CHASING VAPORS WITHIN A DISAPPEARING MIST: CONCEPTUALIZING DEMENTIA NARRATIVES

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Abstract

The built environment within healthcare institutions is of critical importance to persons with dementia, as the characteristics of the interior environment, the lived experience within, and the reciprocal nature of that exchange can be directly related to their well being. Yet the role of the environment—and more importantly, the role of the patient as a primary author towards conceptions of what that physical environment should look and feel like—rarely feature in routine dementia patient satisfaction assessments.

This research sought to understand whether patients with dementia have the capacity to perceive the institutional space and place around them, and if so, how. Participants with mild to moderate dementia living in an institutional setting who could provide consent were asked a number of lived experience questions. The responses were videotaped and scored qualitatively.

The results suggest that patients with dementia are aware of the institutional space around them, and can be "active agents" when contributing to thoughtfully designed environments that promote the health and well being of its residents. If persons with dementia are thought of as active participants within the design of the built environment, then this can lead to new reconceptualization of spatial domains and ultimately impact care.

Autobiography

While conducting an ethnographic research study to determine public/patient experience outcomes in hospital wayfinding, an interview with a long term resident suffering from a cognitive disability forever changed my philosophical outlook regarding the enabling/disabling factors of environmental and architectural design theory and practice—specifically upon persons living with illness or forms of disability.

Despite being equipped with years of professional practice in environmental design strategy, accessibility, critical disabilities, wayfinding, and qualitative research, powerful and moving narratives detailing physical and emotional disconnected experiences to the greater environment illustrated how unequipped I was in understanding narrative psychology, environment behavior relationships, and the residents lived experiences.

My desire to understand the interrelationships of mind, body and environment and the reciprocal nature of these exchanges as it relates to health and wellbeing ultimately led me to scholarly pursuits in order to gain a deeper understanding of interdisciplinary methods towards experienced outcomes and subjective wellbeing.

Acknowledgements

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Introduction

The study of the experiential conditions of persons living with dementia, and of the environmental factors associated with their residence in long term care homes, is of critical importance. It is critical not only for the afflicted, but also for persons responsible for designing institutions of care. Before studies focused on the experiential conditions of persons living with dementia, the role of the built environment and its associations to health and wellbeing, the agency potential of environmental designs interventions, or the phenomenological considerations toward built environments,[1] much of what constituted evidence-based research on living with illness had focused upon the physiological and bio-functional assessments of the afflicted.[2,3] Efforts to understand the living experience of persons with dementia in long-term care homes has rarely utilized a first person perspective, i.e. told from the voices of the afflicted individuals themselves.

Two factors that have impeded the advancement of research in this area are a difficulty obtaining informed consent, and difficulties presented by the dementia condition itself. Deficits and impairments in memory function, regressive language, and communication in general, are each non-conducive to metric translations of qualitative research. But yet, so much of what constitutes a holistic understanding of living with dementia lies beyond the bio functional understanding of the disease, and increasingly towards an explication of experiential human

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[1] Downs (1997), Hubbard et al. (2002), and Sloane et al. (2005), to name a few.

[2] Bio functional assessment is based on a purely metrical assessment of health and well being. It is often a place where the patient feels objectified through the lens of evidence-based medicine and the subsequent reduction of their experiential attributes such as narrative voice, personhood, selfhood and identity.

[3] Day (1990), Blanchard (1958), and Norberg Shultz (1980) have all become influential authors for this thesis; architects and designers that delve into the human factors of agency potential within environmental design.

factors. This is where thematic and interpretive layers of identity and personhood reside, though they remain difficult to reach by modern evidence-based approaches. This remains the case because, “At its most arid, modern medicine lacks a metric for existential qualities such as inner hurt, despair, hope, grief and moral pain which frequently accompany, and often indeed constitute the illnesses from which people suffer” (Kleinman, 1988).

This lack in phenomenological forms of inquiry often leaves a crisis of characterization for persons living with dementia, as “it would appear that negative stereotypes lead people to become apprehensive and unsure in the presence of ‘different or diseased people,’ and to alter their style of communication; disease labels carry perceptions of incompetence” (Shadden, 2005).[4] As a result of these perceptions, a crisis exists within many long-term care homes that are not designed with the patient’s existential qualities in mind. Labeled by the disease as much as by the perception of others, persons with dementia are often left voiceless, characterless, and undefined within an equally undefined space and place.

Listening to and understanding the narratives of persons with dementia may help to reveal the effects of the environmental conditions to which they are subjected. This provides a form of place, citizenship, and autonomy that is often lost when diagnosed with dementia of the Alzheimer’s type.[5] It is for these reasons that the thesis chapters begin with narrative (rather than the built environment) as an entry point toward the understanding of person, embodiment, space

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[4] Crisis of Characterization refers to the struggles of identity post-diagnosis that persons living with dementia face; especially in the mid to later stages as the question of the existence of inner personhood intensifies as memory functions decline. This also extends to transitions of identity (person to patient) that persons living with dementia face when institutionalized, and also the slow deterioration of identity and personhood as the disease progresses into mid to late stages.

[5] Citizenship is a reference to Baldwin’s notion of the creation of frameworks within which persons with dementia can be empowered through inclusion and from patient to citizen (2007).

and place, and whether these elements hold agency towards the appropriation of phenomenological and “Psychophysics Meaning” (Gibson, 1950).[6] The supposition is that the majority of patients with dementia are narratively deposed and that “the loss of story making and telling has its impact on failure to care for the long-term chronic or incurable patient” (Hunter, 1991). Listening to the stories of persons living with dementia may in fact shed light on the living experience within a long-term care home and these narratives may prove instructional in the design of space and place.

The thesis follows an interdisciplinary approach that triangulates three primary disciplines: *phenomenology*, a mode of reasoning towards understanding the contents of consciousness in relation to the physical world, *design architecture*, the composition of aesthetics, atmospherics, and the built environment as defined as space and place, and *narrative psychology*, understanding the cognitive and emotional significance of experiences via communication, presentation (telling), and interpretation (listening).

It is also important to note that the analysis and written perspective of this thesis is qualitatively phenomenological in conceptual thought and research modality. As such, the focus is towards the explication of human experiences as it pertains to the long-term occupation of space and place in long-term care homes. Adopting empirical research with phenomenological intent facilitates a deeper context of meaning beyond the mere quantification of the subject matter. Since able-bodied and able-minded persons often drive the perception of the sick and ill, the thesis will also illustrate contrasting living experiences of both able and non-abled persons living with dementia.

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[6] “Psychophysics Meaning” is the relationship between physical stimuli and mental phenomena, and that this relationship at it’s core is an understanding of environment-behaviour relationships (1950)..

In the first part of this paper I will discuss the importance of narrative as a primer towards understanding the communicable dimensions of personhood, selfhood, identity and embodiment, and that the patient narrative assist in a better understanding of their experiences. I will present several arguments for narrative's place as a form of inquiry within evidence-based medicine or for narrative's inclusion in mainstream therapy. I will also illustrate narrative's role in defining one's (persons living with dementia) embodiment within space and place.

The second part of the thesis places emphasis on the reconceptualization of the term "patient" and with it, the conceptions of persons as patients. It also delves into the theoretical constructs and practices of form-disabling environments. It does so by considering the possibilities of sensitive-enabling environments, designed to accommodate degenerative conditions such as dementia. This chapter also considers design interventions used to promote health and wellbeing, healing spaces, as well as designers of care adopting a patient/person centred ethos. The chapter provides a perspective upon experiences rather than condition and looks at the reciprocal nature of environments and health and wellbeing.

The last chapter focuses on the research methodology as a phenomenological approach, specifically with use of the Hycner (1985) method. I not only detail the benefits of this method as a mode of inquiry, but also the problems related to its adoption, such as the difficulties of a non-consensus approach to conducting experiential research, the role of self reflection as a researcher, maintaining rigor as a systematic approach, and quantifying the subtext of meaning and the explication of research data. I discuss overcoming these challenges, e.g. obtaining consent. It is important to note that the research method employed facilitates the use of the patient's own narrative. The explication of findings was not only based on verbal translations but also non-verbal facial expressions. The thesis culminates with the contextualization of common themes, results, discussions, and limitations. Most importantly this thesis considers the possibility of a new paradigm for applied design practices to therapeutic environments.

Chapter I:
Towards the Phenomenology of Narrative

Much of what can be learned from our knowledge of the experiential world, its subjectivities and perceptions is from forms of narrative as stories and story telling. Stories and storytelling provide “cognitive and emotional significance to experience; they are a means of constructing and negotiating a social identity, and give moral weight and existential significance to actions and events” (Roberts, 2000).[7] “Narrative is an organizing and interpretative structure, linking character, motive, object, and circumstance in such a way as to enable us to ask and answer questions of ‘Who?’ ‘Why?’ ‘How?’ ‘When?’ ‘Where?’” (Mackenzie, 2008). Effectively both G. A. Roberts (2000) and C. Mackenzie (2008) highlight the agency factors and the structural mechanisms that narrative meaning can provide as a form of communication.

However, the dementia condition robs the ability to appropriate the past, anticipate future actions, quantify experiences, or connect a history; at least in a systematic method of recognition or recall. This often brings upon a disconnected embodiment for the afflicted, and as the destruction of memory functions intensifies, so too does the skepticism towards the presence of any forms of identity, personhood, or inner being beyond the mid to late stages of the disease. “When a person undergoes dramatic personal change of the kind brought about by debilitating stroke or dementia, her family might well say of her ‘She is no longer here.’ Such statements

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[7] G.A. Roberts (2000) illustrates the importance of patient voice, the effects of the loss of story making and its impact on long-term patient care. Roberts cites several authors, such as Kleinman (1988), Hunter (1991), Murray (1997), Laugharne (1999), and Rogers et al. (1993) to point out that the loss off voice or story has been in regression and unsupported as a form of inquiry, yet provides significant theoretical and practical truths that its inclusion is beneficial in providing much needed meaning to the subjective and phenomenological perspectives of patient experience.

reflect a painful awareness that the person's particular first-personal perspective has been extinguished or altered so dramatically as to make her almost unrecognizable as the person they have known." (Mackenzie, 2008). How then can this crisis of characterization be mediated between the illness and what people perceive the illness to be? For the afflicted it may start with "telling," not only as an exercise of expression but most importantly as an act of reclamation. For persons responsible for care it may start with "listening" and the "creation of social forum" in which persons living with dementia can exercise forms of narrativity.[8]

Forms of Narrativity as Telling and Listening

As a form of communication, presentation (as telling) and interpretation (as listening) form the basic construct of narrativity. Telling and listening as a product of narrativity forms the fertile forum for stories and storytelling that "bring to reality the tangible and subjective elements of being, contextualizing the inner self(s) and with it the holism of the mental and the unity of the psychological and the corporeal" (Wollheim, 1984). Stories (as remembering) can be "introspectively personal reflections often carried in the privacy of the psyche," yet the act of storytelling also appears to be a socially binding ritual when performed within social settings (Casey, 1987). "Human beings are natural storytellers and that the exchange of stories permeates our everyday social interaction" (Murray, 1997).[9]

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[8] The creation of social forum is the promotion of a social construct that facilitates and encourages participation and human expressions exercised through narrative approaches.

[9] Murray (1997) brings to fore the importance of stories and storytelling within the context of narrative psychology—bringing stories and storytelling out of the shadows of folklore and pastime towards the modernisms of scientific disciplinary approaches. Also, Murray (1997) and others, such as Maines (1993), referencing narrative as a social science and psychology provides much needed legitimacy of its curative properties and potential for inclusion into mainstream therapy, thinking, constructionism's and health psychology.

However, within the context of sickness and illness, persons living with dementia find "their stories marginalized, themselves as narrators dispossessed" (Baldwin, 2008). The act of storytelling becomes less likely to be exercised within a medicalized or social forum because "individuals with dementia can withdraw from social activities for fear of being seen as a burden to others or as failures when their disabilities come to show themselves" (Ryan, Bannister, & Anas, 2009).[10] As a result, many within evidence-based medicine are skeptical of the value of telling and listening, primarily because of the disease stigma, the difficulties of comprehending the patient's experience of living with incurable illnesses, and the perception that dementia narratives often do not come from a place of coherence or cognitive awareness. However, "the dementia narratives reveal to us that the authors are keenly aware of the reactions of others and of how much they must depend on loved ones; their reflections suggest this is a source of sadness and frustration" (Ryan et al., 2009). Therefore, it is the responsibility of others as designers of care to foster socially inclusive forums that encourage various forms of expression as therapy (writing, oral, art, performing art, mobility, etc.). This provides the means of gaining increased levels of control, empowerment, and most importantly reclaiming social identity.

The Conjoint Experience

The exchange of stories creates what I have phrased as "conjoint" experiences: a conversational dyad based upon the dialectics of showing and telling that initiates actions of reciprocity. For persons living with dementia, conjoint experiences facilitate a desire to share and reminisce, and more importantly to share experiences within the company of others. "The most

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[10] Ryan, Bannister, and Anas (2009) explore the assertion of identity, the reclamation of selfhood, the forms and structure of stories within the context of narrative. These insights furnish the thesis writings with new perspectives of the efficacy and agency within narrative psychology and narrative forms.

immediate, as well as the most telling, clue we have as to the inherently communal-discursive aspect of reminiscing is the mere fact that it flourishes in the company of others" (Casey, 1987).[11] Conjoint experiences also provide a forum in which to share familiarity or like-mindedness. In this regard and specifically as it pertains to the narratives of persons with dementia, it is not only the words or the structure of the story that holds meaning but it is also the nuanced nonverbal expressions that form a sharing characteristic—adding to the greater context of self-identity and personhood.[12] As a result, conjoint experiences open other communicable dimensions—such as the spoken word, song, performance art, arts and craft—for persons with dementia, and for those who seek alternate forms of communication in order to diagnose and research. For those unfamiliar with the dimensionality and nuance of narrativity, it would be wrong to forget the narrative aspects of a story and to focus exclusively on content. Whoever insists on doing the latter not only misses out on various thematic and interpretive layers, but also reduces a text to its content or message. In fact, "it is the way in which a story is narrated that turns it into what it is" (Vervaeck, 2005).

Narrative as a Form of Inquiry

The act of storytelling empowers the storyteller, but its true agency is found within a social forum. It is at this juncture that the self (personhood) of persons with dementia comes to be, through content, message, and meaning, whether acknowledged by others or simply in the presence of others. For example, stories are heard, felt, seen, pronounced, expressed and

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[11] The works of Edward Casey (1987) continues to be relevant to the thesis writings providing structure and a foundational basis of the inner workings of the mind's fundamental experience of remembering and forgetting, while emphasizing a phenomenological approach.

[12] Sharing characteristics is the promotion of communicable forums that allow for the sensorium of expressions through listening and telling. Expressions can range from verbal, nonverbal with expressive avenues of art, performing art, music, accessible mobility etc.

acknowledged. Identity comes into being within a non-medicalized forum and in the company of others so inclined to experience—rather than measure. And yet, the dementia narrative (as with many other forms of patient narrative) seems far less common as a form of inquiry in evidence-based medicine or as an important quotient in the design of the built environment.

Persons living with dementia are rarely heard, but continue to be narratively disposed. Baldwin (2008) suggests that it is not a conscious strategy to silence persons with dementia, but rather a prevailing belief that it was impossible to access the experience of dementia—because of their inability to verbally communicate—that excluded contributions from people with dementia.[13] In turn this perception fuelled disabling practices as "people with dementia were not only disadvantaged by the environment but also by the attitudes and actions of those around them, disadvantages well understood in the field of disability" (Kitwood, 1997).

With more knowledge about the communicable aspects of persons with dementia, it would be appropriate to say that it is possible to access the experience of dementia simply by granting forum. People with dementia are able to communicate if given the appropriate environment and inclusive social context enablers. Furthermore, the importance of narrative in the construction of identity is also becoming recognized in the field's study of dementia. "In more recent years the negative view of the capabilities of people living with dementia has been increasingly successfully challenged" (Baldwin, 2008).[14] The "countering of master narrative and attention to small stories" may illustrate the latent opportunities of the dementia narrative

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[13] Baldwin (2008) puts forth foundational frameworks for the inclusion of narrative in that narrative is centrally constitutive of the personhood and the self. That inclusion is also about citizenship through narrative. Baldwin's work provides depth of meaning to the thesis in that human forms of expressions should be placed and framed as human rights issues. Both articles also provide important perspectives of narrative as it relates to dementia.

[14] Narrative in the construction of identity has been recognized in such studies from Mills (1998), Vittoria (1998), and Surr (2006), to name a few.

(Baldwin, 2005). “Hearing the voices of people living with dementia assists in a better understanding of their experiences” (Roger, 2008).

The narratives of persons with dementia are unique in that they are constructed from themes of incurability; but it is often wrongly assumed that incurability is an emotionally indefensible position, rooted in hopelessness and despair. If narrative is found to be an important factor in understanding degenerative diseases such as dementia, then stories and storytelling may help to mediate the enigmatic nature of living with incurable illnesses. As a result narrative may help to mediate one’s identity within it, and in doing so provide the necessary introspective frames to help persons afflicted. Narrative may also help conceptualize the fluidity and ephemeral qualities of such existential questions relating to the dementia condition, such as: Why is this happening to me? Who will I become? Who will take care of me?

Narrative Psychology

Narrative brings to fore states of consciousness that provide an existential foothold, solidifying one’s place and being in and of the world. But it is “narrative psychology or narrative social science that gives weight to the importance of the different stories told, not only for the insight they provide into the actual character of the experience described by the storyteller but for the insight they offer into the identity of the storyteller and of the culture in which she or he lives” (Murray, 1997). In the case of persons living with dementia this is a critical aspect of identity and personhood.

The use of narrative psychology and narrative social science as a method of inquiry by many accounts continues to prove its relevance among scientific modes of inquiry. “Narrative preserves individuality, distinctiveness and context, whereas quantitative methods and evidence-based guidelines offer a solid foundation for what is reliably and generally correct" (Roberts, 2000). Many scholarly inquiries of narrative forms coalesce within several regions of thought and opinion, namely that: (i) "Narrative and narrativity are centrally constitutive of the personhood and the self," (ii) words, stories and storytelling may contain forms of agency, (iii) patients should have a forum in which to assert a voice, and (iv) narrative forms seek inclusion, acceptance, and legitimacy—particularly within evidence-based medicine inquiry (Baldwin, 2007). Although there have been a number of accounts detailing the importance and effectiveness of narrative form, many scholarly inquiries recognize the importance of the convergence of aligned interest rather than the promotion of separatist frameworks (Murray, 1997; Plummer, 2001; MacAdams & Janis, 2004; Baldwin, 1997). "Narrative is endemic to medicine, but has been excluded in the rise of EBM [evidence-based medicine]. It remains to be seen whether narrative's ecumenicalism will be rebuffed or reconciled with EBM's fundamentalism, but there are signs of convergence" (Roberts, 2000).[15]

Science and Narrative

The value of narrative has been measured in incremental gains and cautious acknowledgments. The resulting co-efficiencies can and have produced remarkable results in understanding the deeper context of the consciousness, selfhood, and sensorium of the medicalized being. "Science and narrative, the quantitative and qualitative are not competitors but represent a complementary duality as intimately connected as the two sides of the cerebral cortex" (Roberts, 2000). The contrasts between science and narrative, and the resulting tensions,

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[15] Roberts (2000) mention of "EBM" refers to evidence-based medicine.

have become the tenor of postmodern inquiry. Moreover, within circles of scientific inquiry, narrative remains an adjunctive curiosity rather than a complementary form of inquiry.

Evidence-based medicine research remains skeptical about the inclusion of subjective and phenomenological forms of inquiry. In short, forms that cannot be unequivocally quantified through empirical measure or bio-functioning are often viewed as superfluous within evidence-based approaches. Some scholars acknowledge the tension between narrative and evidence-based approach, but in the same breath assert that both are complementary towards the health and well being of the patient (Roberts, 2000). “Post-modern storytelling can be pitted against pragmatic truth seeking, but having described the difference and tension between these two approaches, I shall conclude by arguing for their complementarity” (Roberts, 2000). In addition to arguing for the complementarity, Roberts astutely points to the importance of drawing a distinction between the patient-person dyad. He writes, “In treating the patient as a person it is essential that we do not forget to treat the person as a patient” (2000).

The efficacy found in narrative lies in the ability to provide a reflective datum that mutually and reciprocally informs the patient doctor dyad. “Relationships between doctors and patients constantly negotiate intimacy and detachment, subjectivity and objectivity: each of these is needed, and there are risks in overemphasizing, or losing, any of them” (Roberts, 2000). In this regard, the helpfulness of the exchange lies within the testimonial content. It also remains true for the design architect in that the patient environment dyad is often dictated by the receptivity of human factors as function over form.

Despite the discourse regarding the validity of narrative inquiry, it would seem that understanding the foundational constructs of narrative aids in the quest for its adoption. In this regard, Roberts again provides the groundwork in acquiring a more fulsome understanding by stating, “The ascendant interest in narrative perspectives is inextricably linked with the impact of post-modernism” (2000). Roberts specifically cites post-modern literary theory giving rise to two perspectives on the creation of accounts of narratives: “constructivism” and “social constructionism.”

Narrative constructivism is “an individual, attributing meanings to events and creating a story to contain and explain personal experience: our knowledge of ‘reality’ is considered to be a story we tell ourselves” (Mair, 1988). Social constructionism is where:

> Narrative acts as a sociological marker defining and continually reshaping the greater cultural homogeneity of our collectively shared perspectives of world and towards each other. Social constructionism focuses on social perspectives and how meanings are negotiated with an individual to create a narrative, constructed by the individual interacting with those around him. (McNamee & Gergen, 1992)

It is at this juncture of both constructivism and social constructionism that we find the loci of the medicalized patient. They are unable to assert a voice; their identity is lost, misunderstood and unwritten. Although their identity is acknowledged in principle through the measure of bio functionality, it is rarely affirmed in a substantive metaphysics or given phenomenological qualifications. This renders the patient a passive witness. “Narrative, emerging as it did from an interest in the experience of powerlessness,” and “was seen as a means of giving voice to those previously at the margins and has effectively, and prolifically, expanded our understanding of what it is like to be marginalized, oppressed, victimized, ignored and silenced” (MacKinnon, 1996; Baldwin, 2006).

In this regard it would appear that evidence-based medicine and design conceptions misses the significance and meaning of narrative constructivism, specifically: personal experience and personal voice, and its effects upon the nature of health and well being. Narrative inquiry could and should be allied to the emergent paradigm of experience outcomes. Yet**,** when the patient narrative is placed within the uncompromisingly hard-edged appraisals and qualitative measures of evidence-based inquiry, that narrative is rarely considered significant. “Ill persons have a great deal to say for themselves, but rarely do I hear them talk about their hopes and fears, about what it is to be in pain, about what sense they make of suffering and the prospect of death. Because such talk embarrasses us, we do not have practice with it. Lacking practice, we find such talk difficult” (Frank, 2002).[16]

As it pertains to efforts in understanding “progressive cognitive deterioration phenomena through patient narratives of incurability,” there appears to be an undercurrent of skepticism towards the relevance of narrative contributions as a credible and reliable form of inquiry (Kleinman, 1988). “Stories have been in retreat for some years, increasingly viewed as the unreliable remnant of an anecdote-based medicine and the unsupported pronouncements of ‘authorities’” (Roberts, 2000).

It would appear that the inclusion of narrative as a form of evidence-based inquiry has been plagued by the negative perception that therapeutic functions of narrative are unsubstantiated. As non-abled persons seeking inclusion and voice within able-bodied conventions, it has always been a struggle against hegemony, valorizations, measure and an assertion of voice. “Medical talk uses disease terms that reduce the body to physiology, the organization of which can be measured” (Frank, 2002). However, value-laden ablest beliefs in

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[16] Frank provides the framework for understanding critical illness, offering (through narrative): “The experience of being taken to the threshold of life, from which you can see where your life could end” (2002). Frank illustrates the importance of vantage point (an experiential positioning) as abled or non-abled can provide a deeper perspective of the relevance of being.

some cases are shown to be “erroneous … based on emotional reaction, illogical reasoning, and faulty generalization” (Lippmann, 1992).

The tension between narrative and evidence-based approaches is indeed plagued by the privileging of facts over anecdotes, empirical evidence over ambiguity, concrete facts over subjectivity, “data overthrowing dogma,” and “languages of practical thought” over felt experience (Eisenberg, 2000; Cherney, 2013). Adding to the divide has been the patients’ desire to express themselves in an alternative manner that is not exclusively bound by empirical diagnosis. “The narratives of people living with dementia may at times appear to be fragmented, inconsistent and incoherent. This, however, may be seen as a ‘function of an insistence on linear consistency and coherency rather than as inherently associated with dementia’” (Baldwin, 2006). “The focus or insistence on linear consistency, coherency and emplotment coupled with a one-sided approach to narrative agency may also serve to dispossess people living with dementia from their (potential) narratives” and may lead to missed opportunities of alternate patient engagements (such as art therapy, music, dance, etc.) (Baldwin, 2006). Examples abound, “there is also a growing concern that modern medicine misses the experience of illness that patients suffer and that there is a tendency for the patient as a person to be overlooked” (Roberts, 2000). Baldwin doubles down on the notion that “the current conceptualization of narrative and narrativity excludes some individuals and groups of people, such as people with dementia” (2008). This leads to important questions towards the inclusion of narrative experiences. How does one counter the perception of relevance? And what place do stories have in an empirical evidence-based world?

Narrative: The Crisis of Relevance

It would appear that much of the skepticism within the adoption of narrative lies in the fact that narrative (in a general understanding) exists within a dichotomous field: one that is born of logical, as well as subjective, framings. On the one hand, narrative testimonials can often be viscerally explicit in depth of meaning and accuracy; but on the other hand, for persons with dementia, narratives can be inconsistent and complex to translate and decode the nuance of expressions through words verbal or nonverbal expressions—especially when read through the distorted lens of incurable illnesses.

Stories and storytelling can contain inter-woven tapestries of latent emotions and experiences, producing a mélange of seasoned distortions, elements of truths and embellishments, all resulting in flavored imageries and outcomes.

> "The very telling of one's reminiscences to others induces or encourages a story like form, and few can resist the temptation to embroider story wise upon otherwise banal reminiscence … Stories bear not only on the real but also on the imaginary, which they help create" (Casey, 1987).

Further still, narrative becomes exponentially complex within the context of sickness and illness. For example, upon early diagnosis of dementia, stories and storytelling becomes secondary to the patients bio functioning. The divorce of words, stories, and storytelling in the face of conventional logic intensifies as the patient descends into the thickets of cognitive decline. The more terminal the condition, the less we place relevance and belief that the patient's experience could in fact contain any form of agency or truth. Baldwin refers to this as "crossing a certain threshold" (2006). The threshold is mirrored by the stages of cognitive decline in the dementia condition as "beyond a certain threshold differences of degree effectively become differences of kind; beyond that point a sequence may begin to display so little narrativity that it can no longer be processed as a story at all" (Herman, 2002, p. 100). In addition, it is the perception that the words and meanings are not born of the patient's own cognizance—that they are simply and completely an effect of the disease, devoid of substance and masked in delusions—since the patient is not attuned to the relativisms and defined logic of time, space and place.

The thesis will show in later accounts that this area of thought has been contested by Downs (2005), Katsuno (2003), Matano (2000), Phinney, Wallhagen, and Sands (2002), and Snyder (2003) through the curative aspects of narrative psychology; specifically qualitative research of lived experiences in persons with dementia.

Narratives of Incurability and the Crisis of Meaning

The crisis of meaning is not only relegated to evidence-based medicine. Patients too increasingly complain about this crisis of meaning and criticize the "impersonality of psychiatric approaches that are mechanistic and dismissive of individuality" (Rogers et al., 1993). If the argument from evidence-based medicine to exclude narrative is that its forms are difficult to translate, or are variable or unreliable, then a counter argument could be that perspective is never a fixed position within the context of one's own reality. As an example, to a patient, pain is never just pain, sickness is never just being sick. Or in the case of dementia patients, memory is not chronologically bound or referenced to the exactness of time. The general constituents of subjectivity and the experiential are relevant and meaningful even though they are often born of uncertain truths and outcomes. It remains difficult but not untranslatable or immeasurable as can be seen within explication studies of narrative, emotion, verbal and nonverbal behaviour—which consider the challenges to be overcome rather than to be dismissed.[17] Narrative is not to be feared or dismissed for failing to conform to the norms of quantitative science; it is to be embraced for its learning potential as demonstrated by Hycner (1985) and Hubbard (2002). Both have developed unique verbal and nonverbal explication modalities. It is an idea of similar proportions, that "narrative, through the process of subjunctivizing reality, can consider 'human possibilities' rather than 'settled certainties'" (Bruner, 1990).

Narrative as the Countering Voice

Dementia narrative facilitates our sense-making in reference to not only the pathology, but also the embodied patient positioning in relation to the arc of sickness and illness, and the incomprehensibility and sense of helplessness of dealing with a terminal illness. Creating forums in which to re-enact storytelling may provide the ability for patients to mediate forms of existential crisis, especially when faced with questioning and reasoning of the intractability of sickness and illness. The answers may start with the use of narrative psychology, "as the person begins to grasp the meaning of a crisis by creating a story about it" (Murray, 1997).

Empowerment through voice can be found even within the ends of irrevocable illness. Although limited in number, qualitative research about the lived experiences of persons with dementia have revealed significant findings. First, they are aware of their cognitive decline, which is contrary to researchers' and clinicians' earlier understanding about the disease (Downs, 2005). Second, they can determine what is important to their quality of life (Katsuno, 2003;

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[17] Progressive examples of studies regarding the explication of human factors of persons living with dementia referenced in this thesis include Marie A. Mills (1997), Linda Clare, Julia Rowlands, Errollyn Bruce, Claire Surr, and Murna Downs (2008), Gill Hubbard, Ailsa Cooka, Susan Testera, and Murna Downs (2002), and Hycner (1985).

Matano, 2000). Third, they can describe how they cope with the stress of cognitive impairment (Phinney, Wallhagen, & Sands, 2002; Snyder 2003). These observations not only validate the importance of narrative but also provide substantive meaning towards the importance of the patient voice in the conception of self-identity. It also proves instructional in constructing forms of patient care. In this regard, narrative becomes particularity salient to the patient, doctor, caregiver, and designer, in understanding the extent of cognitive decline, irrevocable loss, or the ambiguously vexing nature of qualifying incurable illnesses. "Illness is both profoundly meaningful and simultaneously meaningless" (MacNaughton, 1998).

The act of narration especially for persons with patients with dementia is also cathartic and emancipatory in that it releases the patient from anonymity, scientific inquiry or hegemonic forces with an actionable (countering) voice.[18] Even when that voice is silenced by the detriments of illness, exercising forms of alternate expressions provide meaning and therapy towards residents in care. Narrative provides a tacit example that when the mind and body fail, words and nonverbal expressions become powerful tools in the fight against the ailments of illness.

More importantly, it would appear that the dementia narrative allows for a holistic orientation to being, rather than a pharmacological approach to bio functioning. This becomes particularly salient in understanding cognitive deterioration through patient narratives of incurability. However, what makes dementia narratives so particularly troublesome within the context and duality of hope and hopelessness is wrestling with a phenomenon that the patient by

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[18] The potential of narrative as emancipatory has been sited and researched by Murray (1997). Narrative as therapy and a form of creative expression for persons living with dementia is being currently used by Dotsa Bitove Wellness Academy in Toronto. The positive/active effects of performing arts used as therapy has been observed first hand by the researcher

all accounts cannot “put behind them [their illness]. Rather, the patient must construct a story and a life that integrates the continuing presence of the disease” (Murray, 1997). It would appear that dementia narrative is unique among other narratives of sickness and illness since the stories are of the “anticipated suffering,” factors that we could call incurability factors (de Boer, 1997). In analyzing these narratives, Robinson makes the valuable point that a “personal story may be ended before a life has physically finished and conversely for some the storyline transcends the advent of physical death” (Robinson, 2005).[19]

But even within the context of incurability, narrative finds purchase within the context of sickness and illness because “narratives can either create personal distress or have the potential to emancipate” (Murray, 1997). Yet it appears the countering factors of one’s inevitability of life or death is within the simple act of participation and inclusion, since by actionable expression the patient is granted some semblance of mediation. “Once the patient's biography becomes part of the care, the possibility that therapy will dehumanize the patient, stripping him of what is unique to his illness experience becomes much less likely” (Kleinman, 1988).

Amongst the most significant of findings pertinent not only to the research phase of this thesis but also to the reasons for persons with dementia to be included in research studies is that “persons with AD [Alzheimer’s Disease] are able to inform researchers of their feelings, desires, and preferences; albeit the AD affects how well they communicate their thoughts and feelings” (Bourgeois, 2002). But paradoxically as stated by many, “the number of studies dealing with the experiences of having and coping with dementia as expressed by the sufferers themselves have

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[19] The dimensions of loss, as formulated through narrative, have provided significant insight into the importance of narrative as a form of mediation in explaining the unexplainable and intractable forms of sickness and illness. Robinson et al. (2005) provides insights to the universality and relevance of psychological responses to loss. It also provides tacit examples that the patient is not isolated in their own sphere of sickness and illness; in fact it is a shared construction that must be taken into consideration when making sense of loss.

increased relatively slowly" (de Boer et al., 2007).

Narrative in the Construction of Space and Place

In narrative and effects upon environment as institution or long term care homes, it appears that the level of activity or passivity one's voice as patient is able to have—or, more importantly, is *allowed* to have—dictates the level of participation one has towards the design of his or her world. As we have so often found within the power construct of patient versus the design of world, the conceptions of world and care are not often born from the voices that it concerns. It is often the diagnosis that dictates the person's value as well as the conception of personal space and place. "Many people with dementia have a sense of shame and inadequacy and low self-esteem. They perceive their status within society has been reduced as a result of the diagnosis" (World Alzheimer Report, 2012).[20] The strength of the dementia narrative lies in our ability (as doctors, caregivers, and designers) to attribute value to voice. The voices of people with dementia are an integral part of the story unfolding about stigma; and these individuals should be intimately involved in helping to reduce it.

Narrativity in its most basic form is allowing or constructing inclusive forums that encourage forms of expression, as telling and showing. It can reveal an inherently unique perspective of environment and the self within that environment. The willingness to listen or to look beyond the bio medicalized conceptions may assent to conceptions of care that may improve the lives of persons living with dementia. In this regard, this thesis considers forms of narrativity, e.g. verbal and nonverbal expression, as much more than storytelling. Narrativity acts

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[20] This report provides a comprehensive review of the state of Alzheimer's disease and, most importantly, delves into the stigma surrounding its effects.

as reclamation from a disease that robs the body and mind of self-identity, personhood and embodiment. By the nature of the disease, the general perception of persons afflicted is that they are unreachable or considered lost.

Chapter II:
The Reconceptualization of Space and Place

The primary focus of this chapter is to illustrate the interrelationships of mind and body within the built environment, the reciprocal nature of these exchanges as it relates to health and wellbeing, the pedagogic factors contributing to enabling and disabling environments, and the factors of reconceptualization for space and place for persons living with dementia.

The chapter breaks down eight factors that argue for the inclusion of narrative forms in dementia cases. I start with the critique of language—namely a critique of the term ‘patient’—as the first step of eight. This sets the foundational mindset or attitude shift that is necessary for the inclusion of narrative forms of human experiences by unpacking the harm of the term in its colloquial use. The second section explores matters of fact (as language of practical thought or simple truths) that bypass ethical consideration without pause, only to become abject bias through language inequality. The third section looks beyond the bio-functional classification of the term ‘patient’, and places personhood in the foreground of conceptions of care. The forth section explores the intimate nature of inanimate things and the deeper phenomenological significations of space and place, by unpacking what the enabling and disabling factors of the built environment are. The fifth section is an exploration of the root causes of disabling environments. The sixth explores the link between the education of designers and its effect upon the conceptions of the built environment. The seventh delves into the historical theories and design principles that propagate disabling practices. The eighth within the conceptual stream begins to explore space and place conceptions as part of the human biography and what this means to persons living with dementia within long-term care homes.

Dementia is primarily an affliction upon the mind, yet many references throughout the chapter will be of mind and body within the frame of spatial realms. Now consider the further assumption that the mind-body-environment relationship has been theorized as a complete holistic entity, rather than as distinct entities. This assumption, when considering relational aspects towards the built environment, has an objective meaning. Mind and body, when viewed in isolation of the design of space and place, become problematic, specifically as this distinction pertains to relational theories regarding cognition and the built environment. This is because I believe they are experienced conjointly. It is so for persons with dementia as working memory loss is relational to physical and mental functioning such as spatial awareness, balance, breathing mechanics, wayfinding, etc.

Setting the Context: Reconceptualising the Term 'Patient'

Words and terms carry meaning and are the precursor of formulating beliefs, value structures, and forms of association. These associations strengthen or render passive (by truth or misinformation) the architects that are responsible for translating design intent and the value quotients towards conceptions of care and dwelling. Become misinformed by a belief (e.g. "patients with dementia do not have the ability to self-reflect") and one's perception of the idea quickly becomes intent (e.g. "patients with dementia voice and personhood need not be included in conceptions of care or conceptions of dwelling").

Language often gives birth to belief and perception; what seems to be normal often is mistaken to be natural. "The convenient tools of language enable us to decide beforehand what we think things mean and tempt us all too easily to see things only in a way that fits our logical preconceptions and our verbal formulas. Instead of seeing things and facts as they are we see them as reflections and verifications of the sentences we have previously made up in our minds" (Merton, 1966). Unfortunately, commonplace terms such as 'patient' can carry with them hegemonic overtones, abject biases and forms of inequality towards the non-abled body and mind. In the case of conceptions of the healthcare institutional space and place, rational thought and ethical consideration often goes unchecked without criticism of language, imagery, program of use and systems of representation.

As with the design of an environment, the form of language can be a starting point for implicitly biased thoughts and practice of the ill or the non-able-bodied. This thinking can lead to objectification, marginalization or missing the context of personhood or identity, especially within medicalized realms. In this regard language and design intent should not be looked upon as mutually independent in thought and practice, but should be considered interdependent, in order to ensure ethical practices.

In some respects, aspects of language for persons living with sickness and illness lie within hegemonic discourse. This could be considered aligned to extensive work on language and power. In particular, Higgins (1994) works on power and authority in the physician-patient relationship. As in the case of persons suffering from sickness and illness, language as labelling often leads to objectification, third-person hegemony, or misses the context of personhood or identity. However, it is the emphasis towards language and a conscious design intent that is worth noting.

It is for this reason specifically that utilizing the term 'patient' for this thesis would be disingenuous and problematic. I aspire to form a more holistic and personalized view of persons with dementia. Therefore, towards a positive association of the term and towards what is most important, ‘patient’ will be referenced as ‘persons with dementia,’ ‘persons living with dementia,’ or ‘resident in care’ henceforth.

Matters of Fact are Rarely Matters of Concern

Critiquing what seems normal, or what has become natural to our preconceptions and nomenclature, is of such primary importance. It is the starting point towards theorizing ideal conceptions of care for persons with dementia. There are several reasons why this is an important starting point.

First, “matters of fact are rarely matters of concern” (B. Latour, 2004). As a matter of fact, the term ‘patient’ has been applied subjectively or purposefully as a general descriptor towards an object entity “The Patient in Room 201.” This form of classification has significant meaning towards perpetuating negative classifications of identity and personhood, since the patient to person experiential perspective has been largely ignored in evidence-based medicine. “The person with dementia is often relegated to the status of object rather than legitimate contributor to the research process and much can be gained from a systematic study of patients’ views regarding their illness and care” (Cotrell, Schulz, 1993). As a matter of concern, the ubiquitous usage of the term ‘patient’ used to describe primarily the sick and ill often carries with it perceptual baggage steeped in ideological 3rd person hegemony and medicalized labeling. This labeling often displaces individuality, identity, and personhood for the sake of pharmacological conditioning and symptomatic measure. Preconceived notions of terms like ‘patient’ or terms of objectivity, could lead to significant misconceptions of worth attributed to the individual. It is also damaging to the eventual progression of a more holistic definition such as ‘residents in care’ or ‘persons with dementia.’ This method of classification and thinking to a large degree removes the objectivity applied towards the subject.

“We must recognize that the human beings each of us is [is] potentially an objective instrument of assessment. That which many dismiss as subjective can in fact be assessed objectively; entirely new distinctions between objective and subjective can thus arise based upon these new criteria” (Day, 1990). This new criteria promotes a more “human driven” position, one of “patient centeredness” or as the new healthcare lexicon would suggest, “patient first”—a quasi-position forming and reformulating in meaning within the midst of postmodern healthcare. In attitude and practice, the intent of patient centeredness is that the patients’ experiential outcomes are central and commensurate with the design of forms of care; but some are far more skeptical of what the title suggests. “Patient centered approach” or “patient centeredness” is becoming a widely used, but poorly understood concept in medical practice. It may be most commonly understood for what it is not—technology centered, doctor centered, hospital centered, disease centered (Stewart, 2001).[21]

Yet it would appear that if it is a matter of a defined position and perception, then the true intent of patient centeredness is liberating conceptions for those with a critical illness. Patient centeredness should allow them to escape the homogeneity of number classification and labeling. The endeavour by all intents and purposes is liberating, and as such, a precursor to the promotion of human rights and citizenry. Therefore, as an applied language and intent, a ‘person first language’ henceforth will be used.

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[21] Stewart (2001) provides an understanding of how people with dementia experience and value their situation, from the patient’s perspective. Experiences of people with dementia can help those who live with a fear of dementia to develop a more realistic picture, as well as care tailored to their needs.

Establishing the ‘Person’ in ‘Patient’

With a renewed sense of definition, the term ‘patient’ acquires a holistic meaning and value central to the individual placed within the foreground of conceptions of care and dwelling. It relinquishes the symptomatic perceptions outside of a purely objective and bio-functional classification—or in the case of dwelling, one that is solely based on the aesthetic. A designer can then construct and formulate a more hermeneutic translation of a design concept with the patient central and active within the foreground of its conception. In essence, thoughtfully designed built environments used as “active agents”—environments thoughtfully and purposefully designed to promote the health and well-being of its resident in care—hold the resident in care in primary regard as an active participant within its design.

In the case of health care institutions and facilities, it is a desired eventuality that environments should be used for healing rather than sedentary placement and containment. Forming a more humanistic perception with meaning attributed to the latent abilities of persons with dementia and their experiential outcomes has bearing on the forms of conception that a designer imagines or draws upon. For example, if toward a negative perception, a foregone conclusion that individuals suffering from incurable illness such as dementia do not possess the ability to self-reflect, the term patient can so often be applied as a “language of practical thought” (Cherney, 2003). A generalized descriptor and term that subjectively or purposefully removes individualism, increases passivity and suppression while producing disconnected outcomes that reduce or discount the person as secondary to the overall design of an environment or personalized space.

It would be a mistake to think that this is merely a matter of semantics, since terms, words, and syntax relates to a phenomenology of meaning beyond a structural composition of communication, and delves deeper into the often missed embodied sub-consciousness providing dimensionality to the words and their meaning. Words do carry perceptual intent not only as a descriptor but also as a method of hierarchical categorization leading to labeling, stigmatization and rhetoric.[22] Words carry the potential to label and stigmatize. It is especially traumatizing within the medical condition as the words sometimes have finality to the meaning and thus higher potential to stigmatize. "When a disease label is attached to a person, the very label itself has the power to 'spoil the sufferer's identity'" (Goffman, 1968). Labeling as a means of creating diseases must be distinguished from the cause of diseases. So whether the biological state of an individual is a "disease" or not, it's ultimately determined by the doctor when the diagnosis or label is given to the patient (Armstrong, 1989, p. 35).

The importance of understanding the use of these terms within the context of design applied theory and practice is that practical language and the resulting perceptual intent can often lead to forms of practical quantitative practice (a measure of metric and mathematized theories) diametrically opposed to and without the pursuit of qualitative phenomenological meaning (a measure of subjectively personal experiences). For example, how environments are designed to look verses how environments are designed to be felt speaks of the designers' preoccupation with the visual field. "The visual appetites have rendered our senses inert and as such further desensitized our considerations for phenomena and abstraction intuitions" (Bhatt, 2013). In "Rethinking the Role of Aesthetics," author Ritu Bhatt writes, "aesthetics, as a discipline

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[22] James L. Cherney in "The Rhetoric of Ableism" (2011) provides a concise analysis for explaining the hierarchical arrangements of dominance and subordination through which society organizes itself language of practical thought and rhetoric.

originated in the eighteenth century when it was named the 'science of sensory knowledge'" (Bhatt, 2013).

However, the dominance of the sense of sight and visual perception in Western epistemology has resulted in conceptualizations of aesthetics being defined primarily in visual terms. Above all, it is the rediscovery of what would be considered as the "felt experience," that I would consider a new paradigm of applied theory. In order to conceive environments one must also feel them experientially. It is to some degree an application of aesthetic homogeneity and possible hegemonic ableism that there is often no clear distinction between able and non-able environments, besides accommodations towards a disability or bio-functional makeup. Designers uniformly apply thought and practice propagated through ablest designs across many forms of institutional environments, and do so regardless of the considerations of the personal experiences of their resident in care. Designers of the built environment often neglect the subjective personalized experience of the residence in care.

The inevitable results are various forms of psychophysical disconnects for the non-abled cognitively challenged. For example, as a general application shiny floor surfaces may work well for most institutional environments, the perception of the aesthetic value is often based on cleanliness and newness, but in actuality the treatment of these floors can cause serious cognitive disconnects for persons with dementia who view these highly polished surfaces as water, ice, or a bottomless crevasse.[23] A further example would be the windows of dementia care suites facing parking lots that fill residents in care with flight anxiety as each car departs the premises.

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[23] Brawley (1996) and Hyde (1989) reference lighting conditions and wax floors causing visuoperceptual difficulties as glare and 'puddles of light' that residence walk around.

Scholars illustrate modern to postmodern aesthetic architecture using the role of the window and the view it affords (Devlin and Arneill, 2003; Verderber and Fine, 2000). This is of special significance and will prove to be of critical importance in the research findings. The fenestration (the arrangement of windows on the elevation of a building) as well as what the resident in care is exposed to (size, composition, and afforded view) as naturally organic or statically irregular vistas speaks of the sensitivity factors that need to be taken into consideration with persons living with dementia. For example, what the patient sees is often related to what they feel. "The presence or absence of a window and the view it affords include one aspect of the physical environment that has been demonstrated to affect patients' experiences in the hospital" (Devlin and Arneill, 2003). Or the proximity to natural settings and vista can have a positive effect on physiology as researched by (Tsunetsugu, 2013).

The Intimate Nature of Inanimate Things

What happens to buildings once they are designed and constructed? What is left beyond concrete forms and aesthetics, and most importantly, how will it work for persons with dementia? How will design help the in moments of crisis? Can the nature of their construction contain forms of activism? The concept of inert objects containing agency or forms of power seems foreign and awkward to most designers' sensorial constitution; yet there are compelling reasons to look beyond the inertness of objects or concretized forms and towards possibilities of active agency.

In her blog article "Can artifacts be activists?" posted on May 4, 2008, Ann Thorpe poses several interesting questions regarding the life of artifacts post design. "Once designers are out of the picture, have moved on to the next job, can artifacts in themselves be activists? Can buildings, appliances, tools, or items of clothing, in themselves, lobby for change or even ‘force’ it?” (Thorpe, 2008). Thorpe’s article poses several questions regarding form, program of use, and the nature of composition; yet none of these things can gain purchase in the mind and theories of designers if not for the belief that agency can be found in what would normally be perceived as inert objects and concretized forms. This poses several questions about the phenomena of reciprocity, namely: do objects hold agency? Can objects and environments contain meaning beyond the physical nature of their design? Can environments assert a positive or adversarial position within the minds of patients?

I believe if objects hold some form of agency it is through the emotional significance others place upon their worth. This forms the basis of agency that is “to be or act like persons, to have personality, to show volition, to accept certain locations and reject others” or “the anthropomorphizing process by which things are said to have social lives like persons and thus to be appropriate subjects for biographies” (Hoskins, 2006). In this regard, their being or existence by design or naturally occurring formation is of an affectivity (physically and metaphysically). Some relationships are explanatory in that they are based on visually perceptive processes; other encounters (such as the environmental encounters of the visually impaired) are based on “tact operating deductively and vision inductively” (Santos, 2009). Often missed or misunderstood are the deeper significations based on the phenomenological references towards objects, forms, space and place, where in the case of persons living dementia, the form of mediation appears to be transcendental, experiential, and metaphysical. As in typical pharmacological inquiry, the things that are often unseen or experientially felt are often discounted, never inquired about, or relegated to happenstance.

It is so within psychophysics discourse, when environments and objects become adversarial in form and function, asserting an inconsiderate intrusion upon the person's well-being and psyche. Leach states, "the internal, spatial organization of a building does affect the relations among people using the building" (1999). Leach suggests "spatial organization affects which areas are private and which are not who can see or be seen." It determines whether spaces are highly linked, facilitating sociability, or if they are linear and segmented. So the spatial organization, or programming, of the building may give certain groups of people power over others" (1999). Leach also suggest that "while a building through its associations might appear as deeply political, it must be understood that these politics are not an attribute of the architectural form itself" (1999).

However, as it pertains to the politics of form and the politics of use, it is my assertion that it is both form and use that are inexorably linked. A building itself represents a political and social construct, one that should be built on the rare and often missed conception of inclusion.[24] Form and function, in every facet of accessible design can be in itself a symbolic statement of activism manifested within the built environment. But in actuality many buildings as institutions today are a reflection of a history of puritanical aesthetic intent. As a result, objects and environments have lost their aesthetic relevance; instead, they have become background sentinels facilitating our automatized engagements.[25] They are inert because we have chosen to design

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[24] Conception of inclusion in another form could be perceived as following the principals of Universal Design which the main principals upon many are equitable use: a design that is useful and marketable to any group of users. flexibility in use: The design accommodates a wide range of individual preferences and abilities including accessible spaces for the non-abled. Inclusion can also be within the symbolism of a building empowering community, sanctuary, health and well being or a representation of justice.

[25] Often in the pursuit of order and standardization, the built environment loses its relevance of being as it misses (through design) the introspection of how individual differences can be included in the initial design intent. This is true today with the struggles of non-abled needs-states (as a matter of human rights) are often missed in the design of the build environment.

them that way, not because of the nature of their cold composition are they anything more or less than the conceptions we place upon their existence, or the insensitive gestures we grant to their design. In order to move towards this holistic exchange, designers will need to look beyond the static nature of environments and objects moving towards environments and objects as active agents with agency potential. This requires a deeper understanding, beyond the superficiality and surface application of aesthetics, and more towards understanding the essence of experiences and experiential exchanges as phenomenological interpretations. In essence, "the link between objects and non-abled subjects lies within the richness of reciprocal mediation towards accessible spaces." (Casey, 1993)

A Question of Pedagogy: An Exploration of the Root Causes of Disabling Environments

Many researchers have provided valuable findings about the importance of the environmental conditions conducive to health and well-being (Delin, Arneill, & Wilson, 1972; Ulrich, 1984). But what of the root causes? And why in the postmodern era of architecture do many ill-conceived environments continue to be designed or exist? Furthermore, why do many healthcare professionals remain skeptical of the inclusion of the built environment in the assessment of health and wellbeing? A principal factor is that many well-intentioned architects fall victim to the misconception of the maintenance, continuity, uniformity and reliance upon the visual sense over the emotional and experiential sensibilities of persons living with illness.

In the case of persons with dementia this is especially true since it is a perception formed upon measures of inconsequence and hierarchical categorization.[26] For example, 'Why should

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[26] Inconsequence referenced as a matter of measure for persons with dementia as their condition is counter to the logic of sequence of time, history of events, recognition and recall.

we place design in an environment where the patient does not have the mental capacity to appreciate or even remember its aesthetic nuances?' Or, in the case of a belief that persons with dementia have no appreciable memory of change, 'Why then should we apply special design to a non-appreciable population' or 'We cannot change a system to accommodate just for the few' or 'A dementia ward need not have a sense of style or program of use.'[27] These measures of inconsequence render the patient as problematic or inconsequential in design equations where the patient becomes an adjunctive form to be designed around rather than designed for. More importantly, it is this thinking that manifests itself in practice: **"**Environments can be stark and meaningful activity limited. Constraints of physical space and staffing may contribute to excess disability, a reversible disturbance in functioning that is greater than can be accounted for on the basis of disease" (Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004).

As an example, Verderber and Fine (2000) reference the spatial compression and expansion trends within healthcare architecture from big to small, compact verses linearity, low-rise versus mid- or high-rise design, and centralized versus decentralized. These are approaches that can be viewed as factors of accessible design or disabling practices for residence in care. The inevitable result (as a disabling practice) leads to dispassionate formists leaving misconceived disabling environments and inert spatial realms devoid of meaning and substance. This brings to fore the role of pedagogy and the link to disabling practices and architectural forms.

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[27] In my professional practice experience in business forums and design theory exchanges I have encountered a resistance to acknowledge the value of the patient voice in matters of environmental design.

The Paradox of Pedagogy

Lang (1987) writes of his concern about the quality of the built environment and the link to the education of interior designers, architects, landscape architects and urban designers responsible for its formation. While explaining the strengths of normative theory (prescription for action) and the weakness of explanatory theory (the explicit description and explanation of phenomena and processes) within the theoretical applications of design, Lang states: “We designers often jump to erroneous conclusions about the impact of our work on peoples’ lives. This is especially true when we are designing for people whose patterns of behaviour and values differ from our own.”

I believe the erroneous jump Lang is referring to be formulating material conceptualization before fully understanding the role of human experience, and it is within this statement that one of the central tenets of this thesis. A premise that the manifestos and doctrines of design interventions are incomplete without the requisite adoption of the human experience, for example the inclusion of the narrative voice. Human factors have much to offer in the way of designers’ understanding of the dialectical relationship of the built environment and mental wellness. This understanding is often shaped by aesthetics but rarely informed by the essence and sensorium of human experiences. To a large degree, in matters of institutional architecture, the sick and ill carry this perpetuation of thinking in many forms. For example, the additional weight of the physical and psychological traumas of being permanently displaced from “home” and home-like settings due to a critical illness and the emotional decanting from independence to dependence, center to periphery, preference and choice to routine and schedule, intimacy to expansiveness, movement to fixity, proximity to remoteness, and conviviality to taciturnity rarely feature in patient assessments.

The introduction to a healthcare environment for persons living with dementia is an introduction to uncompromising and unfamiliar concretized forms, mathematized spatial realms, and artificially sustained atmospherics diametrically opposed to the home they have left. "Unfamiliar environments in clinics, hospitals, and nursing homes can produce psychological stress that can negatively affect healing and wellness" (Ulrich, 1991). Despite the attempts of institutional environments to replicate the settings of home, it is often without the intangible but perceptible "spirit-of-place," that remains so elusive to designers, so misunderstood and under represented by institutional architecture and so missed by medicalized persons of care (Day, 1990).[28] "Historically, people experiencing middle-to-late stage dementia have been admitted to institutional settings where basic and medical needs are met but home-like attributes are lacking" (Reimer et al., 2004). Even within the depths of cognitive decline, institutionalized persons eulogize (through narrative) a feeling of a lost place (a home) and the centrality (sense of ownership) within that place, even though the exactness of time and description cannot be recalled. "The spirit is brought into being by the physical substance of the surroundings" (Day, 1990). In the attempts to accommodate for the special needs of persons with dementia, institutional environments inadvertently create disabling environments, ones that confine rather than conform to the more fragile receptors of the patient's physical, mental and corporeal being.

It is important to remember that persons with dementia facing the prospect of institutionalized care carry the weight of additional event traumas leading to institutionalized care. The destabilizing effects of leaving home and entering an institution are drastic changes of equilibrium that may exacerbate an already declining state. It is argued "the emphasis of care

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[28] I believe Day (1990) was referring to "spirit-of-place" as being a familiar or welcoming atmospheric, a feeling of welcoming or comfort that is brought into being by the physical substance of the surroundings. For example upon entering a church a parishioner feels an overwhelming sense of emotion as brought upon by the symbolism and aesthetics of the house of prayer. It is relational and becoming of a *zeitgeist* defining spirit or mood of place.

should change from emphasizing medical and physical care needs to being more focused on physical and emotional comfort and resident choice" (Reimer et al., 2004). Moreover, complicating the progression of research efforts in the role of the environment is the belief that the traditional, institutionally designed health care facility has no bearing on the wellness of its patients as long as the level of care is superb is in question (Ulrich, 1992). "Apart from issues of lifestyle, aesthetics, or their specific relation to the reconstituted hospital and medical center, the field of health architecture had not fostered a tradition of research" (Verderber & Fine, 2000, p. 190). Yet many researchers are finding that changes and additions made to the health care facility's physical and social environment, with the patient in mind, can positively influence patients' outcomes (Davidson, 1994; Ulrich, 1984; Verderber & Reuman, 1987; Devlin & Arneill, 2003). At the same time, the role of the physical environment and facilities themselves are not universally included in routine patient satisfaction assessments. For example, "in a survey measuring whether patients were satisfied with their hospital experience, no items directly related to the physical environment were included" (Harris, Swindle, Mungai, Weinberger, & Tierney, 1999). Yet "patients mention the importance of such aspects of the environment as cleanliness, comfort, and privacy when asked about their rooms" (Bruster et al., 1994).

Problematic to the cause for inclusion of the patient voice is that the relativity of this position rarely starts as a matter of interdisciplinary pedagogy, e.g. critical disabilities combined with architectural theory, behavioural science or philosophy combined with architecture, or more importantly design informed by the neurological, psychological and phenomenological dilemmas of sickness and illness, cognitive phenomena or disability and its abstractions. Designers are then left deficient in phenomenological matters or a philosophical base. As expressed within Branko Mitrovic's "Philosophy for Architects" (2011) on the reading habits of working within the field of architecture and philosophy, “architecture and philosophy are immensely different. Architectural education with its studio culture and crits, poorly prepares students to embark on the systematic reading of complex text” (Mitrovic, 2011). It is indeed the dilemma of the modern designer, romanced by the visual field yet undernourished in the experiential humanistic dynamics most essential for building better environments for the critically disabled. Yet these subjects rarely fall under the curriculum of applied studies except under the flourishing interdisciplinary banner. Rather, the preoccupations to referencing of sense making, depth of meaning, subjective acquisitions or creative modalities are largely relegated to what we see but not often what resident in care feel towards what we (designers) see. Furthermore, it is also a preoccupation and dominant manifestation of our acuity and reflexivity toward the aesthetic for that which is visually perceived yet phenomenological misunderstood.

The deeper context to why design theory struggles to grasp what it means to be disabled (physically or cognitively) is that disability culture poses significant problems and challenges to the normalized perspectives of architecture, and most importantly, the perspective of self-worth. In this regard it is the fear of difference as a *dishabille* reflection of the naturalized self that remains problematic. Deeper still is the flawed rationalization and intellectualized justifications pertaining to the dynamics of the non-ablest mind body relationship to the material space and the manifestos that are informing the modern architects, and what this means for persons with Dementia. “Architects’ definitions of disability and disabled people are not surprising in a context in which their training and education barely relates to the design needs of disabled people” (Milner, 1995). Therefore it is in the perpetuation and reproduction of disabling environments that illustrates the non-abled have become a foreign entity in the pedagogic process, and conception of ableist space and place, since by accommodation or by bespoke design it challenges the limits of conformity.

Mathematized Space and Place as an Active or Adversarial Agent

Disabling environments do not just materialize without reason or cause. In fact, genesis and lineage can often be traced to the conceptions (or misconceptions) of form and function and their relationship to the mind/body schema. It is however the body corpus, and with it, the mental conceptions of physiology that rhetoric and disabling practices find a home in the eyes of the ableist, since in the case of the body schema, it is the belief that wholeness of form is indeed indicative of worthiness, character, and social acceptance: “deformity of body symbolizes deformity of soul” (Cherney, 2003). I would add to Cherney’s concise analysis that the challenge lies within our ability to accept an image or condition that is considered healthy or whole that limits our acceptance of the disabled condition. “Physical handicaps are made the emblems of evil” (Cherney, 2003). I would add that matters of brain health are also misconceived.

In this regard we are afraid of difference, we are afraid of our natural selves, we are quick to turn away, we ignore or persecute, we render judgment. The question is how did the non-ableist mind/body corpus become perceived as so different to our normalized conceptions? In the case of persons living with sickness and illness, how did their story become so removed from the philosophies and practices of architects? In regards to the built environment, the perpetuation of form verses function can be found within the manifestos of design and the most famous of purveyors and visionaries of modern architecture.

One such architect is Le Corbusier, who propagated the use of the body dynamic, specifically the Vitruvian model, as a political and social tool to promote and uphold ableist universalities though architecture.[29] This provided Le Corbusier the moral purchase by which to ignore the multiplicities of the human body in favor of a singular universality, one that was based on perfection and ablest norms. Because the core of architectural thinking is based on ablest visual principals, it remains difficult for the non-ablest to gain moral purchase or rational truisms for the advancement of non-ablest requirements. “There is evidence to suggest that the specific mobility and/or access needs of disabled people rarely feature in the theories and practices of designers or architects” (Hall & Imrie, 1999). Since math is a science of absolutes, with principles and logic often thought beyond reproach, mathematizing the Vitruvian man provided

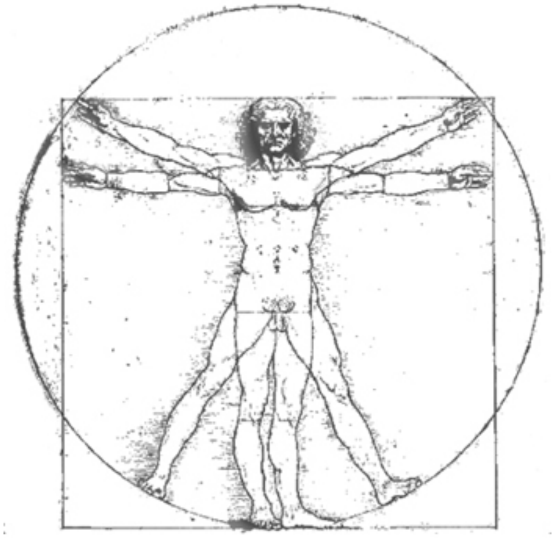

Figure 1: Leonardo a Vinci, c.1490 Vitr 1

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[29] Charles-Édouard Jeanneret-Gris assumed the pseudonym Le Corbusier, was a Swiss-French architect, designer, writer, urban planner, painter and one of the many pioneers of modern architecture (1887- 1965).

the perfect hegemonic vehicle to architects in justifying ableism as absolute and ignoring expansive accommodations to idiosyncrasies of difference in body and mind.[30]

Order, standards, and measure abound in Le Corbusier's theories and design principals. "There is nothing but pure forms in precise relationships," "truths and emotions of a superior mathematical order" (Le Corbusier, 1927, pg. 221). Similarly, architecture is a discipline based on the strict application of aesthetic form, the corporeality of body and architecture through mathematizing the "Modular" provided Le Corbusier with moral purchase to uphold the symbol of ableism (in theory and practice) as absolute and central in the creation of standardizing the

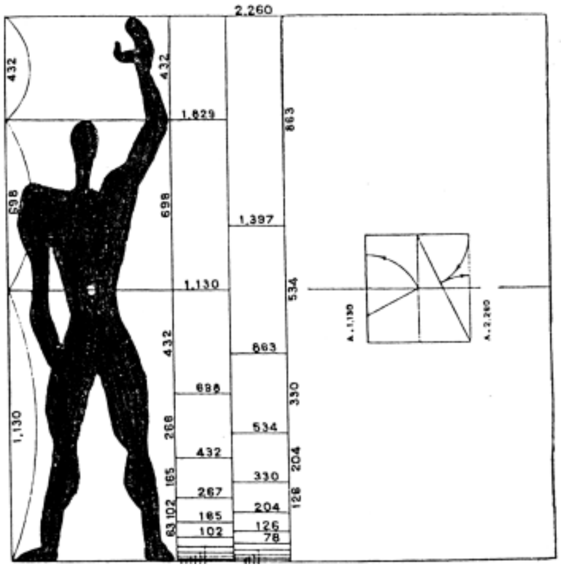

Figure 2: Le Corbusier (1887-1965) The Modulor (Anthropometric Scale) a signification of environmental specificity to body proportionality leading to gender specificity, and ableist universalities

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[30] Based on irrefutable evidence through formulaic principles math is perceived to be a science of absolutes. When contrasted to the variables of human factors the application of mathematics towards the built environment often leads to practitioners of design architecture becoming non-conformists to the potential and acceptance of disequilibria in theory or in practice.

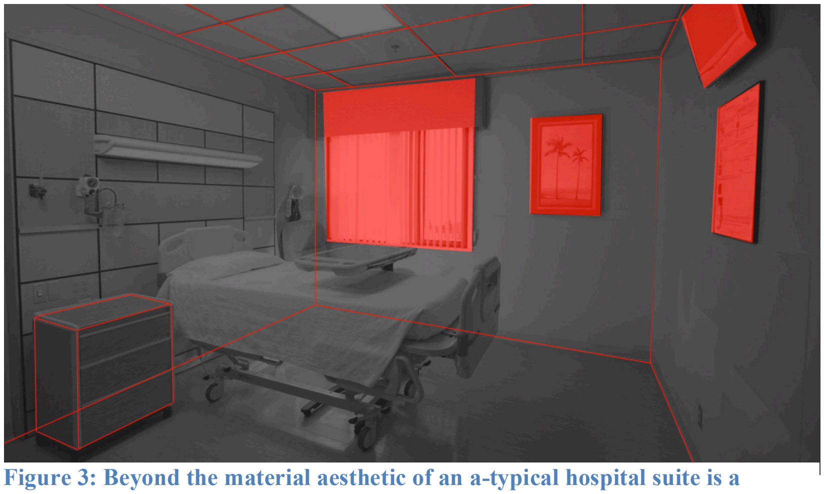

Figure 3: Beyond the material aesthetic of an a-typical hospital suite is a vectorized spatial construct that is diametrically opposed to the naturally organic elements of an exterior spatial realm.

built environment. This relegates expansive accommodations to idiosyncrasies of difference as problematic within the design manifesto: “We must aim at the fixing of standards in order to face the problem of perfection, architecture operates in accordance with standard” (Le Corbusier, 1920). The dominant visual acuity and anatomical preciseness of the Vitruvian Man, or the “Modular,” drives further the personification and identification of the Vitruvian symbol as geometrically, and thus anatomically, perfect. The human body made analogous to the staid perfection of objects gave purchase to his perfection pursuits. Deconstructing the organic elements into geometric properties further objectified the human form and human mind. Notwithstanding the brilliance of his architectural designs, within Le Corbusier’s works exists evidence of his rejection of what he saw as the disequilibria of curved lines and jagged edges--in essence, the organic nature of difference in favor of a linear perspective of symmetry, uniformity and minimalism based on the irreducibility of differences. “Clinical and mathematic in nature, seeking truisms in biology and or a physiology of parts which does not vary, a world which seemingly denied the relevance of difference of the vitality of the knowing individual subject" (Imrie, 1999).

Thus the diversity of the non-able-bodied or cognitively challenged became an adjunct to the architectural experience; in fact, it was problematic due to its many forms of mind/body abstraction.[31] The mathematizing of space and place has been problematic for not only the body, but also the mind, because the insistence on linear arrangements is more mentally confining than liberating. Post-modern examples of this thinking can be found within institutions of care as adversarial environments propagating disconnected experiences.[32] For example, during my hospital visits to various long term care homes, I witnessed floor plans that were designed with truncated corners and dead ends, spatial designs that created disconnection from inside to outside space, a lack of windows and natural light and view to vistas, which I believe collectively contribute to feelings of entrapment, confinement and confusion.

This also stifles mobility and hinders the liberating and natural act of movement. "Straight lines to destinations … are an abstraction. Animals walk in curves. So do people. We do not change direction in exact abrupt steps as does the computer screen but all in the fluid process of walking" (Day, 1990, p. 86). Low ceiling heights and minimal natural light intrusions cause anxiety and feelings of confinement. "The claustrophobically-entrapping quality of harsh meetings between ceilings and wall can be transformed into a welcoming enclosure if the ceiling can rise a little" (Day, 1990). The propensity of geometric shapes, rectangles and squares found

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[31] Tschumi (1996) in *Architecture and Disjunction* has explored the cause and effect relationship between the concept of space, buildings and their uses or space and the movement of bodies within it.

[32] These examples were observed touring various long-term care facilities with the St. Michael's hospital Geriatric Mental Health Outreach team and performing way-finding optimization exercises for health care institutional facilities. Torrington (2006) also notes the relationship between quality of life and building design especially in the form of buildings that people with dementia inhabit.

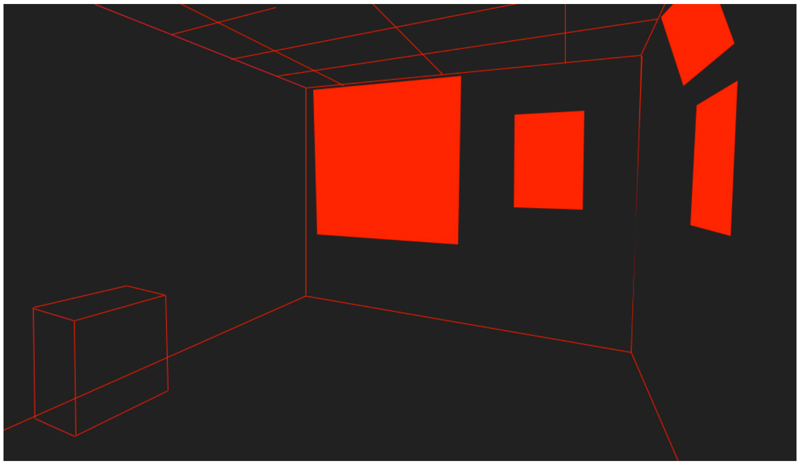

Figure 4: A proposed illustration of an a-typical hospital suite as long term exposure and effects could be a reductionism of materiality and aesthetic to a raw vectored spatial realm devoid of substance and meaning for its residence.

in furniture, floor patterns, wall surfaces, windows, and openings exist without the interruption of curves or natural irregularities: "Hard lines, hard corners, repetitive unambiguous form. Nothing can live in such places if it were not artificially sustained to an immense degree" (Day, 1990).

It is these and other examples that are products of environments conceived without consideration of the specialized needs of the patient in mind or in place. "However striking, sculptural or imposing, architecture like this is the product of the rational but arid intellect, not the heart, for it seeks powerful images at the price of more delicate feelings" (Day, 1990).

How Patients with Dementia Perceive the Institutional Space and Place Around Them: "Looking From The Inside"

The concept of space is as expansive in definition as it is amorphous in concept.[33] Like the air we breathe, its universality and omnipresence is often taken for granted. An acute awareness of space only seems to happen at critical moments of sensory deprivation as it relates to the relational physical and mental phenomena of spatial proximity, centralization and enclosure. For example, the disorientation experienced in a sudden power outage when the lights go out, becoming lost in an unfamiliar urban landscape or forest, forgetting where you parked or being introduced to an unfamiliar environment brings to fore a physical and mental 'un-grounding' as well as a psychophysiological disembodiment. This disembodiment is often accompanied by the disconcerting nature of helplessness, fear, or loss. "The terror of being lost comes with a necessity as a mobile organism to be orientated in its surroundings" (Lynch, 1960, p. 125).

Even for long-term healthcare environments familiarity as comfort or well-being with respect to spatial composition is not a given. Since "man's interest in space has existential roots. It stems from need to grasp vital relations in his environment, to bring meaning and order into a world of events and actions" (Norberg-Schulz, 1971).[34] As such meaningful material and aesthetic compositions become essential to persons living with dementia and their understanding

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[33] The thesis subscribes to Norberg-Schulz's (1971) five concepts of space: (1) the pragmatic space a physical action, (2) the perceptual space of immediate orientation, (3) existential space which forms mans stage image of his environment, (4) The cognitive space of the physical world, (5) abstract space of pure logical relations. Existential space is the missing element with architectural design.

[34] Norberg-Schulz (1971) skillfully fuses being and place within spatial realms through the investigation of phenomenology to bring substantive meaning to metaphysical concepts, i.e. architecture, space, dwelling, and the reciprocal influence of man and environment. His work *Genius Loci* informed this thesis in framing the context of healthcare institutions and patient experiences.

of world and their place within it. Since "the creation of expressive space has always been the task of specialized persons, that is, builders, architects and planners, while aesthetic space has been studied by architectural theorist and philosophers" (Norberg-Schulz, 1971). It is the additional perspective and adoption of the properties of existential space that holds meaning to persons with dementia, as existential space provides a deeper phenomenological meaning to space, place and dwelling.[35] How persons living with dementia view space and place ("looking out from the inside") would be relevant, meaningful and informative for conceptions of care. However, with the preponderance of place idioms and spatial references it would be very difficult to take oneself out of place or mind in order to simulate or truly understand cognitive deficiencies at a deprived level like persons living with dementia. However, Grange's "Place, Body and Situation" draws a striking parallel of describing an alternate universe devoid of cognitive meaning. He writes,

> Without place there would be neither language no action nor being as they have come to consciousness through time. Suppose there were no place. There would be no 'where' within which history could take place. 'Where' is never there, a region over against us, isolated and objective. 'Where' is always part of us and we part of it. It mingles with our being, so much so that place and human being are enmeshed. Forming a fabric that is particular, concrete and dense. (Grange, 1985)

Grange's essay is an attempt to weave and unweave the threads of space and place and its importance in our physiological and psychological being.

What is most interesting about his descriptions is the conception of unweaving, which to some degree is a philosophical description of cognitive loss. Since "people with dementia have an altered sensitivity for indoor environmental conditions, which can induce problematic behaviour with burdensome symptoms to both the person with dementia and the family carer"

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[35] Existential space as defined by Norberg-Schulz is the experience and schemata that makes the image of space.

(Van Hoof et al., 2009). It becomes important to consider how should environments be designed when cognition is not always afforded, specifically for those suffering from dementia.

It may begin by acknowledging that persons with dementia are more sensitive to environmental conditions than once previously thought. If persons with dementia are aware of their cognitive decline, or can determine what is important to their quality of life, then the inevitability of degenerative conditions should not be a reason to decide a patient's capacity for choice and preference. Rather, it is an opportunity to explore the uniqueness and sensitivity for understanding how degenerative conditions respond to environmental fields. "Over time, the accumulated atrophy of sensory receptors substantially reduces the quality of environmental impressions" and "age-related changes to our senses can be an even greater problem when coping with symptoms of dementia syndrome" (Van Hoof et al., 2010). "There is a meaningful coincidence between the aesthetically satisfying and the physical healthy what nourishes the soul nourishes the body" (Day, 1990). Therefore it is with consideration of an enriched interdisciplinary pedagogy, that we must consider that "we do not simply perceive a world, which is common to all of us, as naive realist maintain, but different worlds, which are a product of our motivations and past experiences" (Norberg-Schulz, 1989).

In this regard, the world of persons with dementia is one of declining senses and physical frailty, leading to adverse reactions to environmental conditions. The exploration of the root causes of disabling environments (starting with persons living with illness) is important from a humanistic perspective. Finding and relocating the displaced loci of persons with dementia (voice, selfhood, and perspective) from adjunctive conceptions and accommodations towards a centralized position leads to enabling environments. "Our environment is part of our biography.

It is part of the stream of events and surroundings that can help us make us what we are" (Day, 1990).

A change in psychology could shift the imbalanced calculus so often conceived and applied by dispassionate formists who favor the aesthetic, leaving visually beautiful, misconceived yet disabling environments and inert spatial realms devoid of meaning and substance. Uncovering patterns of human factors can better shape the designed environment and ultimately institutionalized dwellings. Understanding and qualifying the role of the experiential narrative within environments, design practitioners can gain insight to explain and perhaps predict the interactions between human behaviour, mental wellness, and the aesthetic properties that shape these built environments**.** Even for the skeptic it would be difficult to ignore the effects of design upon the mind and body; a sentiment captured poetically by Day:

> Imagine a small white room almost square, one high-level window only, no view - a monk's cell. Softly undulating plaster, a subtle curve on the ceiling and above the window; the clay-tiled floor laid on not quite straight lines; the sunlight enlivened on the uneven surface of wall and floor. Imagine it again, the edges knife-edged, the walls shiny smooth; ceiling, walls, floor meeting each other in hard, precise lines; the sunlight a sharp rectangle. The first is a room for prayer, a place of tranquility set aside from the hubbub of the world. The second somewhere you cannot wait to get out of (1990, p. 59).

Chapter III:
Research

The Adoption of a Phenomenological Research Methodology

The adoption of a research methodology, one that is not confined to a medical or bio-logistic perspective but seeks evidence within experiential conditions of 'being' as is selfhood, identity and dwelling remains critical in the explication of human phenomena of persons living with dementia.[36] "The initial phase of the process in phenomenological research begins with acknowledging that there is a need to understand a phenomenon from the point of view of the lived experience in order to be able to discover the meaning of it" (Englander, 2012). However, with the acknowledgement of the lived experience in mind, the research methodology also considered potential constraints relevant to the explication of experiential factors of persons with dementia, namely:

- The exclusion of environment and behaviour relationships in evidence based medicine
- The exclusion of narrative (verbal and nonverbal) expressions in evidence based inquiry
- The difficulties encountered in the application of the phenomenological method as a mode of inquiry regarding persons living with dementia

Addressing these three areas would ultimately affect how the subject matter would be

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[36] The dictates of 'being' for persons with sickness and illness are often and erroneously governed only by the medical definitions of the disease, as the aspects of 'being' such as narrative voice, selfhood, and identity are rendered inert. It is my belief that this is based primarily upon our perception that none of these experiential elements can truly exist within a debilitating illness especially one governed by memory function. However, the evidence presented here will show that persons with dementia have a sense and presence of 'being,' which is an acknowledgement that forms of identity and personhood resides even within the decrements of illness. It is again my opinion that it is the paucity of alternate methods of communication that renders personhood and selfhood inert rather than the disease itself.

explicated and potentially researched, since “the chief criterion in determining what research method will be used should be the initial research question (based on research interest or research problem), not tradition or norms” (Englander, 2012).

The Constructive Principles of Environment and Behaviour

The built environment plays a critical role as a determinant of health and wellbeing for persons with dementia. This thesis subsumes an environment-behaviour position based on the following determinants, namely:

- Persons living with dementia should be active participants and be considered capable authors for conceptions of dwelling and living.
- There is still much to be learned about the influence of environment upon behaviour.
- Environment and behaviour do not exist independent of each other.

These points are instructional since “knowledge of the basic principles and controversies in description and explication of human behaviour helps us clarify our understanding of the relationship between environment and behaviour” (Lang,1987, p. 99). When the environment-behaviour relationship is considered with respect to persons with dementia, specifically when entering some form of institution, it should be towards conceptions of dwelling designed primarily to counter phenomena of loss and regaining a balanced embodiment. An imbalanced versus balanced embodiment refers to a third person phenomenon experienced by institutionalized patients, whereby the emotional and experiential human factors such as identity, selfhood and embodiment become secondary to the metrics of medicalized and bio-functional care.

A balanced environment aims towards a future context of adaptable environments that can accommodate the scales of variability of condition that persons with dementia encounter. However, many spatial constructs still remain fixed, immovable, or invariant rather than open and malleable to the particularities of a state of being. In order to provide a synergistic environment, "the concrete space of developed man must be considered in its totality, including the important events experienced within it. For the particular quality of this space, its disposition and order reflect and express the subject that experiences it and dwells within it" (Norberg-Schulz, 1963).

It may seem an odd notion that spaces or the materiality of places can be imbued with a spirit or some form of affectivity beyond its inanimate state.[37] But if we accept the premise that space and place are more than the sum of the material construct and aesthetic, then the research potential for experiential phenomena can take root in the design consciousness and most importantly, manifest into new evidence-based modes of inquiry. I believe a by-product of this bespoke thinking gives credence to the possibilities of a phenomenology of meaning in the "imbuing of matter with spirit," and that space and place cannot have a "becoming" without the narrative voice that conceives it into being (Norberg-Schulz, 1963). "Becoming" is an agency construct placing significance upon space, place or artifacts that acquire an essence of meaning beyond the material construct; again, a reference to a form of zeitgeist.

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[37] This thesis subsumes a position that objects as artifacts, space and place become more that their materials construct taking on a deeper meaning and significance which can become "metaphors of humanness" such as notions and feelings of warmth, coldness, intimacy, strength, fear or doubt. It is relational to a *zeitgeist* defining spirit as a mood of place Bachelard (1994).

Capturing the Essence of Nonverbal Behaviour

Since the supporting research methodology is based on the explication of nonverbal responses of persons living with dementia, it was important to acquire insights in documenting methods of nonverbal behaviours. Hubbard, Cook, Tester, and Downs study the ways in which older people with dementia used and interpreted nonverbal behaviour within the context of social interactions. This would become integral in the explication of research data (2002).[38] Hubbard et al. reference four points for developing ways of both interpreting and encouraging the use of nonverbal communications, namely:

> First, it provides a way of understanding what older people with dementia are thinking and feeling as their dementia begins to inhibit their verbal communicative abilities. Second, strategies relying on nonverbal behaviour have the potential to be inclusive, since all older people including those who may have difficulty communicating verbally, may participate. Third, it widens the scope, and opportunities, for older people to develop interpersonal relationships because there is less reliance on verbal communication. Fourth, it enables older people to communicate meaning nonverbally, thus avoiding demeaning themselves or embarrassing others as a consequence of saying things out loud. (2002)

Since many persons living with dementia suffer from linguistic communicative impairment, I believe nonverbal communication could become an integral method of communication when other forms are not afforded, specifically in mid to late stages of the dementia condition.

Difficulties Encountered in the Application of the Phenomenological Method

“In a clinical psychological situation, encountering the person is the goal; in

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[38] Hubbard, Cook, Tester, Downs (2002) acknowledges nonverbal behaviour specifically of persons living with dementia. My research also took into consideration other nonverbal modalities namely Perrin (1997), Magai et al. (1996), Manis & Meltzer (1967), Blumer (1967), Lawton, Van Haitsma, and Klapper (1996), Argyle (1988) and Asplund et al. (1995).

phenomenological research, the aim is to encounter the phenomenon via the person's description" (Englander, 2012). In the pursuit of the understanding of human phenomena, specifically as it pertains to addressing the research questions, I believe phenomenology is the correct choice. However, in adopting a phenomenological method, I have also found there are inherent difficulties facing the researcher. In these encounters I have found several challenges in adopting a phenomenological method, namely:

- A non-consensus regarding what constitutes a phenomenological method.
- The difficulty of qualifying and quantifying the subtext of meaning within evidence-based world.
- Establishing rigor in phenomenological research.

Keen makes reference to the uniqueness of phenomenology in its unorthodox approach, to investigate that which cannot be reduced to a 'cookbook' of instructions. (1975). However I believe it is this free interpretive foundational construct that, to a larger degree, leaves phenomenology exposed to criticism and circumspection; especially from the empirical sciences in its approach to achieving rigor.

Despite its openness to interpretation, I have found, through analysis of various scholarly approaches to conducting phenomenological research, a cautious optimism in many who espouse its use. In fact, Hycner illustrates not only the possibilities of investigation but also the quandary of its adoption: "No method (including this one) can be arbitrarily imposed on a phenomenon since that would do a great injustice to the integrity of that phenomenon" (1985). Finlay addresses the confusion about how to conduct appropriate phenomenological research stating "confusion about how to conduct appropriate phenomenological research makes our field difficult for novices to access" (2009). Englander raises issues regarding evaluative criteria as well as reflective matters that concern the phenomenological researcher (2012). Giorgi addresses the difficulties encountered in the application of the phenomenological method in the social sciences and the lack of consensus towards its use (2008).

Because of these challenges I have found more debate than discourse, which have all proven instructional, by illustrating and highlighting the potential for confusion by practitioners and the avoidance of pitfalls such as "mixed discourse" or shifting philosophical positions "mid-stream" (Giorgi, 1994, p. 192; Giorgi, 2006, p. 317). This is not to say that phenomenology does not contain rigor. In fact phenomenological methods of inquiry can be "systematic, methodical, general, and critical" in order to ensure effective data collection and data analysis (Giorgi, 1997; Giorgi, 2009).

I have also learned that it is important as a researcher to follow a line of theory from its philosophical roots towards its expressions in methodology, its findings, and the quantification of results. "Hence, if one is following 'Husserlian' descriptive phenomenological philosophy as a basis for a phenomenological theory of science, both the data collection and the data analysis need to follow descriptive phenomenology in order to achieve rigor" (Englander, 2012). In this regard, I have adopted a Husserlian approach because it provides a systematic approach in conducting an inquiry into human phenomena (1913; 1983).[39] In attempting to adopt a research methodology befitting the subject matter with philosophical foundations towards Husserl and a

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[39] Husserlian (1913;1983) approach: (1) Adopt the phenomenological attitude, (2) encounter an instance of the phenomenon that one is interested in studying and the use the process of free imaginative variation in order to determine the essence of the phenomenon, (3) carefully describe the essence that was discovered.

systematic approach to the explication of research findings, I have adopted Hycner's "Phenomenological Analysis of Interview Data" approach (1985).[40]

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[40] Hysner (1985) method preserves a foundational rigor while ensuring the methodology (from an ethical and conscious sense) provides insights into the phenomenal reality of human life, but yet is not so restrictive in theory that it cannot open ones perspective to a broader multisensory world.

Chapter IV:
Method

Preparing to Enter the Research Domain: The Phenomenological Attitude

Due to the nature of researching phenomenal states and the proposed phenomenological research methodology, "phenomenological, human scientific researchers tend to choose the interview due to their interest in the meaning of a phenomenon as it is lived by other subjects" (Englander, 2012). However, I have found that in the adoption of a phenomenological research method, one cannot simply adopt (in theory and practice) the role of the interviewer or attempt to enter the research environment without the requisite adoption of a phenomenological attitude. This is an investigative posture that:

- Consciously acknowledges the importance of self-reflection and the subjective elements of one's role as interviewer and researcher.
- Attempts to bracket assumptions in order to shed preconceived notions.
- Most importantly, as it pertains to researching persons with dementia, adopts a radical openness to the variability of condition as verbal and nonverbal expressions and connotations are often amorphous, ephemeral and not easily governed or deduced by traditional forms of intellection.[41]

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[41] The points listed upon the phenomenological attitude are foundational upon the observations of Finlay (2008) and Colaizzi (1973), as to the debates whether researcher subjectivity should be placed on the foreground. The points listed are specifically reflective and true to the research question and aim as to allow for the researcher to be "open to the "other" and to attempt to see the world freshly, in a different way" (Finlay, 2008). In this regard the steps are essential, specific and complementary in the explication of the research question.

These steps were considered because “there is a general consensus that we need phenomenological research methods that are responsive to both the phenomenon and the subjective interconnection between the researcher and the researched” (Finlay, 2009).

Preparing to Enter the Research Domain: The ‘In Situation’ Tour

There are inherent difficulties in accurately documenting the experiential phenomena of critical disabilities. Examples include the experiential factors of deafness, the phenomena of blindness, or as it pertains to the thesis subject matter, accurately documenting the mercurial phenomenon of the loss of one’s memory functions and with it, the loss of an embodied selfhood and identity. A condition such as dementia brings sharply to focus a corporeality that is diametrically contrasting to our prevailing norms. As a result, the opinions and perceptions towards phenomena of disabilities are vast, differentiated, and sometimes misinformed. However, this does point out the required level of immersion one most go to capture a semblance of the condition or even to craft an informed point of view.

Therefore, it was my opinion (pre-research) that the essence of acquiring these fulsome humanistic experiences must be a totalizing immersion, not simply relegated to the reliance of scholarly works, manuscripts, or books. In this regard, it was important (in the process of understanding the world for persons with dementia) that I experienced this world first hand and pre-research, in order to bridge the gap between the interpretation of text and the textural world.[42] In accurately documenting phenomenal states, it was vitally important to gain a real world perspective of the persons of interest before a study design was solidified or persons were

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[42] Ethical procedures were taken into consideration upon adopting the pre-research approach. The engagements to persons or environment were strictly observational with no direct contact with the patient population and with the supervision of the Geriatric Mental Health Outreach Team.

approached. This could only be achieved by an embedded immersive exercise. Several factors precipitated this step, namely:

- The importance of gaining an embedded and conversant perspective of the greater field of care surrounding the persons living with dementia, including the clinical, socio-spatial and environment-behaviour activity field of a long term care facility.
- Touring various facilities in order to gain a perspective of the architectural aesthetics and layouts of the long-term care facility.

The facilitation of an in-situation embedded experience was granted by the St. Michael's Hospital Geriatric Mental Health Outreach Team and the various long term care facility supervisors (who were all briefed about the intent of the research), under the condition that the role would be strictly observational with no interaction except for an introduction as the visiting student researcher.[43] I accompanied the Geriatric Mental Health Outreach Team on their daily patient assessment tours of four long-term care facilities over a four-day period. Over forty hours of patient and environmental observations were accumulated. The in-situation exercise provided the opportunity (as an observer) to tour various long-term care homes and join the Geriatric Mental Health Outreach Team patient assessment interviews. The tours also provided the opportunity to observe under various day-parts and station nurses on their daily routines, as well as collect observations from the directors of care regarding the challenges of behaviours in

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[43] The Geriatric Mental Health Outreach Team consisted of one part time geriatric psychiatrist, one part time behaviour neurologist, one full time psychogeriatric nurse, and one part time occupational therapist. The team is a product of the Toronto Geriatric Mental Health Outreach Team Network providing specialized psychogeriatric consultation and assessment treatment recommendations for various bed long-term care facility within the Greater Toronto Area.

patient environments and facility procedures.[44] These observations provided critical insights that would become scripting points for the research design method.

Overcoming the Challenges of Obtaining Assent and Consent: The Power of Attorney Pre-Interview

Dementia of the Alzheimer's type poses significant challenges towards obtaining assent and consent. Persons with mid to late stages of dementia may have compromised decision-making ability. The protocols of the selection of participants took into consideration that many of the potential research participants would not be able to provide consent on their own; therefore, the patient's power of attorney in all three cases provided consent for the research study. Consequently, I felt it was necessary to conduct individual pre-interviews and briefing with all power of attorney representatives in order to review the research methodology. As a visiting student researcher, my role was strictly observational with no direct interaction with the patient population

It was my intention to obtain a cross section of long term care facilities in order to research a broad spectrum of built environments and patient sets. In this regard each facility director (Rakai Centre at Sherbourne Place, 126-bed long-term care home, The Rakai Centre at Wellesley Central Place, 282 residence, The Heritage Nursing Home, 201-bed long-term care facility of care) was issued a request for research—however, only Belmont House provided approval. Within the observational period I also took into consideration various activity periods of patients throughout the day that varied from person to person.

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[44] Day parts refer to the observation of various activity periods of patients throughout the day, which varied from person to person.

All attorneys were directly related as family members to the research participants and held an association more than a general familiarity. In all cases the attorney was also the primary care giver, making their involvement vital in not only gaining consent and assent but also in the facilitation of the research interviews as patient history, avoidance tactics, red flags, behavioral traits, and comfort factors. Approach and attitude were discussed before the interviews took place.

These interviews provided critical and key insights that would become important scripting points for the research design method. The embedded tours and power of attorney interviews proved integral and instructional (pre-research) towards the scripting of the research design methods; specifically in how to structure the interview questions, the interview format and, most importantly, conducting the research with care and dignity deserved of the persons being interviewed. Both the embedded tours and power of attorney interviews as "pre-method" proved instructional beyond the reliance on philosophical methods alone.

Research Question and Validity

Participants with mild to moderate dementia living in an institutional setting where they could give consent were asked a number of lived experience questions. The responses were videotaped and scored qualitatively. The research question that guided the study was:

"How do the experiential narratives of patients with dementia inform the spatial construct of health care institutions?"

My intention of qualifying the research question was based the following:

- To understand and qualify the felt experiences and structures of consciousness of persons living with dementia and whether their experiential narratives prove instructional in the design conceptions of health care spatial realms.
- To understand and qualify if the aesthetic compositions of healthcare environments, such as objects, materials, architectural composition, natural or processed atmospherics, hold agency and or reciprocation to the patients' embodiment, selfhood, health and well-being.

Inclusion and Exclusion Criteria

Interviews were conducted with persons living with dementia within the clear guidance of research ethic policies at St. Michael's Hospital and York University, as outlined within the research ethics guidelines of the Office of Research Ethics (ORE), Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE), Toronto Academic Health Sciences Network (TAHSN), Personal Health Information Act (2004) and Human Participant Research Protocol.

The inclusion and exclusion criteria was based on patients with dementia who have been recently admitted to a long-term care facility exhibiting mild to moderately severe cognitive decline.[45] For the purposes of defining the patient pathology, I have used the seven-stage framework of Dr. Barry Reisberg, clinical director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center (1982). Patients who are diagnosed no further than stage five met the inclusion criteria for the research study.[46] Stage Five—moderate or mild-stage Alzheimer's disease—occurs when gaps in memory and thinking are

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[45] The exclusion or limitations were based on cognizance in speech since narrative was the primary emphasis of research

[46] Dr. Barry Reisberg et al. (1982) of New York University, School of Medicine's Silberstein Aging, developed the 7-stage framework, which breaks the progression of Alzheimer's disease into seven stages. This framework for understanding the progression of Alzheimer's disease has been adopted and used by a number of healthcare providers as well as the Alzheimer's Association.

noticeable and individuals begin to need help with day-to-day activities. In addition to the seven-stage framework, I consulted with the St. Michael's Hospital neuroscience team, directors of care, and station nurses on the medical records of persons living with dementia, in determining optimal candidates.

Data Collection Procedures

Participants (three female persons with dementia) with mild to moderate dementia living in an institutional setting who could provide consent were asked a number of lived experience questions. The video recording of the interview was used strictly for review purposes only, with the expressed approval of ethics guidelines and the power of attorney assent and consent. The responses were videotaped and scored qualitatively through verbal and non-verbal responses. The data collection procedures used transcriptions and a non-verbal evaluation scale. The method of explication of research data used was Hycner (1985) method.

The Hycner method is 15 step guideline that provides balance between the natural sciences as "reification" (as a set of instructions) vs. of phenomenological philosophy method as an approach, an attitude, an investigative posture with a certain set of goals. The Hycner method quantified specific steps in analyzing interview data. It provided a balance of being true to the phenomenon of interview data while also providing concrete guidelines. As well, the Hycner method provides insight and rationale on issues in phenomenological research, such as: randomness, accuracy of descriptions, generalizability, subjective influence of researcher, validity, reliability, absence of control groups, absence of hypothesis, absence of prediction, absence of interpretation. Methodology provides insights into the phenomenal reality of human life.

Although 15 steps are referenced, it is important to note that not all steps were used and some were exempt from the research. For example, Step 6 “Training independent judges to verify the units of relevant meaning” was done as part of an internal supervisory meeting (Hycner, 1985). Step 11 “Returning to the participant with the summary of themes” and Step 12 “Modifying the themes and summary” were omitted from the analysis because I felt it would place an unnecessary burden on the participants (Hycner, 1985). Also, given the diagnosis of the persons being interviewed, they most likely would not have had the memory to recall the conversation.

Research Questionnaire

The responsibility of the researcher to facilitate narrative forms is as important as the narrative itself. Therefore I have adopted a research methodology that poses a series of questions, based on eliciting the lived experience of the individual, told in their own words. This is a vital step in understanding the deeper context of personhood, selfhood, and identity, as it relates to the design of space and place. The responses on the questionnaire also illuminate the primary research question. Furthermore, the questionnaire and mode of inquiry by its openness to the inclusion of feelings, desires, and preferences promotes a conversational dyad, told by the patients’ with their own words and feelings. The character of the experience can be captured through verbal as well as non-verbal behaviourisms. Their responses increase the level of awareness the individual has of themselves and more importantly, their space and place.

A non-directive style of interviewing, using open-ended questions, was used to allow the participants the freedom to control pacing and subject matter of the interview. Additionally, a more direct style of questioning was used, as needed, when information the participants provided required clarification. The questions were based on past place, current space and place, relationships to surroundings, and personal meaning towards the wellbeing and selfhood of the persons. For example, “what did you like about your other home?” “How did that room and the things in it make you feel?” “Do you have a favorite place to spend time in this care home?” “How would it make you feel if it/they were here?”

The research questionnaire was vetted with six rounds of revisions by the Geriatric Mental Health Outreach Team, power of attorney’s, supervisory committee, and the principal investigator. Each searched for questions that may have been problematic to the persons interviewed. The full research questionnaire can be found in appendix B.

Non Verbal Behaviour Chart

Nonverbal behaviours as a body or facial affect provide a dimensionality of meaning that expands upon the transcriptions of words.[47] “Bodily communication, or non-verbal communication (NVC), plays a central part in human social behaviour. Recent research by social psychologists and others has shown that these signals play a more important part, and function in a more intricate manner, than had previously been realized” (Argyle, 1988). A nonverbal reference scale using pictograms was created to reduce verbal expressions and increase clarity in participants with dementia. In order to triangulate verbal response and nonverbal behaviour—e.g., body position, expressive face, expressive body, vocal pitch intonation, etc.—in an effort to identify general nonverbal affects, I developed a pictogram reference scale. This would

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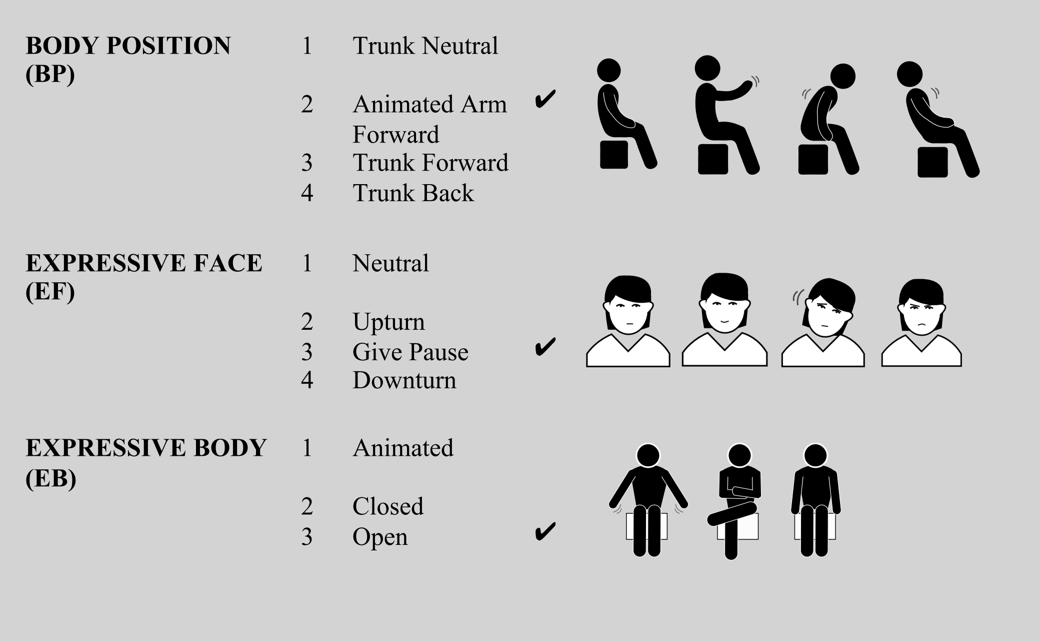
[47] Para-linguistic (intonation emphasis pauses) Nonverbal behaviour needs to be taken into account because it can emphasize or alter the literal meaning of the word. A non verbal chart was designed instead of using previously established such as the Facial action coding system by Eckman and Friesen (1978) due to the potential for the reduction and clarity of facial expressions (Asplund, Jansson, Norberg, 1995).

ultimately be used as a method of explication when combined with units of relevant meanings of the person interviewed.



BODY POSITION (BP)	1	Trunk Neutral	
	2	Animated Arm Forward	✔
	3	Trunk Forward	
	4	Trunk Back	
EXPRESSIVE FACE (EF)	1	Neutral	
	2	Upturn	
	3	Give Pause	✔
	4	Downturn	
EXPRESSIVE BODY (EB)	1	Animated	
	2	Closed	
	3	Open	✔

Figure 5: Non Verbal Pictogram Reference Scale

Para-linguistic (intonation, emphasis, pauses) non-verbal behaviour needs to be taken into account because it can emphasize or alter the literal meaning of the word. A nonverbal chart was designed instead of using previously established systems, such as the facial action coding system by Eckman and Friesen (1978). This is due to the potential for reduction and clarity of facial expressions (Asplund, Jansson, & Norberg, 1995).

Memory is not an exclusive domain to the mind; therefore nonverbal expressions are also expressive forms of memory. “It is the body itself that establishes the felt directionality, the sense of level, and the experienced distance and depth that together constitute the main structural features of any given place in which we find ourselves and which we remember" (Casey, 1983, p. 77-95).

Pictograms represent general emotion prototypes, and provide a more holistic perspective of delineating units of meaning relevant to themes or the research question. It also seemed reasonable to assume that simple facial movements like lip corner pull is easier to produce than complex facial expressions.

Research Facility – Belmont House

Belmont House is a charitable, non-profit home for seniors offering long term and retirement living care. Belmont House is located in mid-town Toronto. Belmont house provides resident-focused restorative, supportive, and palliative care. It also includes a 26-bed secure dementia care unit with qualified staff to provide care to those with Alzheimer's and related dementias.

Figure 6: Belmont House Exterior

Describing the Premises: “Looking out from the Inside”

Before entering the premises, visitors are greeted by large glass sliding doors. For the safety of the residents, the entry securely controlled through an intercom and remote security lock, centrally operated from the reception area. Upon entering, visitors are greeted by an expansive carpeted lobby adorned by classic wood furniture and large upholstered wing back chairs. These evoke a home-like setting. The panoramic views

Figure 7: Belmont House Egress to Garden

of the gardens courtyard courtesy of large floor to ceiling glass windows create an open-air feel. It is one of the rare occasions in institutional design that the exposure to natural light (through the light harvested through the large windows) seems greater than the artificial light inside. Access to the garden is through automatic doors and an accessible ramp that guides visitors and patients to the courtyard.

Figure 8: Belmont House Egress to Garden

A fountain adorns the centre of the courtyard with iron weight seating areas that are often used by visitors and patients. Once the threshold of the ramp is passed, visitors are greeted to an ambient and sensory experience diametrically opposed to the interior spatial realm.

Figure 9: Belmont House Garden

Interview Environment

Interviews were conducted with three persons with dementia. Interviews were conducted within Belmont House long-term care home, in the comfort of the person's own room, with their attorney present. The attorneys—family members in two cases—were present in order to make the introductions. Then, once a rapport was established, the attorney informed the persons that I, the interviewer, would continue with the rest of the interview independent of the attorney.

Instituting the Hycner Method: Transcriptions (Step 1)

Transcription was used as a form of data collection and explication of responses. Each response was numbered sequentially. [48]

Bracketing and the phenomenological reduction (Step 2)

Multiple readings of the transcript were performed. As an added step, in order to provide a more holistic perspective of the interviews, multiple viewings of the video were also performed in order to capture the nonverbal behaviours as they related to the verbal transcripts. The exercise was performed with the required openness to whatever meanings emerged. Hycner references this as "an essential step in following the phenomenological reduction necessary to elicit the units of general meaning" (1985).

Listening To The Interview For The Sense Of The Whole (Step 3)

Once the transcription was complete I proceeded to step three of the Hycner (1985) method: "Listening to the Interview for the Sense of the Whole." This was done independently of the video capture several times, in order to mark the plain verbal text patterns as answers to questions and inquiries. Then the same transcriptions were reviewed again with the video

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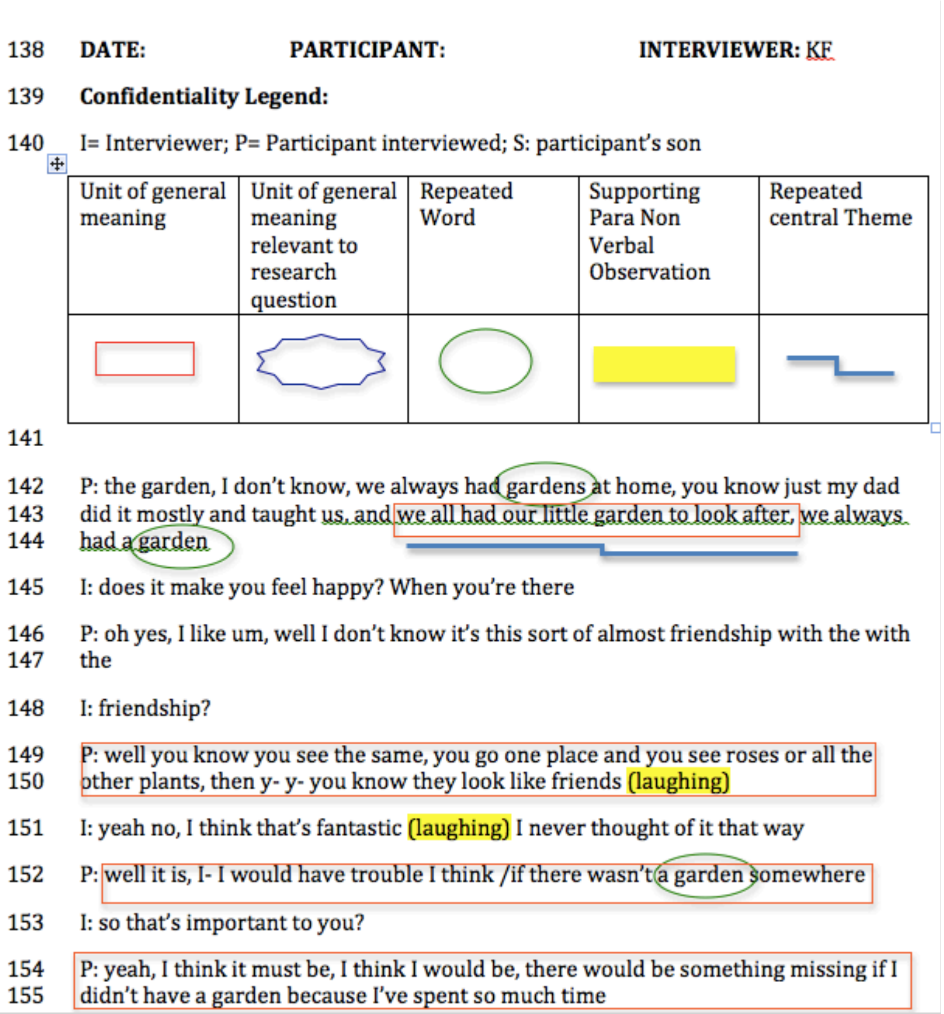
[48] Word-for-word excerpts or quotes from the transcriptions were used to illustrate units of general meaning or themes. However, the transcriptions in its entirety, raw data fully intact were not included in order to protect the confidentiality and anonymity of the persons interviewed. Numbers associated to the excerpts are references to the non verbal pictogram chart i.e. (EF#2) is a reference to Expressive Face # 2= upturn mouth. The numbers i.e. (164,165) associated to the excerpts are reference to the numbered lines within the transcript.

content, in order to mark the nonverbal behaviours in context to the verbal transcription. (Specifically the generalized body and facial positions, the linguistic levels of communication, intonations, the emphasis, the pauses, frequency of use, behaviour to word associations, etc.)



DATE: **PARTICIPANT:** **INTERVIEWER:** KF

Confidentiality Legend:

I= Interviewer; P= Participant interviewed; S: participant's son

Unit of general meaning	Unit of general meaning relevant to research question	Repeated Word	Supporting Para Non Verbal Observation	Repeated central Theme
▭	✷	◯	🟨	⎺⎽

P: the garden, I don't know, we always had gardens at home, you know just my dad did it mostly and taught us, and we all had our little garden to look after, we always had a garden

I: does it make you feel happy? When you're there

P: oh yes, I like um, well I don't know it's this sort of almost friendship with the with the

I: friendship?

P: well you know you see the same, you go one place and you see roses or all the other plants, then y- y- you know they look like friends (laughing)

I: yeah no, I think that's fantastic (laughing) I never thought of it that way

P: well it is, I- I would have trouble I think /if there wasn't a garden somewhere

I: so that's important to you?

P: yeah, I think it must be, I think I would be, there would be something missing if I didn't have a garden because I've spent so much time

Table 1: Delineation chart helps to identify themes (found within the transcription) common to all interviews as well as individual variations

Delineating Units Of General Meaning (Step 4)

Step four of the Hycner (1985) method provided an opportunity for “Delineating Units of General Meaning,” i.e. words, phrases, nonverbal or paralinguistic communications that express a unique and coherent meaning (irrespective of the research question).

Delineating Units Of Meaning Relevant To The Research Question (Step 5)

References were made as to the number of times a meaning (or reference to a meaning) was mentioned, and how it was mentioned from a verbal and nonverbal perspective. For example, the term ‘garden’ or references to nature were referenced by one participant over 10 times, with increases in nonverbal behaviourism such as intonation change, trunk forward and laughing for each reverence. Redundancies were also taken into consideration.

Training Independent Judges to Verify the Units of General Meaning (Step 6)

Although the research committee determined whether the units of relevant meaning “rung true” in their minds, independent judges were not trained to verify these units. It was generally felt that if the researcher bracketed his presuppositions, was open to the data, and utilizes a rigorous approach, then it would seem that the danger of inappropriate subjective judgments creeping in would be minimal.

Eliminating Redundancies (Step 7)

Determining redundancies requires that the research look at how often something was mention, how it was mentioned, and the nonverbal cues associated with it.

Clustering Units of Relevant Meaning (Step 8)

Within the explication of Hycner's step eight, "Clustering units of general meaning," (or any units naturally cluster together), an effort was made to elicit the essence of that unit of meaning given the context. Some units of relevant meaning may be in different clusters. This required insight and artistic judgment.

Chapter V: Results

Contextualization of Theme

Several common themes were found that united separate and discrete units of relevant meaning. However, each was an amalgamation of verbal and nonverbal expressions that coalesced around the general meaning theme headings.[49] Namely:

1. Interpersonal Relationships: The Garden + Friendship[50]
2. Critical Necessities
3. Embodied Emotional and Experiential Associations
4. Memory Tethering
5. My Things
6. Change
7. The Relationship to Space and personhood
8. Fear as Loss

Throughout the course of the research I have tried to ensure the credibility of the data by triangulating the verbal with the nonverbal to get a sense of the data in its wholeness. Hubbert et al. (2002) suggests that they (verbal/nonverbal) can act in a context of shared meanings as others interpreted behaviour in ways intended. e.g. someone with a walking stick could rub the top of the walking stick on occasion to remind him/herself it was there and they need it to walk. Perhaps another example from the study is when the participant laughed when they hear

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[50] Note that when persons interviewed referenced the garden it was accompanied by non verbal expressions as upturn (smile), animated arms and trunk forward (engaged)
8 clustered units of relevant meaning were found. Pictogram descriptions referred to the following;
BP Body position # 2 = Animated arm forward, # 3 = trunk forward
EF Expressive Face # 2= upturn mouth
EB Expressive Body #1 = animated

themselves say something funny or shoulder shrug when they are not sure how else to articulate their thoughts.

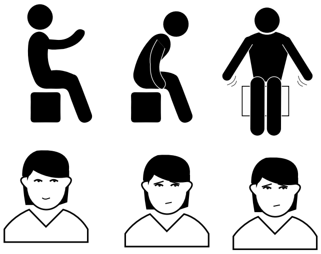
Relevant Meaning	Verbal	Non Verbal
Interpersonal Relationships: The Garden + Friendship	A. I like being in the garden (140) B. …Well I don't know it's this sort of almost friendship with the with the (23)(BP# 2, 3, 5), (EP #1), (EF #2) (161,162) C. …well you know you see the same, you go one place and you see roses or all the other plants, then y- y- you know they look like friends (laughing) (EF #2) (164,165)	

Table 2: Example of clustering units of relevant meaning Interview #1

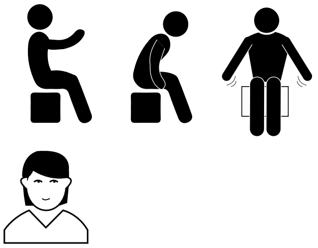
Relevant Meaning	Verbal	Non Verbal
The Relationship to Space and Personhood	A. As long as it's enough space in kind of, know who you are (laughing) (138) B. Oh I could have it a little larger here because I do have a fair number of uh family and friends coming and dropping in and it does get a little crowded wouldn't you say? (116,117,118) C. I had a feeling sometimes that it was a little claustrophobic (laughing) (126)	

Table 3: Example of clustering units of relevant meaning Interview #2

Determining Themes from Clusters of Meaning (Step 9)

After several common themes were listed, an exercise was conducted in order to include each in central themes that expressed the essence of these clusters. The clusters of meaning were reduced to one central theme (in red).

Regarding interpersonal relationships, The Garden + Friendship became the one central theme based on the frequency of the related experience shared by not just one person interviewed but by all. There are more references (verbal and nonverbal) to the garden and its interpersonal relationship than any other cluster of meaning. These six clusters played supporting roles in defining the central theme. For example, “critical necessities” play an important role since on several occasions the persons being interviewed said they could not imagine living without a garden. “Fear” and “My Things” were considered only as general units relevant to the research question and clusters of meaning. Fear was referenced to an engagement to a physical design construct (the window) and how it made the person feel when looking out of the window. The window was reference based on it being part of the room, if the window was not part of the room and living without it and the type of window preferred as large or small and what could be seen out of the window. However the window was not considered a central theme since the reference was not connected to anything else but that engagement with the window.

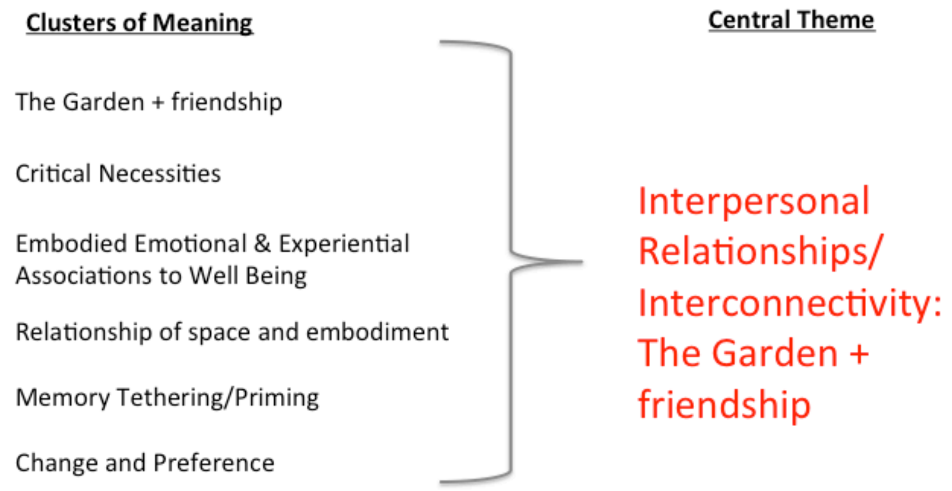


Figure 10: Clusters of Meaning and Central Theme

The results expressed and interpreted through the personal narratives as themes illustrate several important observations that require further research and support the initial suppositions of theory. Namely, through verbal narrative persons living with dementia, they suggest how they use the environment to mediate aspects of loss of person/space/place, constructing metaphors and anthropomorphizing things, indicating surrogate relationships, i.e. flowers as friends. (“Well you know you see the same, you go one place and you see roses or all the other plants, then y- y- you know they look like friends (laughing)” (#164,#165, Interview #1; Delin, Arneill, & Wilson, 1972; Ulrich, 1984; Hoskins, 2006).

Another example: Are able to inform us of their feelings, desires, and preferences, e.g., would have liked a more colorful room? “Well I wouldn’t like to, I wouldn’t be choosing stark white all the time (laughing)” (#144, Interview #2), “I like red” (#79, Interview #2). “I would feel um, I would- I don’t think I would be comfortable without without um flowers and trees and, because of all- I couldn’t I don’t think I could stand, no I would hate it in a place that was mostly building" (#317,318,319 Interview #1), "I don't know how people can grow up on a city street with, without a park and I think um I think I think they miss a lot in their lives if they couldn't um, if they couldn't live in with flowers and trees and little dogs (laughing)" (#342,343,344 Interview #2; Bourgeois, 2002; Katsuno, 2003; Matano, 2000).

Through nonverbal narrative, persons living with dementia can contribute towards preservation of self-identity and thus towards their quality of life and care (Hubbart et al., 2002). They can use nonverbal behaviours for practical reasons; they can become the objects of their own actions (e.g. leaning forward to express interest/hear better).

Design of the environment:

- Presence of a window is positively favoured, (#303) um there's a lot to look at, you know there's a garden down there with a fountain, I like the setup of the room, I love I love being able to have this view, if you look at the rooms going down, they have smaller windows (#127,128) (e.g. Rubin & Owens, 1996; Ulrich, 1984; Verderber, 1982, 1986; Verderber, Grice, & Gutentag, 1987).
- Presence of view can trigger social interactions, and can have positive effects (Park, Tsunetsugu, Kasetani, Kagawa, Miyazaki, 2010). E.g. "forest bathing" had a positive impact on cortisol, blood pressure, and pulse rate.
- Space and place are reflections of embodiment, i.e., a closed space equals feelings of claustrophobia and restrictiveness. "I had a feeling sometimes that it was a little claustrophobic (laughing)" (Interview #1, 126). "Enough space you kind of know who you are" (e.g., van Hoof et al.)

Design of the environment:

- Person-centered physical and social environment facilitates the reconstruction of past experiences that contributes to memory tethering/priming. “We did that as kids, we used to steal plants of the woods + (laughing) and put them over the garden” (#371,#371) (e.g., Davidson, 1994; Ulrich, 1984; Verderber & Reuman, 1987; Devlin, Arneill, 2003).
- Environment can facilitate tethering between past and present experiences. “The garden, I don’t know, we always had gardens at home, you know just my dad did it mostly and taught us, and we all had our little garden to look after, we always had a garden” (#157,#158,#159). “My dad taught us how to do a garden you know, we all had our (laughing) little garden” (#172,#173).

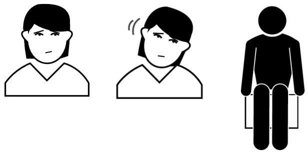
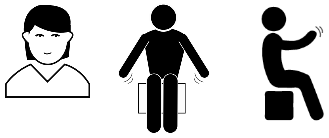
Chapter VI:
Discussion

Writing a Summary for Each Individual Interview (Step 10)

The summaries were based on a reconstruction of the inner and outer world of experience of the participant.[51]

Themes Facilitating Narrative

Initially persons (when asked a leading question) had difficulty answering the question posed (as a whole or in part) or expressing a formed response (verbal/nonverbal). However once a question touched upon an element contained within a central theme (i.e. the garden, the window, preference towards an aspect the environment etc.), an uptake in verbal/nonverbal activity was noticed and documented as illustrated within the chart below.

Question	#1 Verbal: (difficulty expressing narrative) #2 Verbal (engaged narrative)	#1 Non Verbal (closed) #2 Non Verbal (active)
I: yeah, okay so the first question I want to ask you is uh do you remember where you lived? Your home? Your home before you came here?	P: um- - it was ---(laughing) isn't that funny? / (know?) something so well	
I: how does it make you feel when you go, when you're in the garden?	P: the garden, I don't know, we always had gardens at home, you know just my dad did it mostly and taught us, and we all had our little garden to look after, we always had a garden	

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[51] Summary of interview #1, 2 and 3 are listed in the appendix

Table 4 Verbal/Nonverbal Responses

Environment Facilitating Metaphors of Humanness

All persons interviewed seemed to have formed associations with the natural environment outside of their internal living space. These associations seemed to contain a deeper meaning than a general recognition or presence of an object aesthetic.

In some cases persons interviewed seemed to have formed surrogate relationships to the spatial surroundings. This relates to the "anthropomorphizing" of certain environmental elements (Hoskins, 2006). Even in the throes of forgetfulness, the natural constructs like garden, flower, window, sky and personal space collectively formed vital relationships to the individual in making (past and present) connections, facilitating efficiencies in memory or compensating, in two cases, for the voids of family friends and close relationships.

In all persons interviewed, the overall environmental design aesthetic had much to do with the person's embodiment and wellbeing. Feelings of claustrophobia, sadness and well being all were told from the relationships formed between these outer agents, i.e. the environmental constructs of garden, window, and room aesthetic. All were considered portals to the person's inner feeling or living experience. The environmental agents also played a role in facilitating the reconstruction and recall of past experiences. Examples of this tethering were evident in all but one persons' interviewed. Subconsciously or consciously the environment and the elements within were active agents or in one case surrogates in facilitating forms of meaning. The garden experience seemed interconnected to other experiences such as close relationships, reminders of places or feeling of time. The garden references also elicited the greatest number of bodily responses and nonverbal responses such as laughing, vocal pitch fluctuations, and trunk forward posture.

Memory Tethering

The forming of surrogate relationships facilitated a phenomenon that I have classified as memory tethering. Memory tethering is past and present patient biographies linked by a phenomenal singularity, as an event experience or artifact encounter, that facilitates the reconstruction of past experiences through present constructive forms. The phenomenal singularity may survive the decrements of memory loss to be reconstructed within an object, space or place of similar association. The connections or surrogate relationships are experienced through verbal or nonverbal expressions and expressed as metaphors, e.g. flowers as friends, garden as family. Memory tethering is facilitated through environment and environment is part of a person’s biography (past or present). For example, a past event such as gardening with family, linked to present experiences of the Belmont garden construct or vice versa. The present experience of the Belmont garden promotes feelings and memories of past experiences of the family, garden, and friends, prompting visceral responses such as laughing, trunk forward, head tilted and eyes upturned, hand gestures.

Figure 11: Memory Tethering

The Relational Elements of Scale and Embodiment

The built constructs defining the personal space (small, large, claustrophobic) seem to define and mirror the feelings of personhood and selfhood.

Existential Accessibility

The centrality (garden placement) and translucency (as window portals) aid (through aesthetic design) residents in care with accessibility of the outer spatial realms. The combination of panoramic window, light and vista is important to its residents, since it removes the sense of division between inner and outer realms. Most importantly, it promotes a physical as well as a "sensory accessibility" that is seen as well as felt. It is my opinion that the window to wall ratio plays an important role in institutional design (also evident within the interview findings).[52] It is my belief that a full window view verses a truncated or portal perspective by design carries diminishing perspectives, since it is the view afforded to the outer world that is a reflection of one's place within it.

My interpretation of the centralized nature of the garden is that it seems to have an active role in helping each person access (visually, physically or metaphysically) these surrogate relationships even when not physically there. These relationships provide bodily and mental movement in which the mind can exercise experiences even when not present to the physical garden.

The centralized placement of the exterior garden courtyard, by design, can be seen from multiple vantage points and at various elevations of the buildings that surround the green enclosure.[53] So, no matter where you are in the building, patients and visitors are afforded a full view, or simply by proximity, an existential presence of the garden. The garden sets the context of the subsequent experience of the interior environment for patient and visitor since

> The sequence of preparatory experiences we passed through to approach, enter and use a building do more than affect our experience of it. They change our interstate, which can both enhance our receptiveness to health-giving qualities in our surroundings and trigger transformative processes in our innermost being. All

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[52] "Sensory Accessibility" is the facilitation of accessibility (as physical and mental mobility) beyond a built accommodation. For example a structural fenestration as window provides a portal to inner and outer realms yet the view or vista it affords to the dweller can also provide an accessibility experience enjoyed of the mind as escapism or simply a presence of 'outer agents'. For an incapacitated residence 'taking in' view or vista can provide forms of escapism not afforded by bodily means yet both as experiences are liberating as an act of physical or mental mobility.

[53] The centralized placement of the garden as an existential construct may not have been the intention of the Architect. It is through my own personal observational perspectives that values outlined are subsumed under the categories of phenomenology through environment and behaviour relationships.

> healing is founded on such inner transformations, albeit initiated by outer agents. (Norberg-Shultz, 1971)[54]

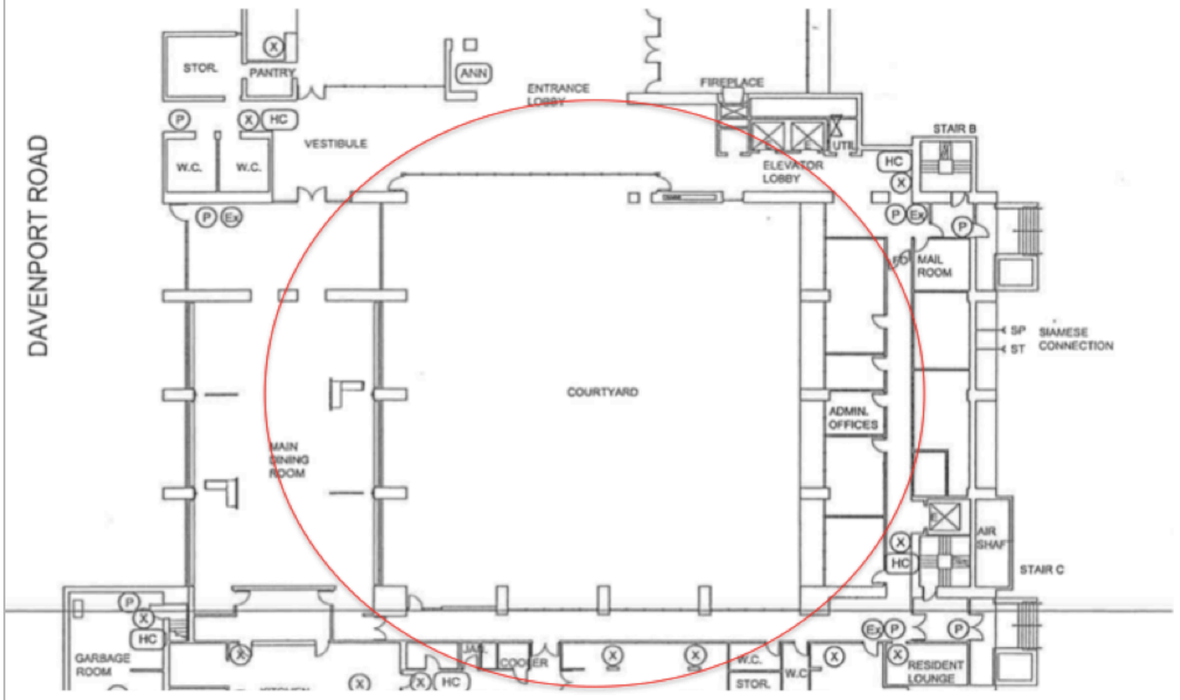

Figure 12: Belmont Site Plan showing the centralized placement of the garden

Accessibility also plays a role in the anthropomorphizing of these aesthetic elements in that their meaning and relevance to the persons in care becomes social rather than objective. The environmental integration experienced through the garden at Belmont House redraws the hard lines of delineation of inner and outer worlds which work best when these lines are visibly or by design physically transparent and, through design, organically integrated and accessible since "it is the character of a place that must be understood as a product of its integration with the

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[54] I believe Norberg-Shultz "Interstate" refers to the inner emotional state effecting the outer being or outlook.

surroundings" (Norberg-Schulz 1971).[55,56,57] In this regard, the garden within Belmont House exists as a naturally organic construct existing in naturally occurring perpetual change. Belmont House seems to many long-term care facilities visited, abnormal in its normality (Blanchard, 1994).

The Importance of View and Vista

The therapeutic value of vista is that "it is possible that a hospital window view could influence a patient's emotional state and might accordingly affect recovery" (Ulrich, 1984). Ulrich also found "in comparison with the wall-view group, the patients with the tree view had shorter postoperative hospital stays, had fewer negative evaluative comments from nurses, took fewer moderate and strong analgesic doses, and had slightly lower scores for minor postsurgical complications" (1984). The comparative benefits of rooms with or without a window was also illustrated by Wilson, who found that "patients in intensive care units without windows had significantly higher incidences of organic delirium than did patients in rooms with windows" (Wilson, 1972). Verderber referenced the dimensions of "person-window transactions" within hospital environments and has noted the attributes of windows, view, daylight, and spaces that he perceives as insufficient (1986).

As it refers to the presence of view, Wilson (1972) found a significantly lower incidence of patients with post-operative depression in rooms with windows compared to those in windowless rooms. Ulrich (1992) showed that patients recovering from surgery in a ward with

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[55] "Inner and outer worlds" refers to interior and exterior spatial aspects.

[56] "Existentially transparent" refers to the aspects of material compositions such as the transparency of windows that facilitate a form of mental mobility from inner to outer realms. This is particularly significant for persons with dementia that are physically immobile.

[57] "Hard lines of delineation" refers to material constructs within the built environment that are typically opaque, rigid, immovable i.e. walls, doors etc.

windows overlooking trees required less powerful analgesic drugs and had shorter recovery times than matched groups of patients in a ward with a view only of a brick wall. From observations in care homes, Chalfont (2007) reports if the building is not configured organically to invite nature inside, then windows and doors become crucial in connection to the outside world.

These findings suggest that psychophysical efficacy can reside in the most mundane of aesthetic. Windows as a portal to the exposure of natural light may have healing and stress reducing effects upon patients and should be considered in hospital and waiting room design. Furthermore, the physiological and psychological effects of viewing what persons with dementia see is of critical importance since the characteristics of the exterior environment that residents in care are exposed to can be directly related to their well-being. Active environments promote a centre embodiment, countering the imbalance of prolonged occupancy to artificial fields, generally fixed organizations and isolation to naturally occurring phenomena such as a sky, natural vista, a garden, trees, water etc. James makes a compelling point towards the understanding of centrality and embodiment:

> Our own bodily position, attitude, condition, is one of the things of which some awareness, however inattentive, invariably accompanies the knowledge of whatever else we know. We think; and as we think we feel our bodily selves as the seat of the thinking. If the thinking be our thinking, it must be suffused through all of its parts with that peculiar warmth and intimacy that make it come as ours (James 1890/1950, 1: 241-242).

In effect, a central embodiment only works if the relational proximity to things that make patients feel in place or in touch is in fact part of the physical and mental schema that encompasses dwelling. The further removed residents in care are, or the position they are placed towards places of substance or objects of meaning, the more or less their proximity or position, or the artificial mechanics of things physical governs their physical and mental equilibrium.

Sometimes it is of the knowing rather than the actuality of it being that brings comfort and balance. For example, knowing that a forest rests within view of a hospital bed, without physically being there may still provide a sense of comfort and tranquility and a sense of being grounded. For persons with dementia being displaced from earth-bound houses to high-rise vertical long-term dwellings may have adverse reactions manifested within a spatial field. This also extends to their own emotional constitution effected by the scale, proximity, and perception of the institutional space and place around them. Phenomenologically it brings to feeling 'how far,' 'how small' 'how high' that brings to fore factors of disembodiment, reducibility and inconsequence that often accompany and speeds the downward slope of incurable illnesses.

An example of the importance of proximity to natural settings and vista is Forest Bathing (Tsunetsugu, 2013). Yuko Tsenetsugu's study investigated the physiological and psychological effects of viewing urban forest landscapes. Tsenetsugu found that "in the forested areas the subjects exhibited (i) significantly lower diastolic blood pressure, (ii) significantly higher parasympathetic nervous activity, but significantly lower sympathetic nervous activity, and (iii) significantly lower heart rate." With the increase in urban sprawl, to the detriment of the geographical placement and exposure to natural settings, healthcare architecture will need to adapt new geographic orientations expanding the relative position towards natural settings in order to overcome and provide balance within primarily concretized fixed dwellings and urban surrounds.

Forest Bathing also plays a significant role in defining reciprocal relationships between environment and behaviour of persons interviewed, since the inclusion of nature enhances the relationship between those parts deemed as essential to the understanding of an embodied space and place. All persons interviewed expressed a desire to engage natural elements, sky, clouds, trees etc. I believe the introduction of “shinrin yoku” (forest bathing) principles to long term health care homes may help patients moderate the physiological effects of long term care such as isolation, boredom, monotony, and lack of transitional space so prevalent for residents of long-term care (Park et al., 2010). Most importantly, the positive attributes of garden settings and nature may in fact contain memory-tethering qualities vital in sustaining positive past and present associations for the health and well being of persons living with dementia.

Chapter VII:
Limitations

Adopting the phenomenological attitude (as intensification of subjective experience) was not easily attained as prescribed. Bracketing preconceived notions or attaining a reflective analysis of the lived experience was and continues to be challenging. However, methodising specific steps in thinking and analysis of a phenomenological modality—specifically the Hycner (1985) method—proves valuable in keeping a balance of an interpretive approach with rigor.

Critics might oppose an experientially-oriented approach or phenomenological style of research. For example, the sample is not random, limited number of participants, difficulty generalizing findings, or absence of control groups and verification of results. However, random samples (without identifying moderate or mild-stages of condition versus late stage condition) would have posed significant issues in pursuing a narrative based approach. The limited number of participants, however small and narrow in sample, is not a reflection on *recruitment*, but rather the difficulties on *obtaining consent*. The verification of results was experiential in explication and quantification and limited in the availability of previous phenomenological based modes of inquiry.

The focus of this approach is to illuminate human phenomenon and not, in the strictest sense, generalize the findings. The phenomena dictate the selection and type of participants and the method used. Only a limited number of participants are needed given the vast amount of data that emerges from one interview, and the results are phenomenologically informative about human begins in general. Also there are a number of validity checks in place. For example, the researcher/research committee has to ensure the findings ring true; findings fit (or not) with the literature; findings submitted to a larger community to be discussed, evaluated from different perspectives, etc. in terms of a control groups. The point is that the phenomenological researcher is trying to determine the uniqueness of human experience.

It was found later throughout the course of the research that the observer–facilitator role and the subjective interconnections between researcher and researched was difficult to maintain, because of needing to bracket assumptions or to simply adopt an observer role. Facilitation (i.e. setting the context) was necessary due to the difficulties (of the persons interviewed), expressing thoughts and feeling without some form of prompting or gentle initiation. The nature (tone, pace, movement as mirror and matching and demeanor) of the interviewer was also an integral element in eliciting any form of response.

It would seem prudent (based on the limited sample size) and necessary to expanding the field of research to other long term care facilities to research whether there is a difference between those who lived in rural settings versus those in urban settings, or opening the research to other gender segments, e.g. male.

Development of a library of nonverbal behaviours in various stages (mid, late) of the disease in order to plot what elements remains consistent or drops off, And ploting through the stages of the disease to see if and what (words, meanings, etc., space place) are lost or retained would also prove valuable long term research goals.

Conclusion

The built environment within healthcare institutions is of critical importance to persons with dementia, as the characteristics of the interior environment, the lived experience of that environment, and the reciprocal nature of that exchange can be directly related to the health and well being of its residents in care. Yet the role of the environment and, more importantly, the role of the patient as a primary author towards conceptions of what that physical environment should look and feel like rarely feature in routine dementia patient satisfaction assessments.

I believe this is a missed opportunity to deepen our understanding about the opposing and complementary environmental forces affecting the health and wellbeing of persons with dementia. The prevalence of age related diseases would undoubtedly stress the social, economic, and medical infrastructure of care. The socio-spatial domains of hospitals, nursing homes and retirement homes will have the greatest responsibilities for handling the influx and prevalence of distressing symptoms; thus the need for research and practice ideals based on innovative ways to treat degenerative conditions, as well as environments used for healing rather than placement and containment.

How persons with dementia interpret these spatial realms through mind and body, how the built environment is designed for the benefit of favourable health and wellness outcomes, and how designers of the built environment embrace the non-abled human dynamic within designed conceptions is critically important since

> Without intervention … over the next 30 years, the excess demand for long term care required by patients with dementia will increase over 10 times the current demand (2008 values). This excess demand will cause more individuals with

> higher dementia severity levels requiring more complex care to rely on community-based care and informal care support (Dudgeon, 2010).

It also remains clear that studies of environmental design interventions on health and well-being is on the cusp of recognition, yet paradoxically still seeks legitimacy as a form of measure for the health and well-being of patients and patient care. Yet, through books and scholarly research papers, the burgeoning interest in environmental design intervention continues today, specifically as it pertains to the relational aspects of the built environment, cognition, health and therapeutic applications.[58] It would appear that all scholarly works reviewed are of the collective opinion that the design of the physical environment affects the health and wellbeing of its residentss and persons with dementia are sensitive to the design of the built environment. Yet, "instruments for assessing physical environment remain in a relatively primitive state" (Lawton, Weisman et al. 2000).

Devlin's paper entitled "Health Care Environments and Patient Outcomes: A Review of the Literature" sums up the benefits of research in this area (2003). "Although this gap exists between research findings and applications, increasingly, health care providers understand that the physical environment of health care settings can affect patient health" (Devlin & Arneill, 2003). Ulrich contends, "Research has linked poor design to such negative (patient) consequences as anxiety, delirium, elevated blood pressure levels, and an increased intake of pain drugs" (Ulrich, 1991, p. 97). Moreover, Allison and Hamilton place full emphasis upon the gatekeepers of applied design by stating: "Today, designers and planners of health care facilities face enormous challenges to be successful, they must accommodate sophisticated clinical

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[58] Reimer et al. (2004), Van Hoof et al. (2010), Evans (2003), Day et al. (2000).

interventions and complex medical technology while providing a humane, therapeutic environment" (1997).

The designed environment has much to contribute towards the health and wellbeing of its residents. There is a role for persons living with sickness and illness far beyond the passivity of simply dwelling. I believe a deeper context of communication exists on a metaphysical and existential level, "for the essence of meaning lies not only in logical analysis but also within the context of the indefinable which is quantified by a consciousness or unconsciousness of felt experiences" (Wilson, 1963). The diagnosis of a debilitating disease need not mean living as a passive and silent witness to one's own decline, nor (as previously stated) is the perceived inevitability of a degenerative condition a reason to draw a conclusive end towards one's capacity or inclusion in life decisions.

Since loss is centrally constitutive of the phenomenal condition of dementia of the Alzheimer's type, it would appear that persons suffer a universal annexation afflicted not only upon the mind as memory loss but also upon body, social, and concepts of home, leaving few 'anchors of meaning'. It would appear that a tangential shift from person to patient occurs upon diagnosis and post institutionalization as the person within patient experiences this third-person phenomenon.[59] As a result it appears that persons with dementia living within long term care homes experience a negligence of absentia, a third-person phenomenon experienced as absence of narrative voice, selfhood and personhood, leading to a systematic removal of the modes of self-expression and identity. The disease itself adds to this reduction of personhood and identity as it masks the true self of the persons living within the conditions of the disease, rendering the

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[59] 'Anchors of meaning' refer to elements foundational to the person's embodiment, selfhood and identity such as home, family and friends. The garden and flowers were used as an anchor of meaning towards past friends or relationships.

inner quotient of self and identity invisible. Furthering this reduction of personhood is the prevailing belief primarily throughout evidence-based medicine that the narrative of persons living with dementia holds little instructional value towards the aesthetics of care environments and the persons embodied position within it.

It is my contention that understanding that progressive cognitive deterioration phenomena through narratives of incurability requires a suspension of all preconceptions regarding the regularities and linear lived sequences that govern our socio-spatial realm. Dispensing any form of relativity and formal logic as it pertains to a cognitive construction of space, place, time, and self-expression, is to allow oneself (as a designer) to understand the human condition as it relates to the heterogeneity of the disease, an essential step in gaining sensitivity and empathy towards the condition and the construction of space and place. Understanding the universality of its manifestations is to understand that progressive cognitive deterioration phenomena such as dementia are not singular in term, i.e. a disease upon itself. Rather, dementia's plurality is in the multiplicities of its manifestations and points to a class of symptoms, with Alzheimer's accounting the majority of all dementias.[60]

The residual emotional effects range from fear and anxiety, stress, hopelessness, undirected wandering, contact avoidance, aggression, depressiveness, suspiciousness, and loss of initiative. These factors by all accounts are subjectively quantifiable through narrative psychology since they provide additional insight into the identity of the storyteller and of the medicalized culture in which she or he lives. Since narrative is also the connective tissue to

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[60] Others, such as vascular dementia, can be classified within the triad of cognitive symptoms: Agnosia –The ability to interpret visual images (does not see the world that you or I do); Aphasia – Language – Loss or reduction of ability to interpret language (speech, written, verbal, interpretation); Apraxia – Loss or reduction of the ability to perform gross motor skills or fine motor skills, i.e. physical capabilities and most importantly memory loss.

relevance of self and social relationships, it is the loss of the conjoint experience or losing a connection of mutual significance that makes memory loss so damaging to social relationships.

Furthermore, it is the variability of recall that is so vexing to anyone conditioned to regimen and sequence that remains problematic to anyone that shares dementia's non-reciprocating experiences. Persons with dementia experience a disconnected existence experienced as a third person out of body event, ultimately becoming a passive witness to their own decline. Thus, the caregiver, family member and patient themselves are subjected to changing scenarios of unpredictability that confound the systematic sequential approach to everyday life that they themselves experience.

Our understanding and compassion towards persons with this disease rests in our ability to embrace a reflection of our own inevitable degradation within others so afflicted. That loss, as ascribed to the dementia condition, is indeed intrinsic to the pathology but not binding to the cause for hope or intervention. That change, either dramatic or catastrophic, is not an insurmountable barrier but an opportunity for exploration of the unfathomable depths of human resilience in the face of sickness and illness. That emotion and empathy provides the bridge between pharmacological and non-pharmacological interventions and the required adopted principals of the next generation of nurses, hospitals, and long-term care facilities. That manifestos and doctrines of intervention are incomplete without the requisite adoption of the human experience. That ultimately our understanding of the human factors associated with sickness and illness will provide hope to the expected generation of dementia sufferers that require love, hope, empathy and education from those who are left with the responsibility of re-conceptualizing and constructing the vessels of care.

Informing Pedagogical Frameworks

In addition to understanding the experience of the person with dementia, it will be important to gauge how the research findings inform the pedagogical frameworks and professional practice methodologies of those responsible for the design of effective and appropriate enabling institutional environments. The receptiveness of new ideas will most certainly be based on the ability of the researcher to illuminate not only the resident perspective, but also the manner in which architects, interior designers and environmental designers have come to shape not only post-modern practices, but also designers themselves, for it is within this paradigm of personal influence that change will occur. Since the goal is to understand why it should be, versus how it should appear, it is also within the building of perceptual capital based on enabling practices that will ultimately influence the rate of adoption and change necessary for the research to gain merit and legitimacy post research findings.

Future Forward

Breakthrough research innovation in integrating design and relational dementia care are worth noting. Many research scholars such as S. L. Dupuis, Pia Kontos, Gail Mitchell, Christine Jonas-Simson and Julia Gray have embraced the need for critical-arts based research with a focus on experience outcomes and subjective wellbeing. “Our research demonstrates the power of the arts to create transformative spaces in which to challenge dominant assumptions, foster critical reflections, and envision new possibilities for mutual support, caring, and relating” (Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016). The results of many of these research programs highlight the fact that exercising expression through creative forums such as art can be effective therapy, and most importantly a liberating act for persons suffering from sickness and illness.

One such example is the Dotsa Bitove Wellness Academy: A combined program sponsored by the University Health Network and York University for persons with mild to moderate dementia, their families and care partners. The programs are based on a “philosophy of care that focuses on relationships and human expression of self through movement and art.” (Dotsa Bitove Wellness Academy, 2016). I was privileged to attend a session and witnessed the practicing artists’ willingness to embrace the spontaneity required to address memory themes through music, art, video, dance, and song, only to be matched by the residents’ enthusiasm to participate. The experience was creative, inspiring and moving.

A joint venture program between the National Ballet School (NBS) and Baycrest Hospital has also embraced the arts as therapy, through dance interventions specifically for people with moderate to severe dementia. The NBS-Baycrest program claims that physical benefits dance interventions for people with dementia in long-term care have been associated with a reduction in problematic behaviours and an increase in social interaction and enjoyment in both residents and care staff. Having witnessed one of these sessions I can wholeheartedly concur that patients participating in the program seemed (even if just for a moment in time) liberated from the restrictions of ailment through the power of dance.

Art as therapy has been recognized in research as the gateway to the reclamation of citizenship (Dupuis et al., 2016). Research studies investigating design for subjective wellbeing (SWB) have provided valuable insights into incorporating happiness and wellbeing into interior architectural design missions. One such study considers designing for subjective wellbeing as performance art in residential care centres. The study considers participation as a social collective (persons with dementia, family members, visual performance artists and researchers) who "come together to interrogate the tragedy discourse and construct as alternative narrative of dementia using arts." (Stevens, Petermans, & Vanrie, 2014).

Prominent art galleries are now incorporating art into healing and recognizing art as a form of therapy, or a way of accessing long-term memories. The Royal Ontario Museum (ROM) and the Art Gallery of Ontario (AGO) in partnership with the Alzheimer Society of Toronto have incorporated dementia tours that run monthly within the galleries. Mount Sinai Hospital has also followed suit with the opening of the Hennick Family Wellness Gallery, which is open to patients and families. The gallery redefines the production of space as environments designed for healing, as a way of combating the psychosocial stress factors affecting patients.

Hogeweyk, a town outside Amsterdam run by a government-funded nursing care company, describes itself as a dementia village and houses more than 150 people. Hogeweyk has adopted a design approach diametrically opposed to the typical institutional construct and surrounds. Hogeweyk has managed to reconceptualize the healthcare institutional architecture template (often designed for placement and containment) with an open space concept that encourages unconfined wayfaring throughout a naturalized rural setting. Hogeweyk comes complete with supermarket, a cafe, a hardware store, a hair salon, a restaurant, and a theater as well as a physical therapy facility and an outpatient care unit (Stevens, Petermans, & Vanrie, 2014). Some, like the Nuffield's (2009) study,[61] argue that false reality concepts are disingenuous in intent but it seems very hard to find fault in the philosophical ethos of Hogeweyk and its commitment to spatial design missions based on Subjective Well being (SWB).[62]

Lastly, the University of Toronto’s new Institute for Architecture and Health, a research initiative of the John H. Daniels Faculty of Architecture, Landscape and Design, are fostering a pedagogy that looks into the causality of health and the relational aspects of design architecture upon patient outcomes. The program’s focus is more than just healthcare architecture but also investigates education’s role towards healthcare design reforms.

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[61] Julian Hughes, the deputy chair of the Nuffield Council on Bioethics in London, England, which studies ethical issues in biology and medicine and advises policy makers.

[62] The authors argue for converting happiness theory into (interior) architectural design missions, as well as designing for subjective well being in residential care centers (Stevens, Petermans, & Vanrie, 2014).

Strategic Foresight

Ultimately the true measure of implementing the foundational principles of this thesis will be based on accepting the experiential and emotional quotient in design theory, and the adoption of inclusive interdisciplinary approaches to design practice. This is where ethical design principles will finds a high rate of adoption and moral purchase among its peers. I have put forth three explicit strategies that design practitioners can use to improve healthcare environments.

Adaptable Space Design

Long-term exposure to fixed environments or characterless geometrics space conceptions can become toxic to the mental state of its residents. As documented by research findings, the character of space and place can manifest itself within the feelings of its residents. For example, small or confined spaces could lead to feelings of claustrophobia, characterless spaces such as the replication of standardized white walls could lead to anxiety and boredom. A consideration towards space and place missions designed to be adaptable towards the variable need states of the residents in order to mitigate long-term exposure to fixed places would have a significant impact on the health and wellbeing of residents. Environment should be a reflection of ones biography. Therefore an increased focus upon the integration of meaningful personal biography themes, preferences, or thematic interpretations may have meaningful results for providing a sense of identify and personhood—a sense that is so often loss when entering institutional environments.

Integration of Garden Spaces

What the patients feel often reflects what they see and experience. Design missions to investigate accessibility, integration, spatial orientation and exposure of gardens could hold significant results on the health and wellbeing for long-term care residents. An interdisciplinary approach towards redefining the space conceptions of long term care homes would provide significant insights in future design missions. For example, what can interior designers learn from landscape architects, urban planners, or horticulturalists in the integration of exterior principles within interior design spaces? One such approach is the introduction of living walls or self-sufficient vertical gardens that are attached to walls, or purposeful integration of garden spaces within the interior space rather than typically applied to adjacent exterior surrounds. Rethinking gardens as an integrated living element in architectural design speaks to the aforementioned intimate nature (of gardens) providing meaning to intimate things.

Adoption of Phenomenology in Architectural theory

The integration of phenomenology into the design process will provide a more holistic and informed view of the built environment and a greater understanding of the bio-functional, psychological and experiential factors of persons living within long term care homes. Phenomenology could provide designers a way in which persons with dementia decode and process the built environment, thus gaining a better understanding of the social, cultural significance of the designs narratives they create.

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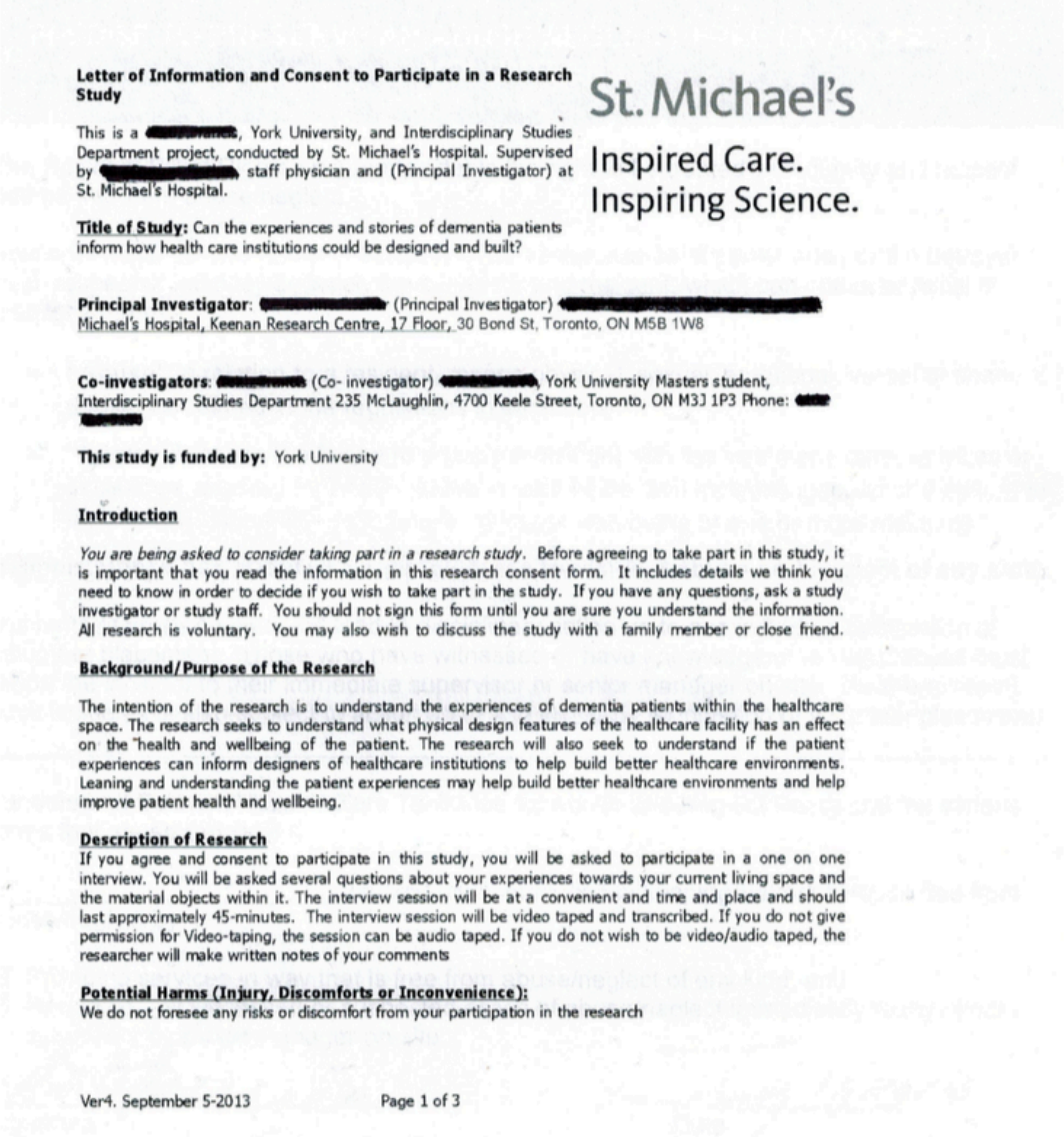
Appendix A: Consent Form



Letter of Information and Consent to Participate in a Research Study

St. Michael's

Inspired Care.
Inspiring Science.

This is a [redacted], York University, and Interdisciplinary Studies Department project, conducted by St. Michael's Hospital. Supervised by [redacted], staff physician and (Principal Investigator) at St. Michael's Hospital.

Title of Study: Can the experiences and stories of dementia patients inform how health care institutions could be designed and built?

Principal Investigator: [redacted] (Principal Investigator) [redacted] Michael's Hospital, Keenan Research Centre, 17 Floor, 30 Bond St, Toronto, ON M5B 1W8

Co-investigators: [redacted] (Co- investigator) [redacted], York University Masters student, Interdisciplinary Studies Department 235 McLaughlin, 4700 Keele Street, Toronto, ON M3J 1P3 Phone: [redacted]

This study is funded by: York University

Introduction

You are being asked to consider taking part in a research study. Before agreeing to take part in this study, it is important that you read the information in this research consent form. It includes details we think you need to know in order to decide if you wish to take part in the study. If you have any questions, ask a study investigator or study staff. You should not sign this form until you are sure you understand the information. All research is voluntary. You may also wish to discuss the study with a family member or close friend.

Background/Purpose of the Research

The intention of the research is to understand the experiences of dementia patients within the healthcare space. The research seeks to understand what physical design features of the healthcare facility has an effect on the health and wellbeing of the patient. The research will also seek to understand if the patient experiences can inform designers of healthcare institutions to help build better healthcare environments. Leaning and understanding the patient experiences may help build better healthcare environments and help improve patient health and wellbeing.

Description of Research

If you agree and consent to participate in this study, you will be asked to participate in a one on one interview. You will be asked several questions about your experiences towards your current living space and the material objects within it. The interview session will be at a convenient and time and place and should last approximately 45-minutes. The interview session will be video taped and transcribed. If you do not give permission for Video-taping, the session can be audio taped. If you do not wish to be video/audio taped, the researcher will make written notes of your comments

Potential Harms (Injury, Discomforts or Inconvenience):

We do not foresee any risks or discomfort from your participation in the research

Ver4. September 5-2013 Page 1 of 3

Potential Benefits:

This study will not benefit you directly. However the results of the study may help build better healthcare environments

Alternatives to Participation:

The alternative to participating in this study is to not participate. You will continue to receive the standard of care available for your condition regardless of whether you participate in the study or not.

Confidentiality and Privacy:

The Research Team is committed to respecting your privacy. They will make every effort to keep your study information private and confidential in accordance with all applicable privacy legislation. No information that reveals your identity will be published without consent unless required by law.

You are strongly encouraged to not reveal any information that could identify yourself, or others. Should you reveal any identifiable information during the discussion, this information will not be transcribed, but rather paraphrased to capture the idea/thought expressed. Any identifying information (such as names, institutions, etc.) mentioned in the recordings will not be transcribed. All audio/video files of recorded interviews and other study data (e.g. interview transcripts, completed questionnaires etc.) will be securely stored at St. Michael's that is accessible only to members of the research team and the St. Michael's Research Ethics Board, who may look at study records (such as the consent form), for the purpose of monitoring the study. No information identifying you will be transferred outside the site of this study.

The results of the research will include information from many people grouped together so that no one person can be identified. For example, we might use a quote by you and say in the publication that the quote was from someone with your perspective. Any responses, records or personal information that could be directly linked to you will not be reported or shared with anyone outside of the study team.

All audio/video files of recorded interviews and other study data (e.g. interview transcripts, completed questionnaires etc.) will be securely stored at St. Michael's that is accessible only to members of the research team and the St. Michael's Research Ethics Board, who may look at study records (such as the consent form), for the purpose of monitoring the study.

Publication of Results:

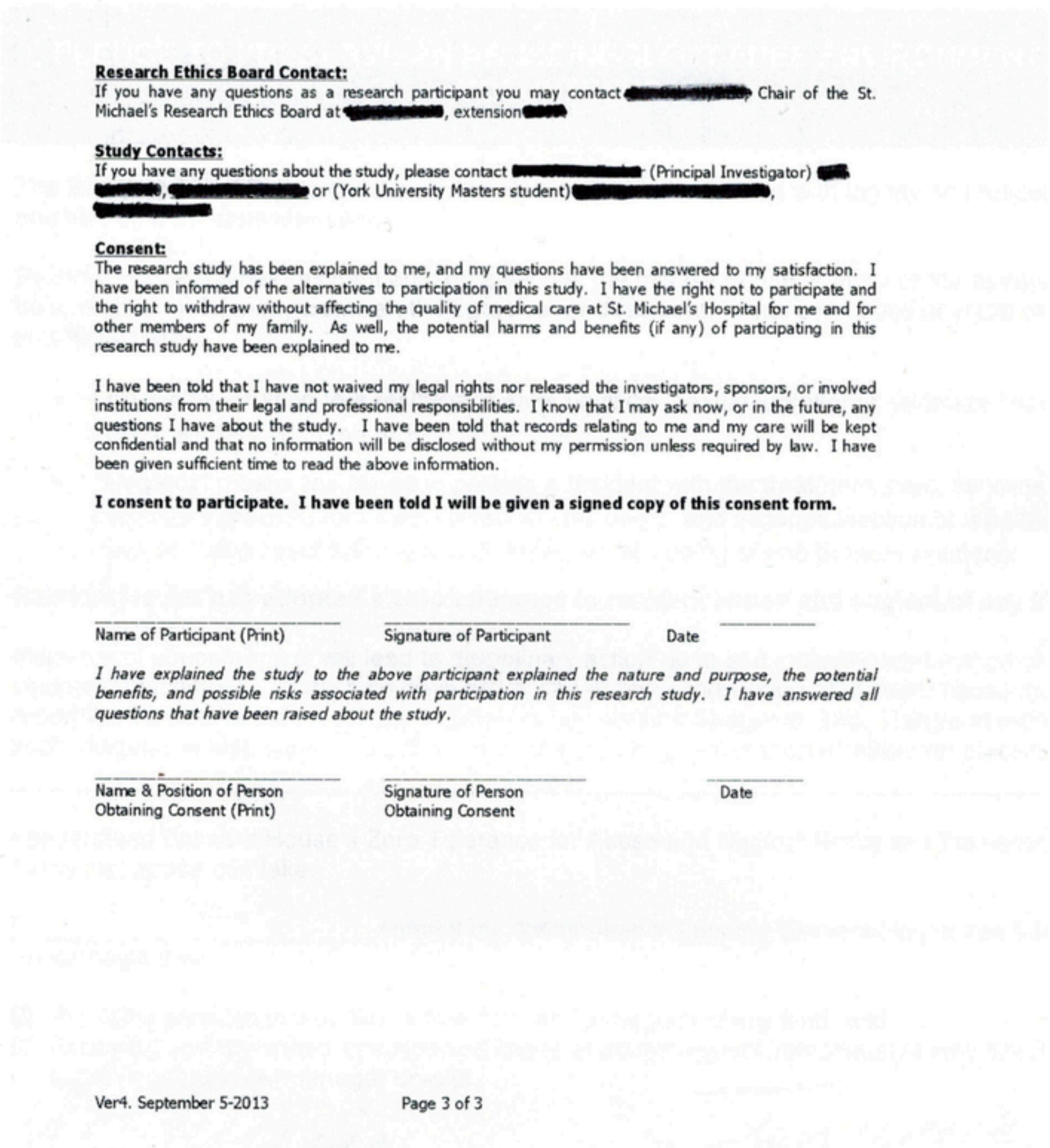
The results of this study will be presented in publications and presentations. No information that reveals your identity will be published without your consent. Video/Audio recordings will be documented and verified by the researcher and then will be destroyed in accordance with REB guidelines; with transcripts kept for 5 years from study completion.

Costs of Participation & Reimbursement:

Participating in this study will not result in any added costs to you, therefore, no reimbursements will be made.

Participation and Withdrawal:

Participation in this research study is voluntary. You can refuse to participate in this study, or leave this study at any time. If you decide to participate in this study you can change you mind without giving a reason, and you may decline to answer any question during that interview. If you choose to no longer take part in the study, the information you had provided will be removed from the study and destroyed.



Research Ethics Board Contact:
If you have any questions as a research participant you may contact [redacted] Chair of the St. Michael's Research Ethics Board at [redacted], extension [redacted]

Study Contacts:
If you have any questions about the study, please contact [redacted] (Principal Investigator) [redacted], [redacted] or (York University Masters student) [redacted], [redacted]

Consent:
The research study has been explained to me, and my questions have been answered to my satisfaction. I have been informed of the alternatives to participation in this study. I have the right not to participate and the right to withdraw without affecting the quality of medical care at St. Michael's Hospital for me and for other members of my family. As well, the potential harms and benefits (if any) of participating in this research study have been explained to me.

I have been told that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional responsibilities. I know that I may ask now, or in the future, any questions I have about the study. I have been told that records relating to me and my care will be kept confidential and that no information will be disclosed without my permission unless required by law. I have been given sufficient time to read the above information.

I consent to participate. I have been told I will be given a signed copy of this consent form.

Name of Participant (Print)	Signature of Participant	Date

I have explained the study to the above participant explained the nature and purpose, the potential benefits, and possible risks associated with participation in this research study. I have answered all questions that have been raised about the study.

Name & Position of Person Obtaining Consent (Print)	Signature of Person Obtaining Consent	Date

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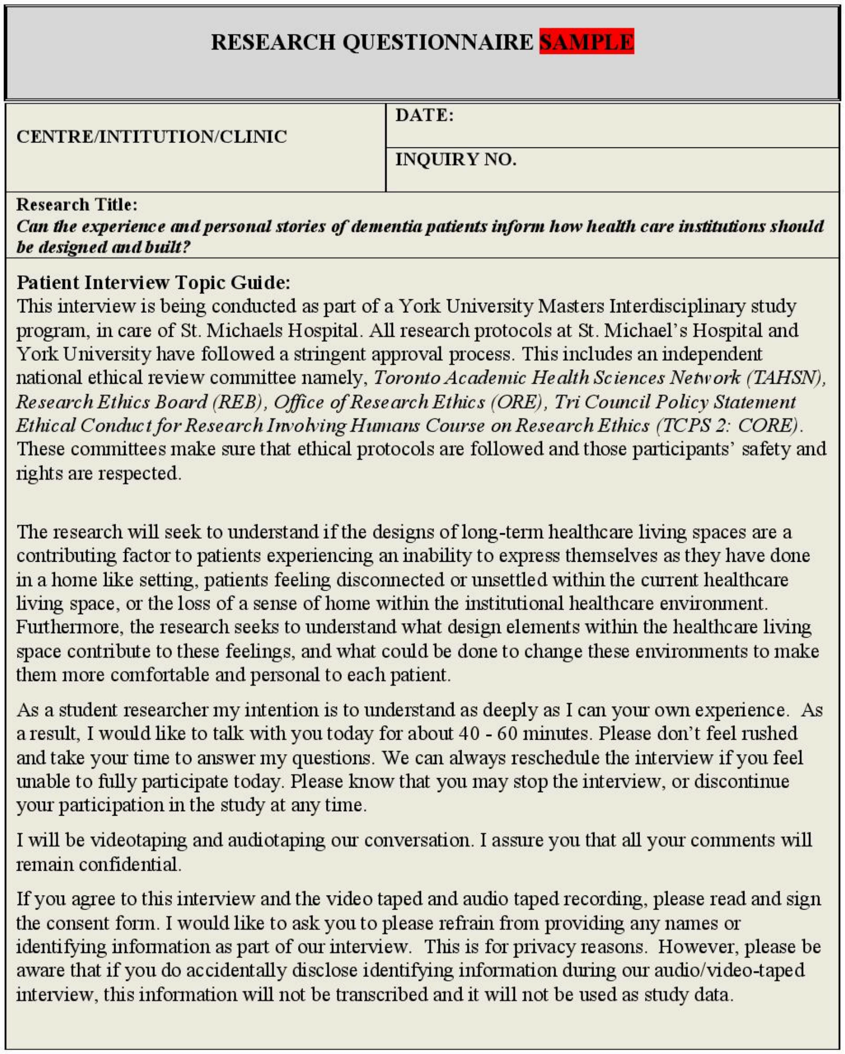
Appendix B: Questionnaire



RESEARCH QUESTIONNAIRE SAMPLE

CENTRE/INTITUTION/CLINIC	**DATE:**
	INQUIRY NO.

Research Title:
Can the experience and personal stories of dementia patients inform how health care institutions should be designed and built?

Patient Interview Topic Guide:
This interview is being conducted as part of a York University Masters Interdisciplinary study program, in care of St. Michaels Hospital. All research protocols at St. Michael's Hospital and York University have followed a stringent approval process. This includes an independent national ethical review committee namely, *Toronto Academic Health Sciences Network (TAHSN), Research Ethics Board (REB), Office of Research Ethics (ORE), Tri Council Policy Statement Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE).* These committees make sure that ethical protocols are followed and those participants' safety and rights are respected.

The research will seek to understand if the designs of long-term healthcare living spaces are a contributing factor to patients experiencing an inability to express themselves as they have done in a home like setting, patients feeling disconnected or unsettled within the current healthcare living space, or the loss of a sense of home within the institutional healthcare environment. Furthermore, the research seeks to understand what design elements within the healthcare living space contribute to these feelings, and what could be done to change these environments to make them more comfortable and personal to each patient.

As a student researcher my intention is to understand as deeply as I can your own experience. As a result, I would like to talk with you today for about 40 - 60 minutes. Please don't feel rushed and take your time to answer my questions. We can always reschedule the interview if you feel unable to fully participate today. Please know that you may stop the interview, or discontinue your participation in the study at any time.

I will be videotaping and audiotaping our conversation. I assure you that all your comments will remain confidential.

If you agree to this interview and the video taped and audio taped recording, please read and sign the consent form. I would like to ask you to please refrain from providing any names or identifying information as part of our interview. This is for privacy reasons. However, please be aware that if you do accidentally disclose identifying information during our audio/video-taped interview, this information will not be transcribed and it will not be used as study data.

RESEARCH QUESTIONNAIRE

Questions for Persons with Dementia

CENTRE/INTITUTION/CLINIC	**DATE:**
	INQUIRY ID.

QUESTION 1: **Where did you live before your stay here?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 2: **What did you like about your other home?**

VERBAL RESPONSE
PARA NON VERBAL RESPONSE

QUESTION 3: **What were the things in that home you miss the most?**

VERBAL RESPONSE
PARA NON VERBAL RESPONSE

QUESTION 4: **What was your favorite room in that home?**

VERBAL RESPONSE
PARA NON VERBAL RESPONSE

QUESTION 5: **What things did you like in that room?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 6: **How did that room and the things in it make you feel?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 7: **How do you like your room now?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 8: **What are your favorite things in this room?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 9: **How do they make you feel?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 10: **Are there other thing(s) you would like to have in this room?**

VERBAL RESPONSE:

PARA NON VERBAL RESPONSE

QUESTION 11: **How would it make you feel if it /(they) were here?**

VERBAL RESPONSE:

PARA NON VERBAL RESPONSE

QUESTION 12: **Do you have a favorite place to spend time in this care home?**

VERBAL RESPONSE:

PARA NON VERBAL RESPONSE

QUESTION 13: **Can you get to this place by yourself or with help?**

VERBAL RESPONSE:

PARA NON VERBAL RESPONSE

QUESTION 14: **How does this place make you feel?**

VERBAL RESPONSE:

PARA NON VERBAL RESPONSE

QUESTION 15: **If you could change or add something about your room, what would it be?**

VERBAL RESPONSE:

PARA NON VERBAL RESPONSE

QUESTION 16: **Do you like your view from your window?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 17: **What would you like to see more of?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 18: **Do you like the colours in your room?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 19: **What other colours would you like to see?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

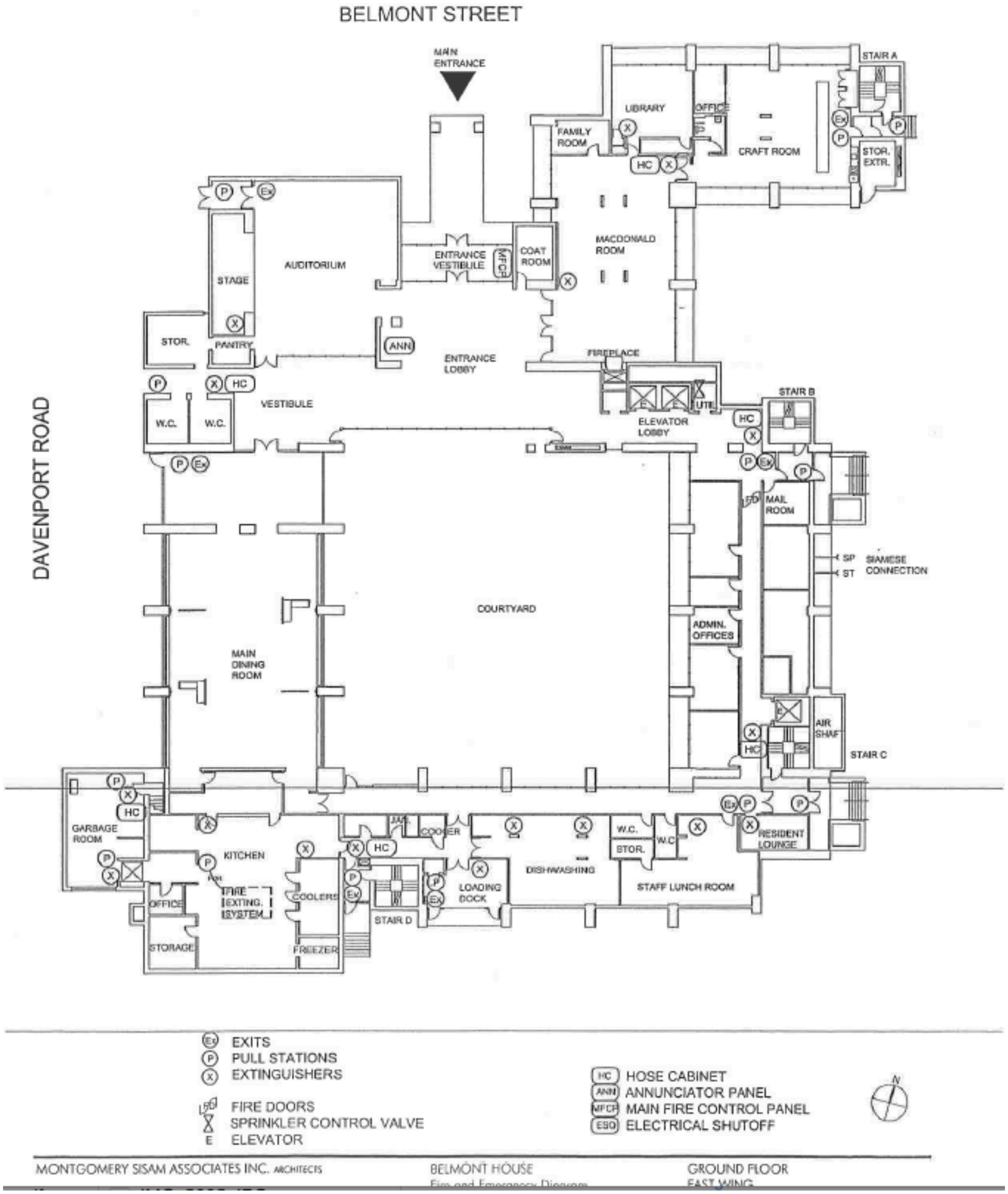
QUESTION 20: **Would you like a bigger of smaller room?**

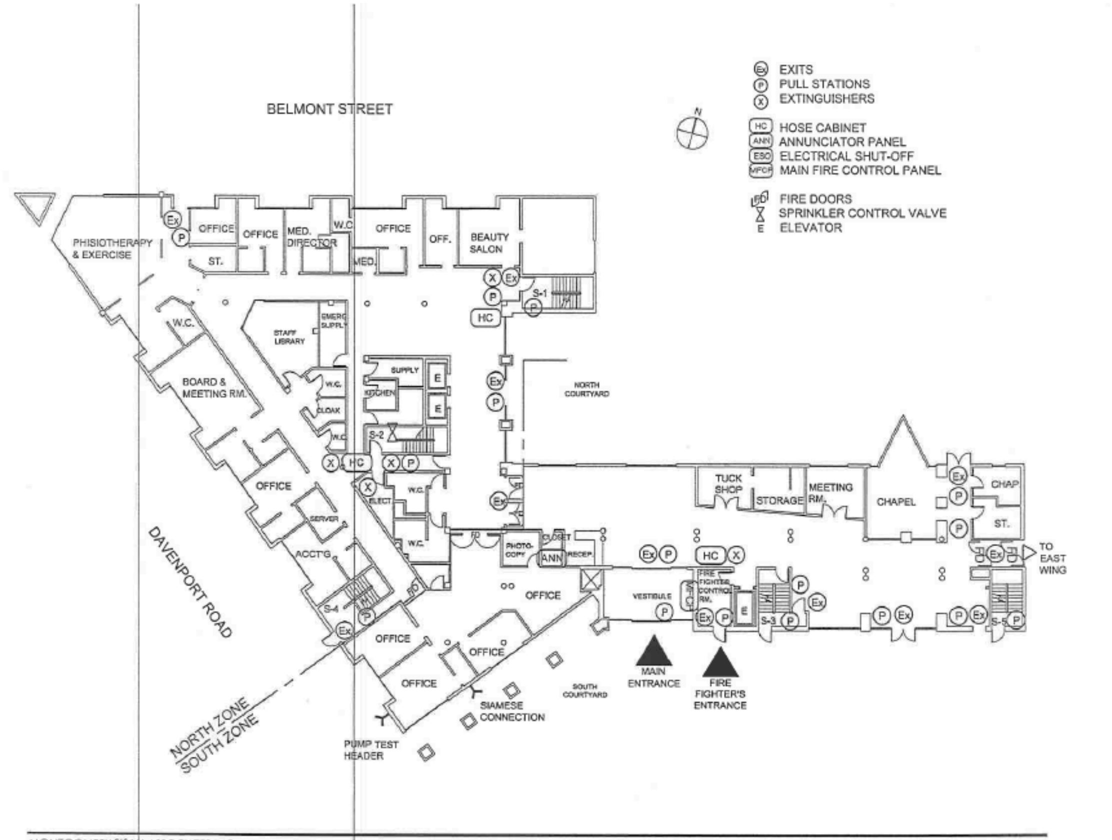
VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

QUESTION 20: **How would a bigger or smaller room make you feel?**

VERBAL RESPONSE:
PARA NON VERBAL RESPONSE

Appendix C: Belmont House Site Plan



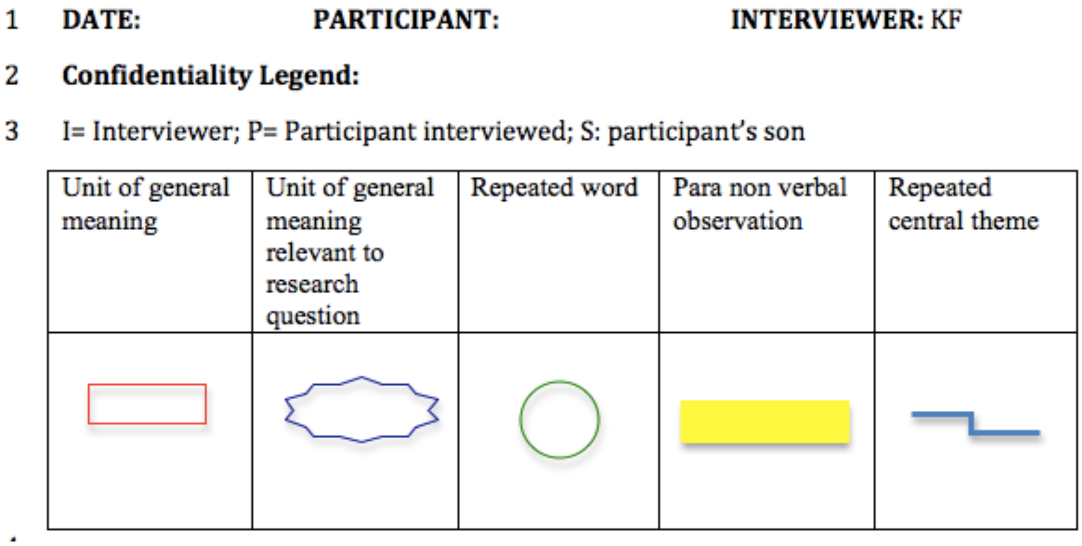


MONTGOMERY SISAM ASSOCIATES INC. ARCHITECTS

BELMONT HOUSE
Fire and Emergency Diagram

GROUND FLOOR
WEST WING

Appendix D: Delineating Units of General Meaning Legend



DATE: **PARTICIPANT:** **INTERVIEWER:** KF

Confidentiality Legend:

I= Interviewer; P= Participant interviewed; S: participant's son

Unit of general meaning	Unit of general meaning relevant to research question	Repeated word	Para non verbal observation	Repeated central theme
▭	✴	○	🟨	‾|_

Appendix E: Clustering Units of Relevant Meaning

The Garden + Friendship

A. well I don’t know it’s this sort of almost friendship with the with the (161)
B. well you know you see the same, you go one place and you see roses or all the other plants, then y- y- you know they look like friends (laughing) (164)(165)

Critical Necessities

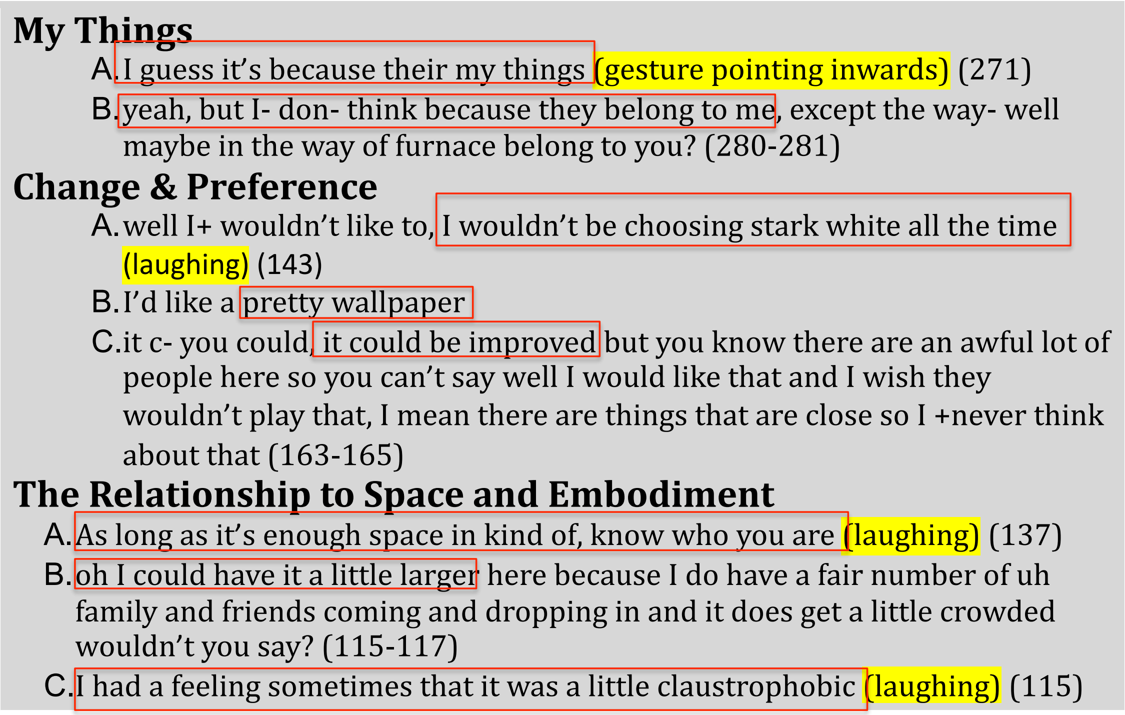
A. well it is, I- I would have trouble I think /if there wasn’t a garden somewhere (167)
B. yeah, I think it must be, I think I would be, there would be something missing if I didn’t have a garden because I’ve spent so much time (169, 170)
C. I never met somebody like that, really didn’t understand why they wasted money and space on a garden when they could’ve had another room with people in it, that’s spending money being here (laughing) (248-251)
D. it does, I don’t know how people can grow up on a city street with, without a park and I think um I think I think they miss a lot in their

Embodied Emotional & Experiential Associations

A. it made me kind of sad, I wanted to be with my family and you know just the other things that go with (shoulder shrug)
B. had a feeling sometimes that it was a little claustrophobic (laughing)
C. I guess I’m not happy without plants (178)
D. uh I thought it was very beautiful
E. as long as it’s enough space in kind of, know who you are (laughing)
F. Lonely
G. I’d enjoy it
H. well the trees too but I love the sky (hand gesture and smile)

Memory Tethering/priming

A. we always had gardens at home (157)
B. we always had a garden (158)
C. we all had our little garden to look after (158)
D. growing up as I did in that part of um Hamilton was all tree and grasses and flowers
E. but um there were just a row of house and nice people and trees that met overhead you know? (314-315)



My Things

A. I guess it’s because their my things (gesture pointing inwards) (271)

B. yeah, but I- don- think because they belong to me, except the way- well maybe in the way of furnace belong to you? (280-281)

Change & Preference

A. well I+ wouldn’t like to, I wouldn’t be choosing stark white all the time (laughing) (143)

B. I’d like a pretty wallpaper

C. it c- you could, it could be improved but you know there are an awful lot of people here so you can’t say well I would like that and I wish they wouldn’t play that, I mean there are things that are close so I +never think about that (163-165)

The Relationship to Space and Embodiment

A. As long as it’s enough space in kind of, know who you are (laughing) (137)

B. oh I could have it a little larger here because I do have a fair number of uh family and friends coming and dropping in and it does get a little crowded wouldn’t you say? (115-117)

C. I had a feeling sometimes that it was a little claustrophobic (laughing) (115)

Appendix F: Hycner (1985) Guidelines for the Phenomenological Analysis of Interview Data

1. Transcription	Noting the literal, nonverbal & para-linguistic communications.
2. Bracketing and the phenomenological reduction	When doing this the researcher especially wants to listen to the nonverbal and para-linguistic levels of communication, that is, the intonations, the emphasis, the pauses etc.
3. Listening to the interview for a sense of the whole	When doing this the researcher especially wants to listen to the nonverbal and para-linguistic levels of communication, that is, the intonations, the emphasis, the pauses etc.
4. Delineating units of general meaning	Words, phrases, non verbal or paralinguistic communications which express a unique and coherent meaning (irrespective of the research question) clearly differentiated from that which precedes and follows.
5. Delineating units of meaning relevant to the research question	The explication of data – An impartial panel of judges to validate, or modify, or invalidate, the units of relevant meaning elicited by the researcher

6. Training independent judges to verify the units of relevant meaning	Partially omitted
7. Eliminating redundancies	The researcher cannot just rely on the literal content but also number of times a meaning was mentioned, how it was mentioned, and nonverbal cues
8. Clustering Units of relevant meaning	Some common theme or essence that unites several discrete units of relevant meaning given the context.
9. Determining Themes from clusters of meaning	A central theme which expressed the essence of these clusters
10. Writing a summary for each individual Interview	This summary gives a sense of the whole as well as providing the context for the emergence of the theme
~~**11. Returning to the participants with the summary and themes**~~	~~omitted~~
~~**12. Modifying themes and summary**~~	~~omitted~~
13. Identifying general and unique themes for all the interviews	Themes common to most or all of the interviews as well as the individual variations
14. Contextualization of themes	After the general and unique themes have been noted, these themes are placed back within the overall context from which the themes emerged.
15. Composite Summary	A composite summary of all the interviews which would accurately capture the essence of the phenomenon being investigated –

	describes the world in general as experienced by the participants

Appendix G: Step 10 of Hycner (1985) Summary of Interview Findings

Summary of Interview # 1

Initially the person interviewed had difficulty describing past dwelling experiences before entering the long term care home; um - - it was - - - (laughing) isn't that funny? / (know?) something so well. (67) I don't know why I can't remember (73). Yet when describing memories within the context of the garden construct these memories become more vivid and descriptive with a greater range of para non verbal expressions (laughing, animated hand movements especially describing trees meeting overhead) "there was a stream that ran down that we could actually skate on in the winter (331,332) "but um there were just a row of house and nice people and trees that met overhead you know?"

When asked about a favourite place within the care home and how often this place was visited the response was (138) "well they have a nice garden and (laughing)" "and I like+ being in the garden (140). "oh everyday if I can, if I go, there's enough room to walk in it you know, lots of flowers trees and um, well we spend a lot of time down there" (150,151)

The importance (as a central theme) of the garden as an essential construct and its experiential associations to personal wellbeing was referenced several time thought the interview. "we always had gardens at home, you know just my dad did it mostly and taught us, and we all had our little garden to look after, we always had a garden" (157,188,159) "I think it must be, I think I would be, there would be something missing if I didn't have a garden because I've spent so much time (169, 170). "yeah, I'm not uh I guess I'm not happy without plants" (178). Past associations also had links to present constructive forms as defining space and place

"I would feel um, I would- I don't think I would be comfortable without without um flowers and trees and, because of all- I couldn't I don't think I could stand, no I would hate it in a place that was mostly building" (317-319). "it does, I don't know how people can grow up on a city street with, without a park and I think um I think I think they miss a lot in their lives if they couldn't um, if they couldn't live in with flowers and trees and little dogs (laughing) (342,343,344).

The Garden construct seem to be an important element in facilitating surrogate relationships "well you know you see the same, you go one place and you see roses or all the other plants, then y- y- you know they look like friends (laughing)" (164,165).

The Garden construct also seems to define the nature of environment and sociability (257,258,259,260) "I go out eat lunch downstairs and sit in the garden and when my people come to visit, this is a dumb place to sit and talk +(laughing) and we normally always go down to the garden, it's pretty and I think um, I- I guess I think it's good for you because I've always had one.

When describing what makes a room comfortable, it was not defined within an aesthetic context or as objects but more towards personal ownership, "I guess it's because their my things" (271)

Summary of Interview # 2

Expressed surprise and wonderment (through verbal and para nonverbal expressions) of how beautiful the garden was and the diversity of things, defined by para non verbal expressions (animated hand movements) "yeah, I go down there and my son had taken me, introduced me to it and uh we- at least I couldn't get over how beautiful it was and how many things they were offering for perusal you know (31,32. 33) “just uh, anyway I was quite surprised that it was as available” (35) Yet conversely expressed sadness of how it made her feel of wanting to be with family, this again defined by para non verbal expressions (shoulder Shrug) (downturn) facial expression. “it made me kind of sad, I wanted to be with my family and you know just the other things that go with” (42) Expressed difficult remembering past home and dwelling yeah I remember but they’re kind of far removed (54) When describing the current space expressed a desire to have a "little larger space to accommodate facility and friends and the space being claustrophobic, emphasized or characterized by (para nonverbal expression of laughter). “oh I could have it a little larger here because I do have a fair number of uh family and friends coming and dropping in and it does get a little crowded wouldn’t you say?” (116,117,118). “I had a feeling sometimes that it was a little claustrophobic (laughing)”

Also “enough space” seemed to provide a form of identity as embodiment i.e. "enough space you kind of know who you are" again space and place taking on human metaphors.

When asked about the space if given a choice of colour, it was expressed as “well I+ wouldn’t like to, I wouldn’t be choosing stark white all the time (laughing)” reinforced by para nonverbal (laughing). (144)

When asked about feelings of looking out of the window this elicited feelings of loneliness supported by para non verbal expressions (downturn) (trunk back). “I don’t want them to put me somewhere else but I can think of things that come to mind when I look out of that window” (190,191)

The suggestion of changing things to suit her was also looked upon as an inconvenience to others expressed as (fear) “better to leave things as they are.”

Summary of Interview #3

Remembering home was expressed in remembering the generalities of home past i.e., “my husband was with me” (21) “it was a good place” (23), “there were a few floors a couple, a few floors” (27) as well as feelings towards these constructs – “I enjoyed it” (33) supported by para nonverbal expression (smiling). When asked about a favourite place to spend time within the past home was, “outside in the living area” (47). Expressed the favourite color as red “/ / favourite colour - - I like red” (79) and would enjoy pretty wallpaper. Expressed a wish to have a large space and liked having and enjoying the view from the window, specifically the sky and trees (supported by para nonverbal hand gesture and smile). When asked about a favourite place to spend time in the care home, “I like to spend it out with other people in in in the hallway” (112).

Expressed enjoyment and appreciation of the set up of the room “I like the setup of the room, I love I love being able to have this view, if you look at the rooms going down, they have smaller windows” (127, 128). The view was expressed as seeing clouds and trees. Also expressed a desire to have I’d like a pretty wallpaper.