regards to routines; making the process of care more intricate. I would like to think that the facility itself can accommodate various preferences and lifestyles; although certain residents do have breakfast in their rooms as opposed to the dining room, but what is the acceptable alternative for a resident when floors are cleaned, and they are not able to have breakfast in their own personal space? No alternative option is available. The facility is considered to have adequate ablution facilities, but these ablutions, and I will contend the dining and living room as well, does not function optimally nor is it personal. A routine so personal as morning bathing and hygiene becomes an activity for a mechanical diagnostic body, as opposed to Annie's or Susan's morning routine with her lifestyle and personal preferences.

The impact of an optimal care environment can be an advantage for both caregivers and residents. The possibility of better emotional reactions of residents and the psychological impact thereof on caregivers can perhaps be alleviated if optimal environments can be achieved. Administrative duties can be better allocated in terms of schedules and spaces required to avoid negligent placing of personal information, or just a distraction from important situations and the care of residents. Although care is the main perspective in question, it can also contribute to a better environment in terms of planning to establish a sense of belonging and *place*, catering for individuals as opposed to the imagined mechanical and diagnostic bodies. In other words, considering both the bodies of caregivers and people living with dementia in a personal and subjective manner. This is by no means an easy task as Buse *at al*., (2017:1444) confirms that caregiving and activities associated with it is a means of dwelling, considering various bodies that act and interact in very specific and complex ways that are often multifaceted and precarious.

5.5 WHAT ARE THE DESIGN CONSIDERATIONS FROM AN ARCHITECT'S PERSPECTIVE TO DESIGN PERSON-CENTRED DEMENTIA CARE FACILITIES?

5.5.1 OVERVIEW

The term *place* has been extensively discussed throughout this paper. The answer to the primary research question of this paper is not easy to address. The complexities have been highlighted in the entire dissertation. From the conception, literature review, developing dementia personas, collection of data, and analysis of the data, it has been building towards this question and the answering thereof. In other words, every part of this paper is in fact answering the question throughout its various domains, theoretical models, headings and discussions. Nonetheless, it is vital to extract the key and essential points of departure and consideration from an architectural perspective in designing non-governmental organisation dementia care facilities in South Africa.

5.5.2 PHENOMENOLOGY

Phenomenology as point of departure for this paper should also be a point of departure for architects when considering the needs and understanding of people living with dementia. Phenomenology is not just a discourse in philosophy, but rather a means of how architects and people with dementia make sense of their work and their worlds, being intentional or not. The way in which architects are taught or introduced to phenomenology and the concepts it entails is not clearly stated in architectural education. This is confirmed by my own experience as a practising student of architecture, as well as by Jordaan in her development of the placial triad. Yet, the way in which many architects conceive and develop buildings rely on the basis of rational and non-rational processes that are inevitably phenomenological. Rational processes by looking at the lifeworld, analysing what is so very evident; but interpreting these obvious edifices intuitively through non-rational processes. Architects do it through building models, literature and drawing, as demonstrated in this dissertation through affinity sessions, and building of miniatures with Lego.

Architects need to understand phenomenology as a point of departure even if they work in phenomenological ways unintentionally. People with dementia experience a life-change to such an extent that the lifeworld really becomes apparent. It is as Trigg describes it: "a *phenomenology of the uncanny*". In the processes of architectural design, considering aspects of people living with dementia's lifeworld architecture becomes the device of turning opportunity into purposeful creation. This is evident in the mappings done by two architects where there was a sincere focus on the individual personas, but a lack of attention to their

lifeworlds; by neglecting the everyday and broader activities associated with their points of interest. This un-intentionality is attributed to the fact that architects focus very much on the concrete provision of functions, as opposed to the totalities of emotion and what they inherently feel and aspire when creating buildings. As Zumpthor implies; students of architecture and architects feel a need to completely explain the rationality of their designs rather than what truly inspired them from within.

Architects should be deliberate and understand phenomenology as the basis of the enquiry in the design of dementia facilities to avoid self-centred commercialised, consumerist architecture. Architecture has become too much of a consumer- pleasing practice aspiring to appeal to the likes and preferences of its buyers, that it has lost its ability to be appreciated through its placial authenticity. Architecture has very much become a visual aesthetic art as opposed to a meaningful experience of all the senses. The architectural practice of photo-realistic-renders that portray buildings in a consumerist manner creates dream worlds that are far removed from the lifeworld, and also from being rooted in the complexities and intricacies of the world. Architecture for dementia facilities should not be a provocative scheme for the purpose of selling healthcare and a quality life; it's a necessity for people living with dementia and their families to have a *place* in society. For this reason, architects should consider how they represent their ideas and buildings; not removing them from their border urban context or their occupants.

The intentional phenomenological process of architecture, and the understanding of phenomenology in general, will therefore be able to anchor architects in their approach and working methodologies, to avoid creating consumable healthcare centres that are piece-of-mind placements by family. Architects should therefore understand why other architects use certain design methodologies such as parametric design, and that many buildings such as the Bilbao museum is more than just flashy architecture driven by form. There is more to the scheme and thinking process than what meets the eye. An appreciation for Pallasmaa's view can be fully understood when designing for people with dementia. Designing for people living with dementia, architects use their own bodies to imagine, dream and eventually create dementia facilities through direct skin contact, the motion of drawing spaces, and the body inference of uncovering subjective but meaningful nuances through one's senses. Therefore, using all the senses to design for a multi-sensory experience. Architectural methodologies must therefore not be driven by visual aesthetics or form as the driving parameters of the design conception; it must rather be driven by experience.

Understanding the importance of the lifeworld through phenomenology, and the process of creation through phenomenology, as an architect, the person living with dementia is pivotal. The person living with dementia is at the centre of the placial triad and one of the pillars of the person-environment-occupation model. Thus architects must understand the occupant in his or

her full capacity. The person-environment-occupation model made this notion very clear; there is more to a person living with dementia as they are intertwined with other people and settings that directly influence who they are and how they operate. This understanding also manifested in the dementia personas created for the purpose of collecting data for this paper.

5.5.3 DEMENTIA PERSONAS

The dementia personas were created with the intention to understand and collect data by using the dementia personas as probes in order to find and uncover an understanding revolving around the person with dementia. The personas were developed by using literature as well as expert input to create two personas that are relevant to the facility chosen to collect data as well as to the South African context. However, the personas proved to be very specific with regards to a socio-economic group, culture and gender; making them quite similar. It is sustained by the literature, that the knowledge and nature of dementia in South Africa is limited. In the understanding or interpretation thereof in a diverse-cultural background it is important that architects should be vigilant in considering the persons living with dementia in their buildings. Therefore, it is important for architects to use local and relevant dementia personas to understand activities and needs through the perspective of a person with dementia. Even better, to engage and come to know various people with dementia should they be in a position to do so ethically.

5.5.4 THEORETICAL MODELS AND THEIR USE IN THE DESIGN OF FACILITIES FOR PERSONS WITH DEMENTIA

With a basis of phenomenology, architectural methods and a good understanding of people living with dementia in the diverse South African context, architects should then consider the dimensions of a person in place in combination with the person-environment-occupation model. Both models have been discussed extensively throughout the paper and the previous questions. The focus will be on how these dimensions and aspects of the models can be uncovered and architecturally used to design facilities for people with dementia for an NGO facility in South Africa.

A person's dimension of place and its three domains identified can be provided for and uncovered through various architectural methods and devices. Starting with a person's lived dimension of place, the dynamics of operations in spaces and questions conceived by its interpretation must be thoroughly considered by architects. Investigate the routines, activities and daily operations of people living with dementia, but also the caregivers, family and other stakeholders within the facility, who are involved in the person-environment-occupation model in collaboration with a person-lived dimension of place. The questions that are important are listed below:

- How will these activities, routines and daily operations influence the experience of place within the facility for people with dementia as well as other stakeholders mentioned? Will the architect, family member, caregiver, and most important of all, the person with dementia feel out of *place* or in *place* when these activities, routines and daily operations occur?
- What are the material aspects associated with these activities, routines and daily operations, and what type of feelings do they evoke?
- How can these activities, routines and daily operations be complemented in material and spatial entities to create a desired impression or feeling when they are performed and carried out by various stakeholders?
- How will the building help people with dementia deal with change?
- Will the building and its operations be period-restricted and how will it embrace a past or present paradigm of existence?

A person's material dimension of place becomes somewhat limited and very personal when living with dementia. In the facility observed and used for data collection, the provision for personal items is minimal, and many areas and their materiality are shared with other residents and stakeholders. In addition, many of the material aspects of dementia facilities are regulated by health and safety rules, restricting the architectural parameters for material design aspects. Risk avoidance is a high priority in facilities; with a sincere focus on the health and safety of residents, but with less focus on the placial and emotional effect of materiality. As demonstrated in the person-environment-occupation model, a person's material dimension and his/her occupation are closely interlinked. Consequently, the following questions need to be considered by architects when considering a person's material dimension of place:

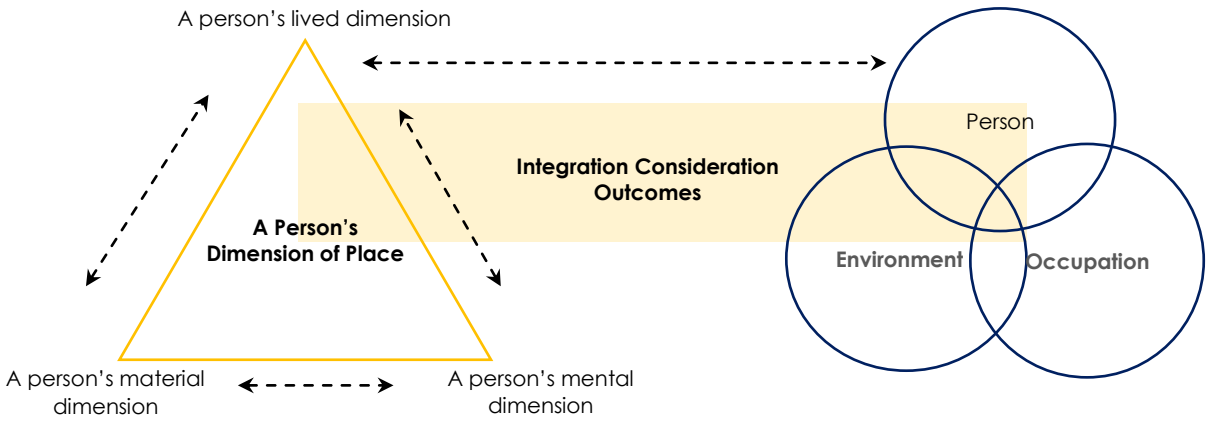
- What other material aspects of routines, activities and daily life influence architectural materiality? How will this concept of materiality be experienced by the person with dementia?
- How can space be allocated and designed to enable residents to allow for adequate personal items of their choice?
- What is the significance of personal objects of residents; are they symbolic, metaphoric or have the power to trigger the replay of memories and stories?
- What archetype does the materiality of the building portray and is it relevant to its residents?
- How collective spaces are designed; are there objects of orientation, and how will residents identify with them?

A person's mental dimension of place is very important for people with dementia; it's inevitably and inherently a psychological event. As Tschumi would argue; if there is any meaning in

architecture it is the meaning of event. The event with a strong focus on the present, and being present when considering people with dementia. People living with dementia, as well as their caregivers and family, need to make sense of the situation while allowing for better mental health and a meaningful and quality existence. The following questions need to be asked by architects when considering a person's mental dimension of place:

- What is the emotional affiliation with a facility for people living with dementia and how will it be perceived by residents, family and caregivers?
- Are these memories individual, collective or social?
- Will the facility be considered as a home or an institution; and what feelings will "home" or "institution" provoke?
- What are the images imagined by a person living with dementia and stakeholders associated with an institution or a home?
- What is the mental impact of this facility and how can it be improved?

The integration and combination of the placial triad and person-environment-occupation models, have merit when considering placial understanding and how to improve the design of buildings, which enunciate place for people living with dementia. By the integration of the two models, architects will have an improved ability to create "dementia-friendly" facilities for people living with dementia. Apart from a person's placial dimensions discussed and interrelations with the person-environment-occupation, the following diagram was constructed to illustrate how the two models integrated as the basis for the data analysis, and how the two models can be used by architects for design considerations of NGO dementia facilities in South Africa. The diagram is a compilation of the key points discussed.



Integration Consideration Outcomes:

a. People are at the centre of any design-decision. Person (as the academic term) should be considered as the person living with dementia as a primary, and equally the stakeholders involved in the lifeworld of the person with dementia. Person(s), especially the person with dementia, should be very specific. Person(s) should not be regarded by architects as diagnostic or mechanical bodies. Architects should use personas or interact with people living with dementia and their stakeholders relevant to their context only if they are ethically cleared to do so.
b. *Person* and a *Person's Mental Dimension* are closely interlinked, nevertheless in a symbiotic relationship with other dimensions and domains of the PEO model. The five questions listed under a person's mental dimension of place must be answered in relation to the PEO model for a full understanding of the circumstances.
c. *Environment* and a *Person's Material Dimension* are closely interlinked, but also in symbiotic relationships with the other dimensions and domains of the PEO model. The five questions listed under a person's material dimension of place must be answered as in relation to the PEO model for full comprehension.
d. *Occupation* and a *Person's Lived Dimension* are closely interlinked, but in a symbiotic relationship with other dimensions and domains of the PEO model. The five questions listed under a person's lived dimension of place must be answered as in relation to the PEO model for a full comprehension.
e. The desired outcome of the PEO model should be equal to that of the Placial triad to ensure that a fully functional, but also an emotional connection is established with the concrete environment.

Figure 35: Overlap Diagram of Theoretical Models

The use of theoretical guidance is the key to understanding architectural processes, in other words the way in which architects intentionally conceive and create architecture. The one, rational design processes, is dependent on the other, non-rational design processes, and cannot be successfully achieved if all factors are not considered. To condense this notion, place and processes must be considered at the hand of scale, illustration of buildings, and the person with dementia at its centre. Understanding and using these considerations can assist architects to interpret and design NGO facilities for people with dementia in a non-specialised context, contexts with little knowledge, education, training and support, such as South Africa.

Chapter Six

CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

People living with dementia often lose their sense of *place* within their concrete environments. This loss of place, emotionally and physically, interferes with the quality of life of the persons living with dementia. It also influences the family and caregivers of the person with dementia. It is not clear how architects consider the needs of dementia care in the design of dementia facilities to enhance the quality of life of persons with dementia.

A further enquiry pertaining to designing for specific needs and situations, designing facilities for people with dementia is a topic that only produced a few qualitative studies in the last decade (Mjørud, Engedal, Rosvik & Kirkevold, 2017:1). There is a need for articulating a method which architects can use to understand and design homes for people living with dementia, which speaks to architectural design methodologies (Van Steenwinkel, 2015:289). Supplementary, a phenomenological development by Jordaan, the placial triad, urges architects to research how the framework can be used in empirical cases (Jordaan, 2015:224). These notions inspired the quest for uncovering placial understanding in NGO dementia facilities, as well as how architects can be more vigilant in considering placial understanding in design. It was through my experience as a practising architectural student and the granddaughter of a grandmother living with dementia that it became unquestionable that architects need to better understand and design for place.

With reference to the original problem statement in this dissertation it is clear that there is a lack of architectural understanding and engagement in the design process of dementia facilities in South Africa. The limited number of dementia specialists in South Africa, as well as a lack of understanding among various cultures and socio-economic groups is essentially the problem; consequently, sustaining the inadequate design resolutions for people living with dementia. In essence the dementia syndrome and manifestation thereof in people are not understood well enough in the South African society and consequently nor by architects.

Currently in South Africa there are various facilities for people with dementia, but they are only available to a small percentage of the population when considering the average annual income of people living in South Africa. Limited resources are available to a larger percentage of the population; where a focus on dementia is absent. Additionally, facilities, such as the anonymous NGO facility observed, do not consider placial qualities in its design and are not fully able to provide for the needs of caregivers as well as residents with dementia. Also, these types of facilities are extremely expensive.

These expensive facilities are more of a consumable commodity to facilitate peace-of-mind placements for family members rather than facilities of placial understanding promoting a sincere quality of life existence for people with dementia, their families and caregivers, or, a

consumable commodity in the realm of politics. This notion is sustained by the literature confirming that political structures often use dementia as a device for political gain. People with dementia should never be or become devices of political favour; however, the literature shows interest in the domain of scientific medical treatment for people living with dementia as opposed to other disciplines. Governments should rather focus on how to better design for people with dementia in order to establish a better quality of life, especially in South Africa. This can create economic opportunities and growth in the built environment sector.

The architectural profession also contributes to dementia facilities as consumable commodities. The literature confirms that architectural education is not clear on how the creation of *place* is achieved, however, it has become a popular concept in architecture. Architecture as a visual form of art has become the key ingredient in design; causing a lost sense of belonging. This can also be attributed to the fact that architects do not consider real people in their design process, but rather Cartesian bodies absent from authentic characteristics pertaining to context, culture, individual experience, including people's wants and needs. Architects also do not involve other relevant stakeholders in their design considerations and process such as caregivers and family members. Architects design for diagnostic dementia bodies, and mechanical caregiver bodies with no personal attributes. The personal attributes and experience of these bodies are important in the conception of architecture. The literature put forward by Tschumi and Pallasmaa confirms that the meaning of architecture lies in its experience of all the senses and the individual characteristics associated with it. Techniques as parametric design are not fully understood, although more than visual aspects are considered, but ultimately perceived as very fluid and ocular-centred architecture.

The development of personas as probes for data collection proved that there is little knowledge and insight of people living with dementia in South Africa. Using the dementia personas as a design research tool posed many challenges. The data gained from the affinity sessions with caregivers provided rich, insightful data conveying placial and occupational insights into a non-specialised context such as South Africa. The data showcased stories of different cultural understanding; such as the stories attached to objects and how they are understood and seen by various stakeholders.

Consequently, insight was gained on residents living with dementia and how its manifestation is understood by the caregivers. In practice, this type of information would enable architects to unravel and better understand the placial configuration for people living with dementia. The development of the personas from the theoretical frameworks strengthens them as a placial-architectural design tool for the design of dementia facilities. Other dementia personas might not be able to adequately address the intricacies of place and occupation.

The use of personas as an architectural design tool in South Africa is rare, therefore making the use of personas as design research probes quite challenging. The concept of the persona as a probe needed to be explained to caregivers to ensure that the function thereof as a design research tool in affinity sessions is successful. If the personas were not as realistic as developed in iteration 03, the collection of data would have been even more challenging. Nevertheless, the more abstract dementia persona template developed in iteration two helped with the interpretation and understanding of data collected. As designers we solve problems, therefore the persona templates developed in iteration two help to access what areas of design needs to be focused on. In other words it helps architects to identify key architectural elements that can improve the quality of life for people with dementia.

It can be concluded that the research problem is inherently phenomenological as it focuses and searches for phenomenological understanding with a practical outcome. Phenomenology, being concerned with the lifeworld and the manifestation of dementia, making the realisation of the lifeworld so evident, uncanny, justify phenomenology as being more than just a discourse in philosophy. Phenomenology is concerned with *place* and must be taught and understood by architects as a placial enquiry that can be practically implemented, especially for the design of dementia facilities. It is about the experience of architecture through all the senses by means of creating architecture using all the senses. It is about place and not space; a qualitative whole. Architects need to consider all the aspects that constitute *place*, especially the outcomes derived in the overlap of the two theoretical models in order to create meaningful environments and ultimately places for people living with dementia in NGO facilities in South Africa.

6.2 RECOMMENDATION FOR FURTHER STUDIES

With limited design knowledge of dementia facilities in South Africa, and dementia in general, further research is of vital importance. It is necessary to increase the body of knowledge available to architects and create public awareness considering the rising statistics of people living with dementia in South Africa. It is also important to create awareness and understanding that the quality of life for people living with dementia must be prioritised to maintain self-worth and a sense of belonging. The impact of dementia is not isolated; it has devastating effects on communities, families and caregivers if not understood and the necessary support provided. Accordingly, the need for further research is evident; the following recommendations should be considered for future studies:

a. It is recommended that additional personas are developed and tested for various socio-economic groups in South Africa. Despite the limitation of only considering a representation of a small percentage of a much larger population, the method seems to be a good starting point for using personas in dementia research in non-specialised

contexts to obtain important insights in the complexity of such contexts, where information about persons with dementia is limited. More research is needed to expand the persona method to include persons with dementia in the persona development process, and to incorporate specific cultural aspects in the process to represent the diversity of such contexts, especially in South Africa.

b. The design of a dementia facility prototype with current and new personas, as suggested above, can be an insightful study to test the personas as design informs in the South African context, especially in rural communities.
c. Additionally, the outcomes derived from the overlap of the two theoretical models can also be tested in the co-design of a dementia facility prototype, incorporated with people living with dementia, caregivers and their families.
d. Study content in architectural design specifically orientated towards dementia, can also be furthered and explored in the architecture curricula at schools of architecture as well as Continual Professional Development courses for practising architects.

6.3 RECOMMENDATION FOR ARCHITECTS

Although various recommendations have been made for further studies, it is important to make one specific recommendation for architects. It is recommended that a practical method be developed to bridge the theory of *place* as a phenomenological construct to enable architects to use the method in design practices. As a consequence, the consideration developed in combination with the recommendations for further studies can be used to develop a practical method specifically for dementia design in the South African context; considering various culture groups and economic challenges.

6.4 REFLECTIONS AS A RESEARCHER AND ETHNOGRAPHER

In order to stay objective, as far as any researcher is able to, it was imperative to ensure that the data collected and insights gained was a true representation of architecture, and people living with dementia in a facility. It was truly through inscriptions in the format of a diary entry and telling a story of observation that the true nature of the facility, and residents with dementia was uncovered. Therefore the importance of narrative in research proved to be of immense value, and should be encouraged specifically in architecture.

Architecture as also initially perceived by me, is often considered to be a very logical, rigid and scientific, but beautiful profession that can also be quite profitable. The shock of this notion was intrinsically experienced at the beginning of my studies in architecture, completely focusing on artistic expression detached from business and clients. Once I fell in love with the creation and intricacies of non-rational processes in architecture I was dismayed when I started to practise

architecture. There was juxtaposition between the academics and practice of architecture; where many architects perceive academic architecture to be idealistic and impractical for application in the industry. Yet in practice buildings are often created that are divorced from the real world and its intricacies, consequently manifesting in idealistic renders as advertisements with perspective views that will never be experienced in that manner by its occupants.

For that reason the research endowed with and ethnographic nature in which the data was collected for this dissertation, provided me with valuable and meaningful insights on dementia, but also how to consider the notion of architectural training and the use thereof in practice and staying true to creating authentic experiences in architecture and not be distracted by the worldly associations and pressures of the industry. The anticipation is to provoke further research to contribute a quality life for those and their families living with dementia, as well as to create awareness among architectural students, and rekindle the meaning of architecture, and further provoke a conscious intentionality in design for practising architects. To design and create environments for people; and ultimately a place where one would like to be as person having dementia or knowing a person who is living with dementia.

6.5 PERSONAL REFLECTION

The inquiry for this paper and the research outcomes was a very personal journey. As stated in the introduction of this dissertation the enquiry of dementia and its relation to architecture came about as a practising student in architecture, but also as a result of being the granddaughter of a grandmother who lived with dementia. Even more personal, my grandmother passed away in the beginning stage of my dissertation, making the research very important and difficult, but a healing experience. Upon starting the research and with the passing of my grandmother, I had to take time away from the research to ensure I was strong and objective enough to continue. During the research process I became aware of other people struggling with similar experiences of dementia and how little knowledge they, their loved ones and the facilities they were situated in have of dementia in order to fully maintain a quality life. The lack of empathy and compassion observed and experienced was not due to a lack of care, but due to a lack of really understanding people living with dementia, their loved ones and the impact the physical environment has on all stakeholders.

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APPENDIX A: LIST OF TERMS

Caricature: An imitation of a person, or a comic representation of a person.

Caring facility: A long term facility that offer shelter and medical care for persons with dementia.

Coherently: The consistent and logical organisation of ideas or themes.

Concretised: To give form and characteristic, or to make something specific.

Conscious: Being aware of something, where one's attention is constantly directed towards something, someone, or a situation.

Corporeality: Relating to physical attributes of the human body.

Diagnostic: Characteristics of specific phenomenon such as an illness or subject.

Dialectic: Discussing or reasoning about a theme or phenomena; taking all views into account.

Dimensions: A facet of a physical and mental structure, and feature or problem.

Domain: A specific jurisdiction about a subject, theme or phenomena.

Dwelling: a process or means of exploring, informing, and understanding a situation, aspect or feature. It is a combination of exploring, informing, and understanding of both physical and mental aspects.

Edifice: An organisation of beliefs and ideas, or a large construction of a structure.

Eidetic: To have a detailed mental image of something to the point that it is almost real.

Elucidate: To make a matter or point of perspective clear.

Empirical: Based on interpretation, experience and awareness as opposed to logic, rational and theory.

Ethnography: Explanation of peoples habits, routines, culture, and customs.

Extroversion: Social and outgoing behaviour.

Geriatric: Elderly people.

Geriatrician: A person with medical education training specialising in the care of elderly people.

Gesticulation: A motion of the human body used to communicate, also known as body language.

Hermeneutic: The study of interpretation with regards to subliminal meaning of texts, or written information.

Holistic: Referring to a whole; ideas, concepts that are interrelated to serve one main concept.

Hypertension: A condition where a person has high blood pressure.

Ideological: To have the positive interpretation, hope or belief about something.

Incontinent: Inability of a person to have control over their bodily functions.

Ineffable: A phenomena that is a person is not able to describe in words; it is too great, extreme or emotional.

Inherently: By means of characteristic and the nature of something.

Lifeworld: The recognised state of how one experience the world on a daily basis.

Manifestation: A symptom, characteristic of an event or illness.

Mechanism: A tool or method used to accomplish a desired outcome, especially for the purpose of bringing change to an existing paradigm.

Miniature: A smaller version or impression of something such as a building or environment.

Morph: To change something's characterises, shape or attributes systematically.

Post-mortem: The scientific analysis and investigation of a body after death.

Neuropathology: A domain in the medical field concerned with the nervous system and the brain.

Neuropsychological: The study of the association of emotions and the brain.

Ocularcentrism: The phenomena of visual dominance**.**

Onset: The inauguration of something unpleasant.

Ontological: The nature of existence.

Paradigm: A set of ideas, or construct that influences the way in which a community, or society perceive events, concepts and ideas.

Parametric: A set of constructs for the purpose analysis.

Periphery: The border or outskirts of something such as a physical environment or mental construct.

Persona: The collective dominant characteristics of people represented by a fictional person**.**

Phenomenological: The art of phenomena concentrating on consciousness and being**.**

Place: Space that has significant and meaningful.

Placial: An environment with specific qualities, being personal and collective. It is the description of a physical or mental space filled with certain characterises.

Epistemological: The theory of knowledge.

Prevalent: Something that is very evident.

Procure: To obtain something through effort and planning.

Resonate: Concepts or actions that agree with someone.

Retrofit: To ad or something to a space or to change it in a manner in which it is different from its original conception and manufacture.

Subconscious: Repressed structures that actively influence one's behaviour, decisions, and feelings.

Surreptitious: To conceal or to keep something secret due to disapproval.

Temporality: A time interrelated concept, where something exists in connection with time.

Thematic: Ideas and concepts relating to a dominant sphere.

Transcendental: Concerned spiritual and nonphysical phenomenons.

APPENDIX B– INFORMAL INTERVIEW TRANSCRIPT

Izoné van der Vyver: Benay thank you for meeting with me.

I would like to hear about your morning and afternoon working routines with the residents. How do you go about and what do you find difficult while working with them, e.g. the facility where you work with them.

Benay: *At the moment the area where I work with them very difficult. As you can see this is the only area where I can work and before I can start with Occupational Therapy (OT) I have to wait until all the residents here have finished eating their meals. The occupational therapy session is supposed to start at 9h30, but due to residents still eating I have to wait until they have finished eating. I do understand that they sometimes arrive late for meals and that they also eat slowly and I then have to move the time of the occupational therapy session to 10h00 or until they have finished eating.*

We have a program which we follow from Monday to Friday every week of which the times are between 10h30 and 12h00 and 14h30 to 16h00 every day. On Mondays, Tuesdays and Thursdays we do sports activities and exercises with them. These activities comprise of games like basketball, bowls, *and skittles. During the afternoons on Monday and Tuesdays we do some perception activities like Dominos, Bingo, and Lotto games. On Wednesday afternoons they take part in activities like Scrabble or building puzzles or doing crosswords. Thursday afternoons we do quizzes which they very much like as it lets them reminiscence about their past and we encourage them to tell us the stories of their past, but some of them do not want to talk about their past. Friday mornings they have the opportunity to watch a movie of their choice. Sometimes I choose a movie which I think they would like to watch myself and on Friday afternoons they take part in activities like board games e.g. snakes and Ladders and Ludo.*

IvdV: What kind of stories do they tell during these occupational therapy sessions? Do they tell you about themselves?

B: Yes, as I said, it is a kind of reminiscence we do with them. We shall ask questions to encourage them to narrate about their past and you can see that some of them enjoy speaking about the past, but some of them don't like it and we don't force them to do so.

IvdV: If you think in terms of dementia, the people who do communicate with you during occupational therapy sessions, would you say they have severe dementia or is it moderate? Are there people who communicate more than others?

B: Yes, there are quite a few e.g. Sarah, she talks a lot.

IvdV: Do you think she has moderate or severe dementia.

B: Currently I would say she has moderate dementia as she sometimes still remembers things. Residents who have severe dementia are Sandy and Mary. Sandy actually speaks a lot for a person with severe dementia. She can keep a conversation for a while, but then you can see she loses the thread. She will speak to you and then loses the thread of the conversation as to Mary whom one can see that she wants to say something, but is unable to communicate. Mary is the one with the skirt.

IvdV: What do they talk about?

B: Mary e.g. talks about activities taking place here at the village and reminiscence about the past. She speaks about the place she grew up, but then can't remember the name of the place which is Caledon. They will talk about their childhood, children, husbands and her parents. They mostly reminiscence about the past and not about the present times.

IvdV: How do they identify with the environment where they live here at the care centre, do they see it as their home?

B: Some of them like Sarah who says "I doubt people, but this is like home" accept it as their home, because everything they need is available to them here at the care centre. Other residents long for their homes as they encounter the environment very different from what they were used to at their own homes e.g. Mary. She is very quiet and does not communicate much and it takes time to have a conversation with her. For her it is quite an adjustment although she is here at the centre for quite a while already. She tries to adjust, but is afraid of speaking, thinking that she might say something wrong. I encounter this with activities like the quizzes we do with them. One can see that she knows the answer, but does not have the confidence to say it.

IvdV: Does Mary stay in her room often?

B: Yes, she does, but we encourage her to join the other residents in the dining room. She is the only one who talks to Sarah as the other residents do not like talking to her.

IvdV: So…the two of them like talking to each other?

B: Yes, Sarah talks a lot and will encourage Mary to talk and have a conversation with her.

IvdV: Are the rooms of the resident's representative of their personalities. Do they have their own furniture and possessions in their rooms?

B: The furniture in the rooms are their own. Their children would usually bring them their possessions which they value for them to keep in their rooms e.g. Mary has a sculpture of her husband's face in her room that always reminds her of him and she does not allow anyone to touch it. Many of the residents have personal items which they value in their rooms, but some of them do not like to talk about them while others enjoy telling one the history and stories behind these items and photos.

IvdV: Does the paintings in the corridors belong to the residents or to the care centre?

B: The paintings used to belong to residents who passed away and were donated to the care facility. I don't think they really take notice of the paintings, because they will never mention or say anything about them. Our dining room needs an upgrade in terms of posters and pictures in order to be more informative regarding news and daily activities for the residents. The space where I work with residents is not very conducive for my work as the kitchen forms part of it and it becomes very noisy. There is no dedicated space or a room for occupational therapy with residents.

IvdV: Who is that man sitting in the chair, the one with the hat on?

B: It is Uncle Henry. He has severe dementia. Sometimes he is very calm, but he can also become very aggressive and will start beating us with his walking stick. We usually leave him and give him his space when he becomes aggressive; he calms down when he walks around in the little garden outside the dining room.

IvdV: I noticed him carrying some personal items and his hat walking towards the door leading to the garden.

B: Yes, he is one of the people who do not accept the facility as his place of residence. He always wants to go home either to his daughter or his brother.

IvdV: Do you know what his profession was, what he did in his early years?

B: I think he was a farmer or a hunter, I am not sure. He always carries his Bible and radio as well as some books of animals when he decides to leave and "go home"

IvdV: Does he often come to the dining room or does he prefer to be alone by himself.

B: He prefers staying in his room, but when he is in the dining room he is very much aside and does not participate in the occupational therapy sessions. He will watch us doing exercises, but will not participate.

IvdV: What was Sarah's profession?

B: She was a teacher and also an inspector of education. She had an important job and now she feels that she can do whatever she wants here. When we get busy she will always help to fetch people and bring them back to their chairs.

IvdV: So...she likes to form part of the group and assist with tasks?

B: Yes, she is very eager to assist, but sometimes she does it on the wrong time and in a wrong manner. Some of the residents have to be handled in a certain manner because of disabilities and she doesn't like to be warned that she won't be able to physically assist with these people. We try to explain the situation in a good and friendly manner to her in order not to upset her.

IvdV: Benay, thank you for your time and information shared with me, it is much appreciated.

APPENDIX C – A PERSONAL STORY OF DEMENTIA

Experiencing Dementia

Dementia is not a condition that is easily recognised when being presented with it; ironically dementia is quite common. Thinking I knew a fair amount about dementia, I was very much awakened by the experience thereof. Confusing general aging with symptoms of dementia syndrome was a serious mistake that I only realised in hindsight, when reflecting on the behaviour of my grandmother Eapé Kruger. She often made jokes about being old and struggling to remember things:

Alzheimer's: "Die heimer onthou ek, maar die als vergeet ek"

Deconstructing a word that closely embody the nature of dementia that she incongruously suffered from, and being facetious about it, reinforced my denial about the severity of what was happening. To my understanding, and to hers, it was quite normal to be forgetful and confused at times being an elderly person.

It was only when she was ninety seven years old when the disease was progressively evident. Before then, it was considered normal that she sometimes burned food, forgotten ingredients when baking, being paranoid about her children's safety, and reliving the events of the past. Evidence of the severity of the disease only came about when interacting and caring for her became strange and very challenging. The following accounts were triggers that made me aware that something was very wrong:

CONFUSION ABOUT HER IMMEDIATE CONCRETE SURROUNDINGS

Undergoing surgery after a bad fall, my grandmother was given the option to move in with my mother. After some discussions she decided that she would rather move to frail care facility. Her decision was based on her ability to maintain some independence from her children, and not wanting to be a burden. After staying in the frail care facility for more than two years, she suddenly became insistent that the room she was staying in for two years was not her room. After a short period she also became insistent that she was not living in the frail care facility anymore, but in a Medi-Cilnic hospital. Nevertheless, she was still using the correct name of the frail care facility when speaking with friends about her residence.

SEVERE OUTBURSTS OF ANGER AND MATTERS OF INDEPENDENCE

Being prone to falling, and having trouble with stability after a few bad falls, I was helping my grandmother to walk to the bathroom. Upon entering the bathroom she forcefully closed the door and lay against it. Being unstable on her feet, and laying against the door at an angle, her feet started to slip on the tiles. In a panic I pleaded that she stabilises herself to allow me to open the door in order to help. When eventually being able to open the door, my grandmother smacked me.

EXPERIENCING THE REAL AND THE UNREAL

It was late afternoon at work when I received a call from a caregiver, asking me to speak with my grandmother in order to calm her. When talking to her on the phone, I explained to her that I am doing well and that I am at work. She was severely upset because she saw me a few minutes ago; playing on the carpet with my toys, and some man took me. However, she was comforted by the fact that I am safe at work; not realising I am all grown up.

My grandmother, Eapé Kruger, was diagnosed with dementia only in the very late stages of her life. With medication and person-centred care, her condition was managed to the best of our knowledge and ability. Nevertheless she still had days of severe outburst and confusion, especially within her environment.