

Understanding Sensory Experiences in Palliative Care

by
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Abstract

The qualitative study used the perspectives of 2 residents, 3 family caregivers, 4 professional staff and 3 hospice volunteers at the Kensington Hospice in Toronto, Ontario to understand holistically the sensory experiences of the residents. Individual semi-structured interviews were undertaken to collect the data. Analysis followed the principles of the constant comparative method where data collection and thematic analysis occurred concurrently and continued until data saturation (n= 12).

Findings from this study revealed the current sensory experiences of residents, with themes rooted in highly interconnected categories: Shrinking Personal World, Decline, Personal items, Objects, Sight (quality of what is seen), Design and Services. A wide variety of positive and negative experiences were reported that touched on these main categories.

The study yields preliminary insight into how sensory information mediates perceptions of quality of services in this context.

Keywords: hospice; sensory needs; patient experience; care recipient; qualitative; design research; foresight

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Dedication

To all those dear in my life who have supported this work:

Matt for his unequivocal support and partnership.

Alesia and my parents, Anna and Victor, for believing in the work I have been doing for the past several years.

Also for my late grandmother, Halia, who passed in an environment that was not her own, and whose experiences at the end of life could have been enhanced through the exposure to a broader sensory world.

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1.0 Foundation

1.1 Introduction

The palliative management of the end of life may take place in a variety of settings, including at home, in hospital, in nursing homes or chronic care facilities or in a residential hospice. Hospice palliative care refers to end of life care in any of these settings, which aims to improve the quality of life for those living with life threatening illness. Residential hospices are an important component in the continuum of end of life care, the purpose of which is to deliver compassionate care and comfort for terminally ill residents in a more home-like environment.

The importance of understanding more fully the present and latent experiences of residents who are approaching the end of life and their family caregivers (the recipients of care) is growing.

The preservation of dignity is an important goal of palliation in all care settings, with the nature of care delivered at the end of life governed by this notion (Chochinov, 2002). The various care processes, including hydration, nutrition and symptom management of the patients who are approaching the end of life, is meant to be provided with respect and the dignity-conserving model for palliative care is intended to bolster the dignity of dying patients through all the various care processes in hospice. Chochinov describes the way in which dignity-conserving strategies are meant to support residents by offering care for the “whole person”:

Dignity-conserving strategies should attempt to reinforce the patient’s sense of self-worth by adopting a therapeutic stance that conveys steadfast respect for the patient as a whole person with feelings, accomplishments, and passions independent of the illness experience (Chochinov, 2002, 2257).

Existing frameworks for measuring the quality of end of life include both physical and psychosocial sources of influence in the terminal phase. These include measurements of

symptom severity, performance status in palliative care, and mental status exams (Jones et al., 2010). Existing frameworks do not, however, capture the perception of the aesthetics of care environments and patients' sensory needs as contributors to their quality of life.

Ambient and sensory design is defined as the orchestration of spatial stimuli in built environments, arranged to lift the quality of experience for the occupants (Lehman, 2011). To date, few studies have addressed ambient/sensory experiences, and fewer still have touched on sensory needs of patients in terminal stages who are in palliative care environments.

It is commonly believed that embedded in the psychosocial dimension of care is the sensory environment that influences the experience of end of life care for patients and their families in this circumstance. Such beliefs pivot on the idea that there is a spatial dimension to quality of life of the terminally ill, in addition to the physical and psychosocial dimensions. The spatial dimension of care includes the interactions between the artifacts and the resulting experiences that take place within the palliative care environment. These stimuli can be organized within space, contributing to ambiance that develops over time.

Privacy in palliative care has also been linked to the preservation of dignity. It is said that privacy provides individuals and their families with opportunities to enhance intimacy, manage grief and enact spiritual rituals (Street and Love, 2005). Privacy for the dying patient (and patients in other care contexts as well), from the physical perspective, is often described in the context of having a single, private room, where a sense of privacy and private bounded space are interconnected (Street and Love, 2005). The same study by Street and Love (2005) revealed that privacy that is limited solely to a spatial concept of a "private room" can have unintended consequences, particularly in terms of encouraging unnecessary practices of concealment. But that through a different concept of privacy, one that takes into account the inter-relationship between the spatial and psycho-social dimensions of privacy, the opportunities for rituals and communication are more properly accommodated.

In the case of Kensington hospice, there has been a clear effort to provide both private space and a communal space to meet the needs of both residents and visitors. All private resident rooms have a shared washroom; an arrangement that lends well to the analysis of the dimensions of privacy in an institutional context.

There is a deficiency in the literature on the topic of sensory awareness and sensory needs of palliative patients and their families, from their perspectives. The patient-centred perspective of the physical environment in end of life care is intended to feed into an adaptive system of care that evolves to meet their wishes. But many of the existing studies supplement the voices of residents with those of the caregivers in order to identify how settings can support states like joy when death is imminent (Tofle, 2009).

Our understanding of the difficult transitions into palliative care (Marsella, 2009), including the ways in which aspects of the care environment are experienced post admission by residents and their families over time needs to be better understood from the perspective of the resident, and better designed for.

By beginning to broaden the model of care provision to include personalization with regard to the qualities of sound, what is seen, touch and smell and taste in the care environment, we might enhance the quality of life for residents. This might be especially relevant for those who might be experiencing increasing needs as they decline. The intention of this report is to communicate the results from an interview study exploring the ways in which ambient and sensory design can enhance the experiences of palliative care, and specifically of hospice care, for residents and their families.

1.2 Research Site- Kensington Hospice Site Analysis

Kensington hospice operates through a partnership between the Kensington Health Center and the Princess Margaret Hospital/University Health Network in Toronto, Ontario, Canada.

Opened in August 2011, the 10-bed residential hospice provides palliative and end of life care for the whole person, with the promise to meet all needs, including physical, emotional, social and spiritual for patients and their families in a home-like setting:

Our focus is on improving quality of life and getting the most out of each day. Our home-like community setting provides an alternative to the institutional setting of the hospital, combined with the 24-hour care not available at home.¹

Images below show the quality of the design of the private rooms and the communal spaces.



Figure 1: A resident's room before personalization and decoration.

¹ <http://www.kensingtonhealth.org/index.php?page=hospice>



Figure 2: Residents might be able to leave the private room to experience communal areas

The Hospice is located on a quiet, residential street just west of the University of Toronto. The urban hospice construction houses many varied social flows and connections to the wider world. The location of the hospice also helps to preserve the idea that life is happening all around, and that the continuity of care and of life are interconnected.

The hospice was originally built as the Chapel of St. John the Divine in 1888, and served as a hospital for women for several decades.

Over a three year time-frame the Kensington Health Centre has retrofitted the building in an effort to preserve its vaulted ceiling and stained-glass windows, while adding the modern amenities of a new medical facility. Each room has a bed, a wall-mounted television set, a dresser and a chair that folds down into a bed to allow a guest to stay overnight.

The Kensington hospice has several limitations, given that it is located in an urban setting. The space is highly vertical with a small footprint, meaning private rooms share a washroom and not every room is offered a view of nature from the window. The

building is also a retrofit of an existing church, preserving the open concept design, which retained some of the spatial limitations of such a conversion.

The scale of the hospice is akin to that of other residential homes on Major street, and offers residents of the hospice a sense of familiarity with regard to the humanity of the scale, along with a sense of intimacy.

The advantage of the hospice's location in the city centre appears to be the proximity to everyday things. The proximity appears to reduce the likelihood of social and physical isolation for the residents, family caregivers as well as the staff who are able to experience life as its happening within and outside (through sight, hearing) while on the premises.

Ken Worpole (2009, 48) writes about the advantages and disadvantages of inner-city hospice locations. Some of the other advantages include: cheaper access to public utilities and services, good public transport connections, the ease of attracting and keeping staff and volunteers, and the visibility of a symbol of local community endeavour. Some of the disadvantages include the necessary construction of multi-story buildings due to the high cost of land, noise and pollution, minimal landscaping and challenge of negotiating 'death in the midst of life.'

A distinction can be made between palliative care units in hospitals, hospices in rural locations and the study site as an urban site. Worpole (2009) has labelled the hospital as a microcosm of the wider society, treating and accommodating the young and the old, the rich and the poor, the seriously ill and the short-term clinical patient.

The palliative care unit at Princess Margaret Hospital in Toronto provides a serene place for people who are approaching the end of life, with an effort to preserve some level of tranquillity in a hospital setting. The 16th floor of the hospital is devoted to palliative patients and their families, with the design elements of the environment showcasing nature on hallway panels.

The first impressions for residents, family and visitors might be different if they were to enter such a hospital palliative care unit versus a rural (Figure 3 and 4) or urban hospice.

The entry points are different (the use of the elevator to get to a palliative floor in a hospital versus the ground level access to a hospice), along with the architectural style of the building.

The replication of the appearance and ambiance of a private house as a place of shelter and peace appears to be a common expectation for urban and rural hospice environments (Figure 2). Images below are of a rural hospice (Bethell Hospice)² located in Inglewood, Ontario. The rural hospice is a single floor residential hospice, with a larger footprint and views (along with access to) nature from each room.



Figure 3: Bethell Hospice front entrance

² <http://bethellhospice.org/?page=home>



Figure 4: Bethell Hospice private room with a view

1.3 Research Question and Aim

The focus of this study is the inquiry into the qualities of a residential hospice care environment within an urban setting.

The research question that guided the study was:

What are the current and desired sensory needs of residents in the Kensington Hospice residential palliative care environment?

The aim of this research was:

1. To understand how sensory needs of palliative residents (and their families) at the Kensington hospice are currently supported through the qualities of the care environment (the built environment + the psychosocial care); and

2. To understand how residents' experiences are mediated by their sensory perceptions of care within the hospice environment.

The underlying assumption that guided this research has been that a more robust understanding of the qualities of the care environment that are most meaningful to users, can lead to recommendations that can enhance the comfort for all users of hospices.

Another assumption was that residents were developing a sense of ownership of space, especially if they were spending many days in the private rooms. The assumption was that they were working to define the space through an ownership model where perhaps a sense of self would emerge through hyper-personalization of space and object display.

1.4 Intended Audience for this Research

It is anticipated that the results of this research would be relevant to researchers interested in the design of patient-centered environments for residents who are approaching the end of life. This research is intended to generate knowledge that connects the disciplines of palliative care, gerontology, paediatrics and the design. It is also expected that architects and interior designers that operate in the field of healthcare environment design would also take notice of these findings and that it would contribute to the generation of new tools and design principles that support the needs of residents and their families in a more relevant and informed way. These findings should also be relevant to public health policy makers with regard to the development of guidelines and standards for addressing the end of life sensory needs of hospice residents and their families. Lastly, this research may inform public discourse about the importance of patient-centred research and the importance of aesthetic experience in palliative care.

2.0 Background

2.1 Palliative care in hospices

A hospice has been referred to as a house at the end of life (Worpole, 2009) and is an important philosophy of care, intended to enhance the quality of life until death for people who are terminally ill. The term hospice is used in many settings to refer to end of life care, which is often provided at home. A dictionary definition of the term is as follows:

- a. health care facility for the terminally ill that emphasizes pain control and emotional support for the patient and family, typically refraining from taking extraordinary measures to prolong life.
- b. a similar program of care and support for the terminally ill at home.³

The World Health Organization has also defined palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁴

In the institutional context, the hospice *atmosphere* emerges as a major point of distinction, and the creation of a home-like environment takes on great importance. The hospice atmosphere, in contrast to the atmosphere in hospital settings, is at the intercept of the psychosocial and physical environment and multidisciplinary care (Rasmussen et al., 2000, Rasmussen and Edvardsson 2007) It has been said that these elements of care, when taken together, interact to produce a somewhat intangible ‘atmosphere’ of a place. Comfort, then, can be assumed to be experienced only through an embodied

³ <http://dictionary.reference.com/browse/hospice>

⁴ World Health Organization. WHO Definition of Palliative Care. 2003. Available at <http://www.who.int/cancer/palliative/definition/en/>. Accessed March 5, 2012.

learning of the myriad of sensory cues that provide information about the environment. The unique combination of sensorial perceptions that contribute to a feeling of comfort may be enhanced by ambient technologies for residents and their families who are the receptors of care. Such technologies may facilitate difficult transitions and enhance experience in this treatment setting. By hearing the unique perspectives of hospice residents and their families, we can gain knowledge that can lead to improvements in the experiences of residents who are approaching the end of life in residential hospice settings. This can improve the sensory experience by aligning the design of the services offered in the hospice with the ways in which the service is experienced by the residents and their families through the cues of touch, smell, sound, sight and taste.

The research into this field was originally inspired by an unpublished grant application written by Carol Tishelman titled 'Designing sensory experience in end-of life patient care: transdisciplinary interventions.' The author hypothesized that the dying person's experience of the sensory environment is of particular importance as cognitive and physical functions deteriorate with decline. Furthermore, Tishelman points out that the exposure to new sensory stimuli from unfamiliar institutional environments might contribute to disturbance in familiarity (Tishelman, 2011). This area of research from Sweden is a signal that indicates the importance of thinking about sensory needs of more sensitive population segments and the importance of sensory qualities from spatial dimensions for their optimal experiences.

Therefore, with little prior research in the area of sensory perception to guide this effort, this research has the potential to add to existing ideas about quality of care. It can generate data that creates a more rich tapestry of user-centred data, and shift the dialogue about satisfaction to that of *experience*. Albeit more measurable quantitatively, satisfaction rates do not address the intangible moments of care that define the holistic experience of the care journey for those who are approaching the end of life.

2.2 A Design lens for understanding sensory needs in palliative care

Our understanding of the world and ourselves comes through our senses, yet there are only a limited number of methods that are currently used for understanding sensory experience of the environment. Traditional survey methods are not ideal for capturing the tacit and latent needs of users because, in many cases, these needs cannot be articulated. Design thinking, as it connects to business thinking and futures thinking, is therefore a way to start connecting the dots that are missed by traditional research methods (Van Alstyne, 2010). Design thinking informs how things ought to be by first understanding, through the divergent and convergent design process, the feelings and cognitive patterns at play within a research context (Rhea, 2003).

The people who are approaching the end of life, along with their families, are not often the subjects of research in strategic design. There is lots of research on patients and families in palliative care but not on sensory experience. Research around sensory perceptions is often aimed at uncovering the responses of consumers of products (Gulas & Bloch, 1995, Bradford & Desrochers, 2009), and at most, aimed towards stimulating responses for older adults with severe learning, sensory and other disabilities⁵ or rehabilitation programs and services for children (snoezelen rooms).⁶ As a result, the use of qualitative research methods to understand sensory needs in the context of palliative care has been limited. Palliative patients are not typically considered part of the system of consumption, since there is little value in changing their long-term preferences to a particular product or service. This presents an interesting question about the value of the gathered insights about sensory needs, since the outcomes are present-oriented rather than future-oriented and not measurable in the patient population (i.e. the patient population is no longer present) as compared to a patient with learning disabilities that picks up new abilities and preferences. Further, transactions in palliative care environments do not involve products, but rather involve emotional currency as it is afforded by an atmosphere of care. The experiences of palliative patients and their

⁵ http://www.baycrest.org/documents/Baycrest_Matters_090909.pdf

⁶ <http://www.hollandbloorview.ca/programsandservices/communityprograms/snoezelen.php>

families cannot be quantified as transactions. These experiences do matter however, to those facing mortality and to others who are close to them (Lindqvist et al. 2012).

The value of more meaningful interactions and connections that are made possible through emotional exchange within a tranquil hospice environment are embedded in memory and in sentiment of the living. The sometimes intangible multisensory cues (touch, scent, sound, texture of food, quality of what is seen) contribute to an atmosphere of comfort and personalized care. Sensory information, therefore, shapes in many ways the experiences that in turn inform memories of compassionate care at the end of life.

2.3 Overview of Literature

While there is a growing regard for the *importance* of supportive environments, there is still a lack of literature specifically focused on the *user experiences* of the care environment. In the literature on the effects of the atmosphere on the care environment, there is still a significant gap in understanding the effect of the atmosphere on people who are at the end of life. Along with our limited understanding of the social care processes that contribute to supportive care settings (Edvardsson et., al. 2005) there is also a void in knowledge about the ways in which sensory perception mediates the perception of care from the point of view of the resident. Data on the atmosphere of care in palliative care settings emerges from previous research, although it was not the focus from the onset of such studies (Lindqvist et al, 2012). Within that data, there is limited attention to the specific dimensions of sensory qualities (the types of smells, touch, taste, sounds and quality of what is seen that contribute to the optimal care) that define the care environment.

A study by La Cour and Hansen (2011) describes the involvement of people with cancer in activities such as making jam and working in the garden as opportunities for aesthetic engagement. The authors argue that such everyday aesthetics that are experienced at home are important because of the intuitive, emotional and sensory experiences that are

embedded in everyday conduct by a person with advanced cancer. What is perhaps most relevant is the way in which everyday activities were found to effectively negotiate emotional colouring and evoke an atmosphere of enjoyment and appreciation for living under the circumstances of advanced cancer. However, the research setting for this study was the home environment of participants, which is different from the residential hospice care environment.

A study by Stomberg (2009) aimed to understand the internal and external essentials for the well being of the individual at a hospice. Essentials for well being in a hospice, according to the study, include the following: encouragement from the staff, the alleviation of pain, a pleasant and calm atmosphere, visits from relatives and time to reconcile to one's life. Not only was the close community of staff and family important, but also the need for privacy to reflect on life was said to be critical. The various qualities of a calm atmosphere were not directly identified.

A literature review by Rigby and colleagues (2010) identified themes regarding the specific environmental needs of older people who are near the end of life.. Four main themes emerged: the physical environment must be 'homely,' it should support patients' need for social interaction and privacy; it should support the caring activities of staff, family and patients; and it should allow opportunities for spiritual expression. The paper calls for a deeper understanding of patients' understanding of 'homeliness,' dignity and privacy in relation to the physical environment.

The evaluation of hospice care from multiple perspectives (Hiatt et., al. 2007) is helpful, but stronger evaluation of the care environment from the perspective of the patient through the patient-centeredness framework (Rigby et. al. 2010, Mead and Bower 2000) is often referred to as valuable.

2.4 Patient Experience

Residential hospices are places and settings where it is said that emotions can be orchestrated creatively by good design, and even on a “minute to minute” temporal basis, to develop a greater sense and understanding of the intangible mysteries of life and its passing (Worpole, 2009, 36). This implies, of course, the need for a human-centred look at the places in our society that house and service these difficult transitions and the experiences of people who find themselves in these situations. The patient-centered lens through which quality of care is assessed has potentially gained more momentum with the new Excellent Care for All Act (ECFAA).⁷ One challenge of this legislation is to translate what excellent care is for the segment of people in palliative care.

The Excellent Care for All Act came into law in June of 2010. The act is said to put Ontario patients first by strengthening the ways in which accountability and delivery of high quality patient care play out on the ground. The Act identifies the experiences of patients as being central to the healthcare service model. The understanding of how to best measure the quality of care delivered to patients within the context of the ‘excellent care for all’ should be measured not only by levels of satisfaction but also by the experiences of users as defined by the quality of their interactions within the palliative care environment. Unfortunately, surveys aimed at measuring satisfaction with the care people receive do not typically address the dynamic relationship between experiences of families and residents in a hospice care environment and their perception of care.

Looking at satisfaction in a different context, a daily user of city transit can be satisfied with the service (e.g. the train usually arrives on time) but may not be satisfied with the experience of the journey (e.g. the aesthetic, the intercom system that forces announcements to be extra loud due to the acoustical properties of the tunnel design, the sticky floor and the poor quality of lighting both on the subway cars and inside the station, etc.). The measurement of these sentiments is a qualitative undertaking. The

⁷ Excellent Care for All Act, 2010, SO 2010, c 14

assessment of perceptions, which might be informed by prior experience and expectation; not just by a situation at hand, lead- up to this context and the memory of the situation (including mental models) from a previous similar encounter. Rasmussen and Edvardsson (2007) discuss the experience of 'at-homeness' that emerges from the intercept of dimensions of the atmosphere of hospitality, atmosphere of safety, atmosphere of everydayness and the needs and *expectations* of the person in the palliative care setting. The expectations that people come in with, in turn define their experiences within the environment.

The residential hospice as a care environment for those who are approaching the end of life is unique and, unlike daily commutes on the subway, only experienced in the challenging context of a loved one who is terminally ill. The first admission to a hospice often occurs without any previous experience for residents and their families. In some cases, as in the Kensington hospice, the professional staff are experiencing the hospice care environment for the first time as well. This presents an interesting challenge for human-centred design research and design futures because most users of this environment do not have a gauge against which to compare their current experiences. The hospice is intended to meet the emotional needs of families going through fear, pain and suffering together. The focus on quality of experiences of patients is therefore a relatively contemporary one, introducing the question of how best to integrate the language of 'effectiveness of services' and 'efficiency of services' in the context of sensory design.

One way to begin answering this question is to use the following formula to look at the data through the lens of contextual perception:

$$\frac{\text{Perceptual Systems}}{\text{Cultural modifiers}} = \text{Contextual percept}$$

Figure 5. Contextual perception diagram (Malnar and Vodvarka 2004)

The formula $PS/CM = CP$ developed by Joy Manice Malnar and Frank Vodvarka (Malnar and Vodvarka 2004, p.56) specifies that perception as organized sensation and cultural modifiers represent the enviro-cultural factors that influence what, when, where and how we look.

For the purposes of this study then, perception can be understood as an integrated system that is informed by many factors that might play out prior to the arrival at the hospice. Prior to arrival, residents have had exposure to the acute hospital environment or a palliative care ward. These experiences would, according to the formula, in some way shape their perception of context which is also informed by the sensory cues around them. What is also apparent is that sensory perceptions are not static but change and develop over time. The information gathered by the sensory systems of residents and their families are subject to disease progression and sensitivities, with fatigue and weakness particularly debilitating in its affects on daily life of people with advanced cancer (Rasmussen et al. 2010).

In the context of an emerging field of research, the quality of care in palliative environments is more than the sum of its parts. With the hospice designed to bring forth specific qualities of comfort for those who cannot be at home any longer or who choose to transfer from hospital care due to the progression of their illness, hospice care environments take on the responsibility to support the sense of dignity for terminal residents and their families.

Lastly, the hospice might be one of the few institutions that is able to stretch the lens of how quality of care is defined, to include not only accountability and efficient delivery of service, but also the effectiveness of the care facility, including complementary therapy (Fellowes et al., 2004) in mediating difficult end of life experiences.

3.0 Study Design

Qualitative research on sensory experiences in the hospice connect the Kensington Health Center and Princess Margaret Hospital with OCAD University's Ambient Experience Lab and the masters program in Strategic Foresight and Innovation at OCAD University.

This collaboration was unique because it offered a cross-pollination of ideas on an innovative topic, sensory experience of residents who are approaching the end of life.

The objective of the study has been to uncover the sensitivities of residents and to inform the program of experience research and design in palliative care at Princess Margaret Hospital. It is hoped that this research will contribute to the future design of hospice environments that will be more in tune with the needs of palliative residents.

3.1 Methods

Four (4) groups of participants were recruited to take part in the research study. These include the hospice residents, their caregivers, professional caregiving staff along with hospice volunteers. The participants were required to give their informed consent prior to data collection (Appendices A and B). The participants were also notified about the study via advertisement several weeks in advance of the study (Appendix C).

On average, residents stay in the residential hospice for 1-2 months, receiving standard care. The sample size was determined in part by the patient turnover rate at the hospice. The totals for the participants included 2 residents, 3 family members, 4 professional staff and 3 volunteers. Semi-structured qualitative interviews were used to guide the discussion with participants (Appendix D). This method of research was chosen in order to have flexibility, and to allow for relevant discussion topics to guide the discussion with participants.

All statements were audio recorded, transcribed verbatim by the researcher and were imported in an unedited form into Dedoose, a web application for the analysis qualitative, quantitative and mixed method research data. All interviews were between 15-60 minutes in duration.

Constant comparative analysis was initiated immediately upon data collection and continued throughout the study. Grounded theory is a method that can facilitate insight into people's values, understanding and experience with iterative data gathering and analysis (Furniss et al., 2011) Grounded theory's essence is in exploratory conceptual and theoretical development which is ideal for an emerging area of research.

The analysis focused on the types of sensory information that contributed to atmosphere of care and how sensory cues mediated residents' experiences.

Observations were also conducted within the public spaces of the hospice.

Recruitment was coordinated by the team at the Kensington hospice who facilitated access to hospice residents, professional staff and volunteers. Three contact people were crucial to the recruitment process: The Director of hospice care, the Intake and Residential Care Coordinator and the Volunteer Coordinator at the Kensington hospice. These three contacts facilitated the recruitment of participants through an empathic assessment of whether participants were able to take part in the study.

3.2 Inclusion and Exclusion Criteria

Given the sensitivity around the recruitment process, participants were screened by the medical team at the Kensington hospice to identify the following exclusion criteria:

1. Patients who cannot speak English; 2) patients who are in distress or cognitively impaired and are unable to respond to interview questions.
2. Family care-givers who: 1) Were less than 18 years of age; 2) not fluent in English; and 3) did not identify as a care-giver to a patient at the Hospice.

3. Professional caregiving staff and volunteers: Staff members who were not working or volunteering in the Kensington Hospice, and those who were directly involved in the study coordination.

3.3 POEMS Framework

The use of an innovative framework was trialled for the purposes of understanding the artifacts and processes in the hospice care environment. The POEMS framework was developed at Design Institute, and captures the lived experiences of people in various contexts. Kumar and Whiteny (2003) created a set of ‘activity-focused’ research methodologies, of which POEMS is one. The POEMS framework is a tool for recording user interaction, and helps researchers plot interactions by giving them lists of words in five categories: people, objects, environments, messages and services. The use of POEMS for this study helped to categorize moments of the lived experiences of all participants into the People, Objects, Environments, Messages and Services groupings in order to isolate pain points/hot spots that require/inspire intervention. This framework has served as a data gathering framework, an organization framework, as well as an analysis framework for this study, since it informed the design of the interview guide, the organization of data, and was used for coding and analysis. The traditional use of the POEMS framework is around assessing the usability of software applications and has not been used in the context of healthcare in the past. This framework, however, has helped to focus the attention on the dynamic nature of services (including interactions) and objects that define experiences of end of life care.

Even though demographic information was collected for some of the first participants of the study, this step added a layer of data that exceeded the scope of this research project. The remainder of participants were not asked for their demographic information, because:

1. The process of going through the consent, the interview as well as the demographic forms was getting too lengthy.

2. The time limitations of the study would not permit the analysis of participants' demographics.

3.4 Ethics Statement

This study was reviewed and approved by the UHN Research Ethics Board after two sets of amendments.

Ethical principles for recruitment have been followed. The team was mindful of the sensitivities of the resident and family participants and the potential burden of the study on residents and the family members at a difficult time of transition.

Empathic and human-centered approach was upheld for this study with the gestures and feelings of respondents towards questions and general presence kept at the forefront of the design process.

4.0 Data Analysis

4.1 Early Thematic Model

As a first step in the analysis process, and prior to the use of the web application for systematic code analysis, a thematic model was developed as a benchmark for the kinds of relationships that were thought to be at play. The process of creating the thematic model followed an open coding approach, reading of the interview data in a pair and noting themes. The initial model emerged after the open codes were grouped and labelled as focused codes close to, or derived from the texts. The codes were continuously compared and organized spatially around a category of 'choosing' at the centre.

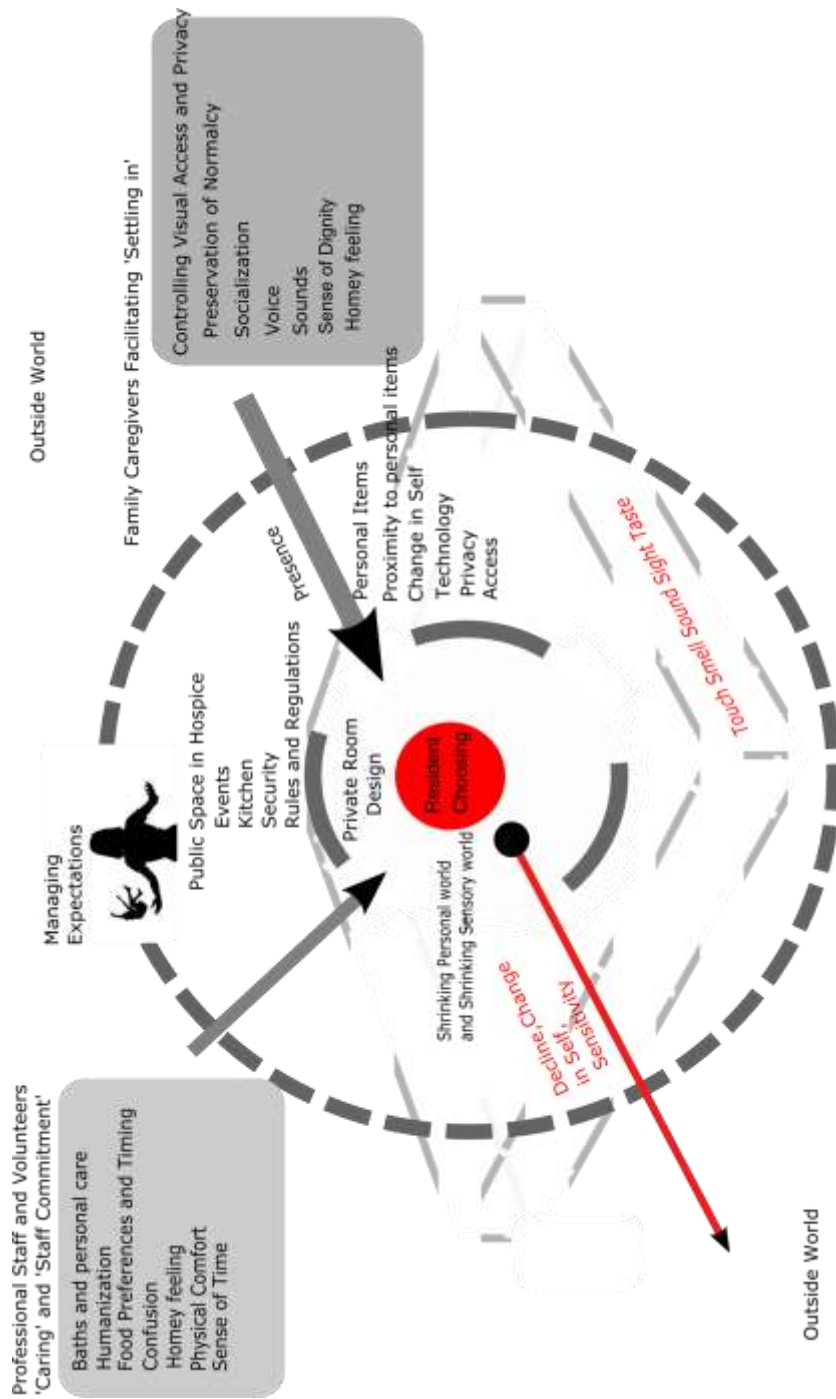


Figure 6: Early thematic model

The original model that was developed placed the resident at the centre of the care process as a journey, within a double layer of permeable outer shells. One shell is the door that marks access into and out of the private room and that defines the extent to which the private resident room is experienced from the inside out and from the outside in.

In total there appeared to be 3 doors- one which was used for the access of family, one for the access of professional staff and volunteers and one for the resident. The outermost layer denotes the hospice as a whole.

Movement of residents out of the private room is less frequent than mobility into the room. This is shown in a thin red line indicating little movement out of the hospice interior due to decline and changing personal world.

The world of residents in hospice care may be reduced to their private room once they make a transition into this final care environment. Their physical space that is created by a single room begins to define their sensory reality and is especially true for those residents who are confined to their beds due to their illness trajectory and those who will not be returning home.

The traffic in and out of the resident's room by family and professional care staff and volunteers appeared high because these stakeholders ensured continuity of care through presence. The management of family caregivers' expectations around the care processes by the professional staff and volunteers appeared to be significant.

The sensory world of the family caregivers is also important. Their sensory world is as limited as that of the patients, but includes their interaction with the public space that may be important for families who are part of the unit of care. Family members are not bound by the private room and act as a link to the outside world through their movement in and out of the residents' private room (Figure 6).

The shrinking personal and sensory world of the resident was evident in the less frequent movement to the outside, due to the fact that the majority of residents are or become bedridden. The decline of the resident along with their change in personal world limits their access to the stimuli of the public space in the hospice and to the outside world.

The five senses were shown as mediating factors in the model. The rationale for this was that sensory perceptions mediate the experiences of the care in the hospice context.

4.2 Coding Matrix

The data collected was analyzed to identify focused codes from openly coded common themes around the differing perspectives of residents, family members, professional caregivers and volunteers.

Working independently, we developed a matrix, presented in Figure 7, to describe and explain the complex nature of recorded statements around the experiences of making the transition to hospice and the quality of life within hospice.

The two dimensions of the coding matrix represent 26 categories and incorporated the following frameworks:

5 Senses	touch, smell, taste, sound and sight (quality of what is seen)
POEMS	people, objects, environment, messages, services
Place based- journey activities	admission process, getting to know, settling in, personal care during the day, meals, receiving visitors, passing time, personal care during

	the night and passing
--	-----------------------

Table 1: Research frameworks used for coding

The intention was to understand the challenges and tensions presented at the touch-points (ie. journey activities) as assessed by each of the four participant groups, with their accounts of the people, objects, environment, messages and services that needed attention. By adding the senses to the collection of codes, we were able to understand the ways in which positive and negative occurrences and perceptions were mediated by qualities of light, sound, taste, audition and what was seen.

The original unfiltered coding matrix (Appendix F) had a lot of noise, showing the many co-occurrences that appear once or twice in the data sets.

A rigorous filtering process revealed a succinct and relevant matrix below. The total co-occurrences was taken, and the bottom quartile of the highest relationship number (28) was eliminated from the matrix. This eliminated co-occurrences 1-7 which were considered noise. The average of the new filtered co-occurrence numbers was then used to filter for co-occurrence numbers that were higher than 51.1.

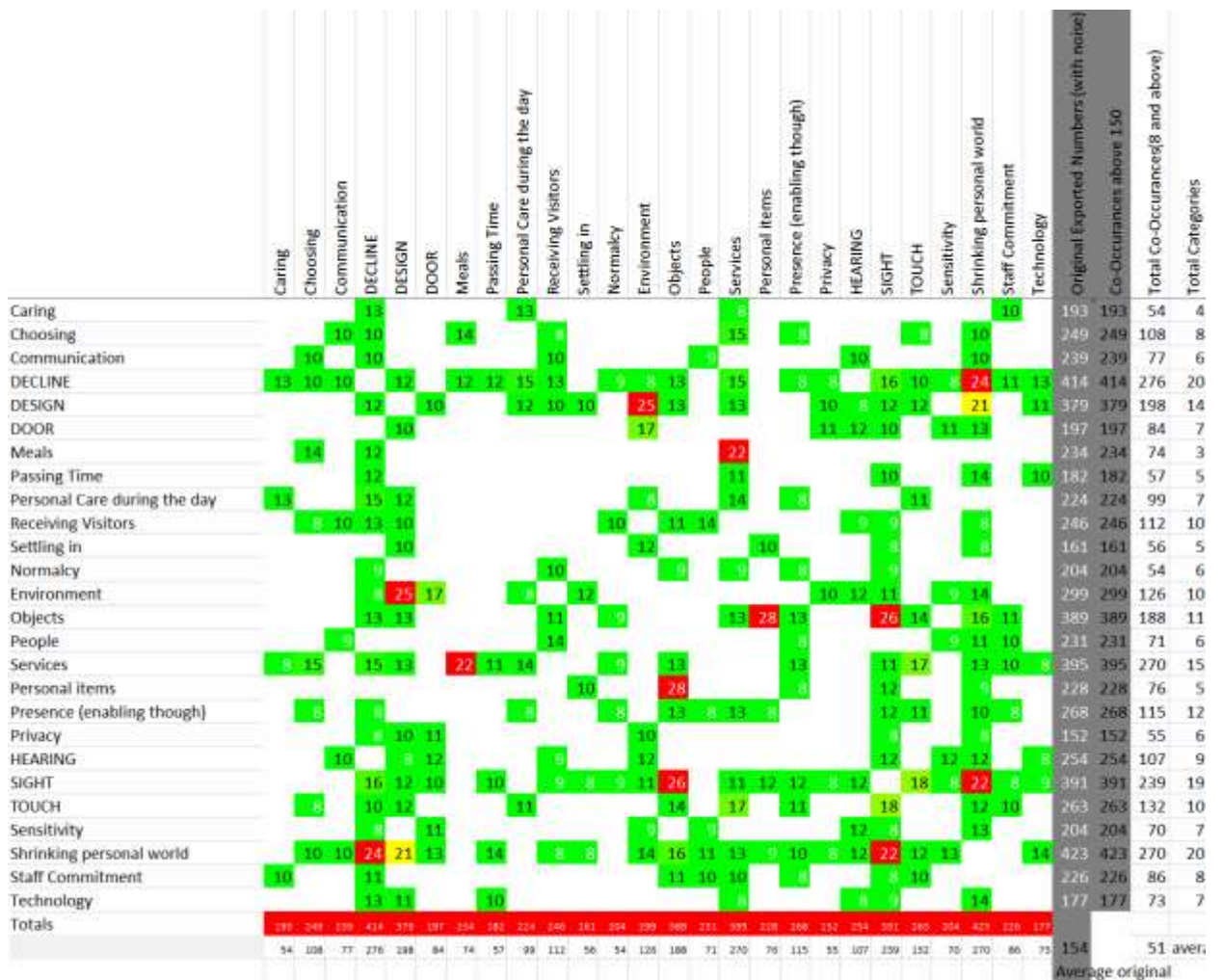


Figure 7: Code co-occurrence matrix (minus code co-occurrences 7 and below)

The resulting co-occurrence numbers were labelled with appropriate line thickness to represent strength of code co-occurrence, yielding the below model of relationships from the filtered coding matrix.

The majority of the prominent relationships are the ones represented by the outermost nodes: Shrinking personal world, Decline, Services, Sight, and Design. The code

relationships that had the highest code-co-occurrence numbers can be seen in the centre of the web: Objects and Personal items.

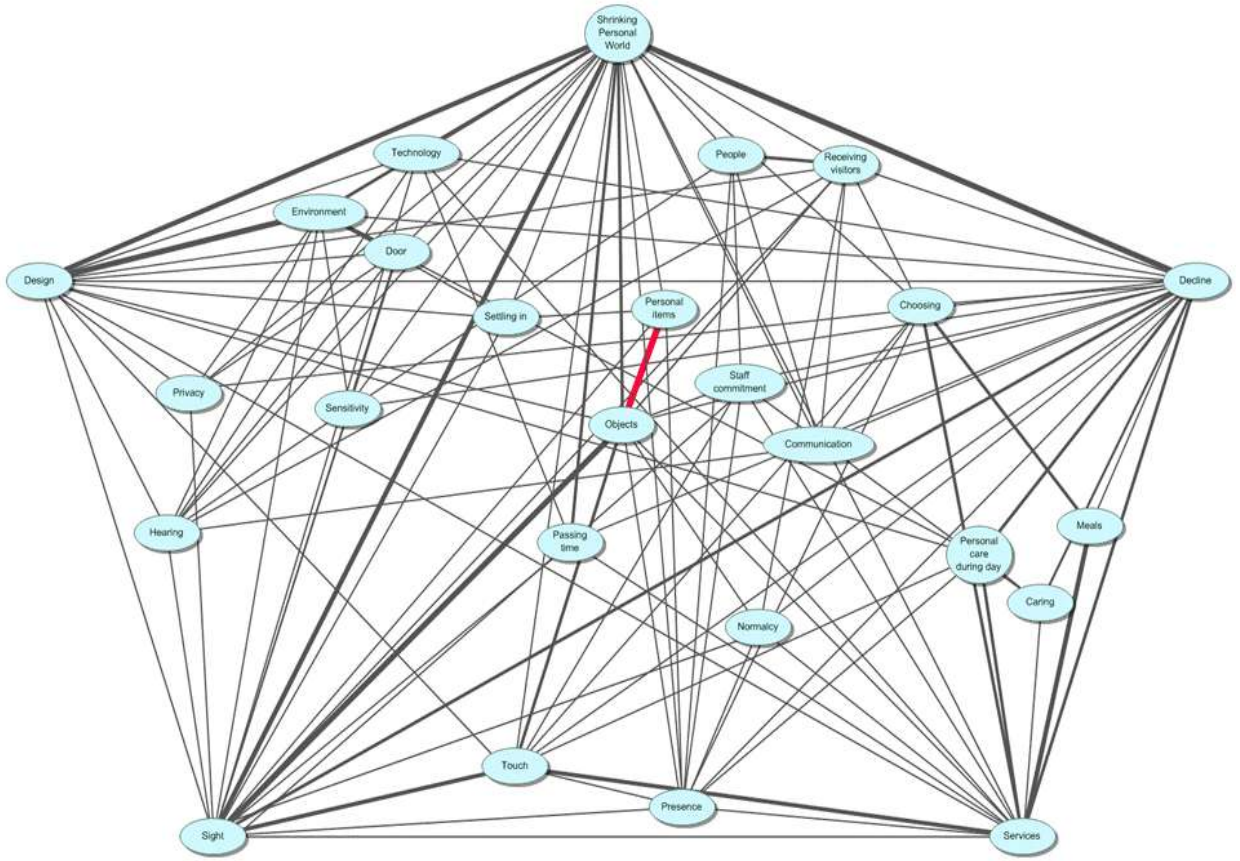


Figure 8: Model of relationships as a network, with the most prominent relationships represented by nodes on the exterior of the web and in the centre

5.0 Results

The exercise generated a total of 371 excerpts for the 12 participants with 28% of the excerpts coming from family care-givers, 16% from residents, 30% from volunteers, and 26% from professional staff. The most prominent categories are presented below. These categories are highly interrelated, but are separated for the sake of clarity and ease of discussion.

The common qualities of the users of the Kensington hospice should be mentioned at this time.

In many instances, the residents were coming in from other hospital environments and thus expressed appreciation for the contrast in atmosphere. Most of the residents were:

1. Rapidly declining, with their physical, perceptual and cognitive changes diminishing the control they have over their lives
2. Bed-ridden and spending many if not all hours of their day in their private rooms that share a washroom
3. Visited by family members and friends who wanted closeness and proximity to the resident

Even though there were many commonalities, in needs and wishes, the overarching message that was evident in the statements below is that choice and choosing are important for residents and their families.

The following results are framed in terms of the whole experience of care which includes both the positive and negative experiences, with the emphasis on the sensory experience.

5.1 Personal Objects

The most common statements described dialogues around personal objects, including the feelings towards these objects and theories around why people brought in personalized items while others did not.

The most common artifacts residents brought with them to hospice were photographs (of their families). One family member describes her mother's choosing of the photographs and the significance of the choice around this tangible and visible personal object:

She wanted to feel somewhere homey. So what we did was we brought a lot of photos. We asked if we could put them on the wall. They said we could use those hooks that don't leave a mark, so that's why they are up. I think it helps her to have those up. And those are the pictures that she chose...when she was getting sick, I think she always thought that she would be needing home care, but in her own home, and so she did go through her pictures and she chose those pictures. And that's why we brought those ones, because those are the ones that she wanted.

A staff member describes the special experience of having a special quilt that offered tactile and visual qualities for the residents:

They have their own blanket. There is one resident that has a particular blanket, so when we do her bed, we have to put that blanket on top of her. I guess it makes her feel like she is home.

Another resident, she passed now, she used to have a blanket that was her son's baby blanket...so she would ask us to lay that blanket down before she laid down. We would place it on the bottom so she would lie on top of that.

The option of using one's own bed linen and special items like quilts were accommodated by the staff and provided visual and tactile reminders of the familiar for the residents.

Dialogue about personal items contained language or suggestion about 'things from home,' 'sense of home,' and 'settling in.' The popular sentiment was that personal items made the hospice room more homey, but it turned out that another popular expression was that the space would never be truly an extension of home. Residents missed their

homes, and dialogue about how the hospice actually felt revealed this. The below statement was repeated many times, and by different participant groups:

It isn't home... but it *feels* more like a home than a hospital.

The data that was gathered did not indicate that residents were making comparisons between their home and the hospice. In fact, they saw the two environments as very different, with the hospice being closer to home than a hospital, but not home by any means. When asked if residents made comparisons between their homes and the hospice, one volunteer said the following about the experiences of residents:

No I don't hear them talking like that. They do bring in a few artifacts and primarily photographs from home and it's a good way to start up a conversation with somebody.

There was one woman who kept talking about how her children were dispersing her home furnishings, which she had asked them to do. But she had some pretty sharp things to say...'so and so just came to visit me...that's just because she wants my couch'....So she wasn't making a comparison between where she was and home, but she was remembering her identity, I suppose, as a home owner, and as a furniture owner.

What emerged was a dialogue about identity through personal objects and not necessarily ownership of space. Interestingly, personal identity was strongly connected to the retention and proximity of personal objects.

One professional staff member spoke about how residents felt about settling into a new environment and the role of families in preserving normalcy by introducing personal objects and tangible projects:

We've had family members come in advance of residents arriving at the hospice to make it...so that when they come in, it all ready has their pictures and things in the room. Family members want to help, and this is something that they can help with, it's a more tangible thing. Often, not only does the resident experience a loss of control in this situation, but so does the family. And so its one thing that they can have some control over...to make that gesture, to bring in things, and to help make that space. Some family members find projects to do...things that are tangible at a time of intangibility. This seems to be tangible and helpful.

Most residents whom I have spoken to about things like that- they say that it's their family bringing in the stuff- it's not actually what they want necessarily. So

sometimes, it's a need for the family and to help and to create a home-like space. Maybe it's connected to the fact that they are no longer able to care for that person at home. Who knows what the psychology of all of that is. But sometimes residents find it difficult to have pictures around... Depends on the person. There is no one answer. Everyone's experience is different because every person is different. But some people like to be surrounded by things and have requested family members to bring things in, and other people maybe didn't request anything, but family insisted on bringing in things and putting things front and centre to the point where residents will ask for staff to take things down off the walls. And they would ask staff, not necessarily family.

The theme of family wanting to 'help' in some way was a prominent one, and through their presence at the hospice, family initiated ways to remain relevant and in control. This connected with the language of 'settling in' and 'forced settling in' that defined the larger theme of personal objects.

Two of the residents held onto personal items in order to feel a sense of self through tactile interaction with something from home. It appears that specific artifacts like keys and mobility devices brought a sense of comfort to the residents and helped them ground themselves with a sense of assurance and a sense of ability through tactile interaction:

He also just wants to hold on to his keys. And he would grab them and keep them. And now we put the keys around his wrist. This makes him comfortable. Those keys are his house keys. So I don't know and his family does not speak English. It makes him happy to hold onto those keys. Maybe it's a way of holding on to that part of him

...

Interviewer: what about this...do you use this? (referring to the walking aid)

Resident: It's helpful sometimes when the girls come to transfer me. It gives me some support, to hold on, for them. So to stay strong. Little bit, otherwise you know, otherwise, if I have nothing, I feel kind of worried. Because I might fall or something. With this, I have some support. That's what I think.

Personal items appeared to be important for residents, and the experience of these artifacts was enhanced through tangible interaction with the items. In the later statement, the resident preferred to have a walker that she brought from home in close proximity,

even though she was not using it independently. It's an artifact for reassurance and for comfort. It also allows her to retain a memory of independence and mobility.

Other less personal/intimate items like coffee makers and humidifiers were also brought in. In some ways, these objects in the private room were as much for, or even more for the family members themselves who desired a sense of comfort and were able to arrange the space to their liking:

I brought him a bar cart, a mini coffee maker which is more for me than for him. I found that there was not much storage in the bathroom so I brought a chrome stand to put all of his stuff like his toothbrush. I am guilty of bringing too much stuff. It's all about being comfortable, and about having important things at your fingertips.

The normalization of the situation by grafting items from home into the hospice interior was done by families.

Statements also indicated the importance of personal items that were able to be worn and felt by the residents as truly their own, like a nightgown from home. One family caregiver describes the process of helping her mom feel more comfortable, and associate less with hospital experiences, by introducing familiar clothing items:

You would have noticed that she wore pyjamas, but those are her own. I did that - I sewed them. I did that with all of the nightgowns that I found in her closet. And for the baby shower I did that for her dress that I found in her closet. Those are the things that I feel like I can do so that she feels more like at home instead of wearing hospital gowns. Because she wore the hospital gowns for that whole time she was in the hospital. So that is one way I can spoil her.

Family, staff and volunteers aimed to create an aesthetic, safe and pleasant environment. A final notable service that allowed residents to preserve the norms and habits from the past was the use of personal items like body creams and perfumes that allowed their traditions to live on:

There is a resident that uses this amazing smelling lotion that I put on her today. Some of them have their own lotion. And I have another resident who uses cologne on his body; just a little bit when he knows his family is coming...he puts a little bit on his body to help him feel like himself

Personal items were connected to sense of self and also to the services around those items. Services of applying personal colognes and lotions into the bodies of the residents were associated with personal items. The *scent* and *touch* associated with lotion application was a favourite service of the residents. Their experience of the care quality was augmented through the sensory stimulation through scent and touch.

5.2 Shrinking Personal World

The transition of people in decline to a residential hospice and to being bedridden contributed to the sense of a shrinking access to real world sensory stimuli (less use of things) and reduced possibility for mobility beyond the boundaries of the hospice. The number of statements about the reduced personal world with decline and the retention and sight of personal items was significant with language about 'options shrinking,' 'immediate access', 'neighbour', 'proximity' (closeness), 'going for walk', 'mobility' and 'inward time'.

One staff member described her effort to help a resident feel closer to everyday things by offering the option of having her bed face the window to see the seasons change, recognizing the importance of the resident having access to her own dishes along with access to her personal paintings:

I am reminded that one resident moved her bed so that she was facing out the entire time, and it was fall, so it was like she had a painting she was looking at. It was all the leaves on the street, and she brought in her painting and her own dishes.

A volunteer described the importance of residents having personal items that define them and the proximity and use of those personal items in an ever shrinking personal world:

One lady had a number of shrines around her room with religious artifacts. But lying sideways on the very deep window sill were a few painting, and so I asked her about those. It turned out that she had taken up painting at the age of 80, or

something, and had painted those herself and was very proud of them. She had her water colors with her.

At one point I took them out and gave them to her. We were talking about them and she was saying how she wished she could do that again, so I gave them to her. She did a few lines and kept filling in the portrait of her grand daughter that she was doing. So it certainly meant a lot to her to have her own things around her and to have that sense of her identity. Not just the religious artifacts, but her own paintings. And her achievements.

One resident described her journey and adaptation to the hospice environment that, in hew view, did not allow her to bring many of her personal things. She expressed a lack of choice, difficult adaptation and subsequent redefinition of her world as a result of moving to the hospice care environment:

It's not too bad. In the beginning, I was not too thrilled. But then the days goes, and you get used to it. You know you have to, you can't go anywhere. That's the way. At the beginning I felt a little bit lost. I was lost in myself, because I had to live a different style. Or have to leave everything behind. I can't take everything. It won't be like it was before. I felt very cold. But now, I am okay. I changed a bit. I changed quite a bit. It will be okay. I have no choice.

The transition to a hospice was marked by perceptions of reduced control with regard to the number of personal things that could be accommodate by a new environment and by need for comfort through personal things and personal style of living.

Access to personal items and to technologies like the television, the call button and the telephone were revealed to be emotionally laden. Residents' narrowing worlds and their decreased sensory perception zone had made these items seem more important. Perceptions of their own reduced abilities was diminished through access to these technologies.

Statements revealed that residents were rarely mobile and in many cases had no way to experience the hospice environment fully. Mobility and use of the larger hospice space was also uncommon for residents who were bedridden or needed assistance to get into a wheelchair to be wheeled out into common areas or outside:

I can't go around here. See, I can't walk. So somebody would have to push me. The workers here are busy. My daughter...there is a lot of problems. I have to go with the oxygen tank. - Resident

Major activities like meals, personal care during the day, passing time and receiving visitors occurred in the residents' private rooms:

Very rarely do the residents take their meals in an open space in the dining room or spend time in the living room. I see it slightly more here at Kensington...just yesterday we had two residents take their lunch in the dining room with their family members. So that's pretty rare. We don't see that very often. - Professional Staff

Feelings towards being seen in the common areas at a stage of changing appearance also emerged, with the private door taking on some meaning as the physical mediator of visual access and a buffer between private world and a more public world:

It's a hard time- they are focused on other things like their own symptoms- their own emotional...inward time. It's a focus time on family...And a lot of people have body image concerns at this stage in their illness. They have gone through a lot of treatment. They don't look like they used to look. And even if they were physically and cognitively able to chat with someone, I don't know if they would want to present themselves. It's a very vulnerable time.

Through their active presence and the time spent with the resident, family caregivers tried to normalize and to mediate the shrinking personal world by organizing personal articles closer to the residents and to allow them to experience some independence in their narrowing worlds:

Access to the telephone can be problematic. The last thing I do before I go is, I call it, 'fixing the table'. I put things in such a way that she can get at them. If someone comes and brings some dinner or they do something on the table and move things around, and if I call, she might not answer. And I will know that she can't get at the phone. If I phone back in 10 minutes and if she still doesn't answer, then I would be inclined to call the nursing station...In my experience, it's the little things that seem inconsequential to somebody else, they become gigantic things...So she can't watch tv, she can't read. The one thing that she has access to is classical 96.3fm. We purchased a radio that has earphones, and we leave it always on. So she simply has to take the earphones, put them on or take them off. She keeps the headphones on the rail of the bed.

The family caregivers create some of the conditions for easier access of personal items, which are sometimes placed on the bed itself. The resident's world shrinks from the institution, to a room in the institution, and finally to a bed.

The time spent in the private room appears to overshadow the time spent in the communal areas, and especially for those who are close to end of life. The estimated time concentrations around main activities (passing time, meals, personal care during the day etc.) for those who are admitted closer to the end of life are represented in Figure 9. Those residents that were able to be wheeled out in a wheelchair to participate in common events like holiday dinners and private functions like baby showers would have a slight inversion of the concentrations, to show slightly more time spent in the communal areas, like the Great Hall. Those residents who wanted to have their baths in the Tub Room experienced more of the hospice environment.

The figure indicates the estimated concentrations of sensory stimuli within the interior of the private room, demonstrating the use of space:

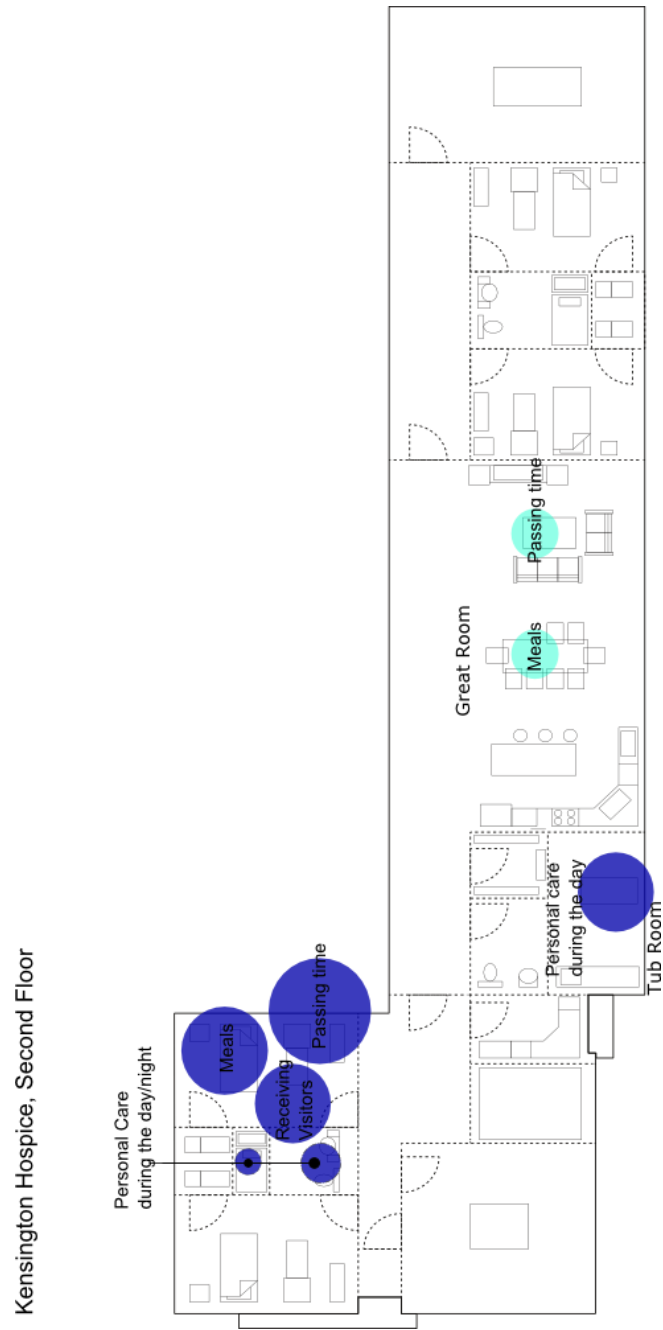


Figure 9: Estimated concentrations of time spent in private room versus the communal areas for those who were admitted closer to the end of life

What were notable were the limited possibilities for engaging in spontaneous interactions within the private rooms that would contribute to a positive distraction (for both passing time and for the waiting for family members). With many residents confined to their beds, the access to technologies for distraction became important and ensured a degree of normalcy, comfort and exposure to the exterior world:

Something as using satellite versus cable for your television. A person's world gets reduced to that one space. If you didn't have satellite at home, and if you are not really ready to learn where your favourite channels are on the satellite...not knowing how to access your favourite channels can be so disruptive to people.

The room door then becomes a central boundary through which people and objects funnelled into and out of. It served as a buffer between private experiences that were customized and tailored (massage therapy) and public experiences (common sounds and smells from the outside, traffic in the halls, piano playing in the Great Room).

With a shrinking personal world and reduced mobility, the management of visual access also became an issue. One resident expressed her frustration with people peeking in as they passed in the hallways, in turn visually invading her small, private world. When asked whether she liked her door open or closed she responded with the following:

Depends on the traffic. Some people take their time and really look in which I don't appreciate. So I usually leave it partially open and partially closed to give me some privacy and to give me some airflow.

Leaving the security of one's room was also seen as daunting when residents had not had the opportunity to develop a mental model of the spatial configuration of the hospice interior and were faced with transitions into unfamiliar environments. One resident described her confusion during the transportation to the tub room on the second floor for her bath. Even though she was uncomfortable and unfamiliar with the new space to which she was brought for the first time, she was able to overcome her fear and to enjoy her bath and expand her sensory world:

The first day, it was a little scary. I was scared because I have not seen such a bath. I saw the bathroom in the hospital. They mostly shower you there. It was a little scary, but after you get used it then its okay. ...To be honest, I just accept it.

Because I do like to take a bath- I like that. It feels good. It makes me feel good. The first time it was a little bit funny. It was a funny situation- how to get there (referring to the movement between floors) Now, for me, I think of nothing. I think that's the way it goes. Don't make too much fuss about that. I am very happy if I go. The foam, and the water. And the rinsing of, it's very nice. And then we come down here, and get dressed.

Interestingly, the resident agreed to some discomfort with regard to unfamiliar transitions, because of her affinity for bathing. She loved the bubbles and the warm water, and relied on these sensory qualities to guide her experience.

And always, the residents longed for independence and the activity of walking and seeing things that were other than their rooms. One resident expressed that she felt well enough to go walking, but she couldn't use her feet. The same resident, when asked if she had an interest in going outside said her new oxygen tank may now liberate her to move outside of the interior environment, and to explore the outside world:

Yes I do have an interest, but I have not done it. I do not know who I would approach (to ask about going for a walk). The people who work here should probably do that. Right? Or when [my daughter] comes, she can take me. So I think that may happen because I now have the oxygen.

5.3 Decline

This category is comprised of statements about physical and cognitive decline of residents with interesting revelations about the relationships between decline and the physical environment of the hospice and between decline and their shrinking personal world. Language in the statements included discussions about being 'bedridden' 'duration of residency,' 'duration of active dying,' 'energy (loss of strength), 'tired,' 'sleep,' and 'night gown.' The time around gradual decline of a terminally ill patient is often marked by reduced independence and by the complex and rapidly evolving symptoms that require ongoing and multidisciplinary care approaches.

With rapid decline, many changes in residents' mobility and sense of self also emerged. The socialization process with respect to behaviour in the hospice environment as well

as the education offered to families around difficult transitions were also noted as important.

An environment where people are declining at different rates requires social negotiations between resident- family and between staff-family that are unique to this care institution.

Statements showed that staff and volunteers worked to accommodate important social events for residents who were in decline but who wanted to participate in social events like a baby shower. One family caregiver described her enthusiasm and gratitude to the staff at the hospice for helping her family host a social event where the quality of what was heard, seen and tasted transformative her mother's hospice experience:

We had a baby shower for me here at the hospice. My mom moved in, and it was the next week. It was nice to have her participate. My aunt organized it. We asked my mom who she wanted to invite and have there. I think that was really nice and they were so supportive here. They let us book the room (great room) for the afternoon and had an extra volunteer on staff to help out that day. I think that really meant a lot to my mom that she was able to participate in that..its something that is...for me it meant a lot because it was something that was normal in such an abnormal situation...my mom getting sick and me being pregnant at the same time. And having a baby shower was a normal thing to do- it was really nice for me and for my family members who attended.

She did appreciate it. And it was something that she could look forward to, it was an event.

Statements showed that professional staff were often given a multiplicity of tasks, including managing the expectations of family and offering education to families about their loved one's decline and the need to adjust their expectations. One staff member offered the following account of the difficulty of managing expectations of family at a time of rapid decline of the resident:

[The resident] had one sided paralysis. And eventually the side became weak as well. We used to get this individual up out of bed and put him on a commode and push him to the toilet. But because his dominant side became very weak as well, he could not leave him to wait there. It became a safety issue for us as the caregivers. So we had to use a lift to get him out. Turns out he loves being on the lift, but his wife was not fond of it. Because when he was at home, she could lift him herself. He was able to do it himself, because he was somewhat able to help her. Because of the progression of the disease (and I mean this is days apart)

these changes happened very quickly. So we had some doctors speaking with her. I think she is starting to understand it- that he can't stand up straight anymore. He can't sit in a wheelchair and not have his seatbelt on, for his own safety. All those things were a challenge for us- because she would not be happy and she would vocalize her dissatisfaction...it's very frustrating. We were not using the lift to take away his dignity.

The lift as an object defined the rapid decline that was happening and the new levels of assistance that were needed to preserve some of the daily activities like bathing in the tub. Mobility to the washroom and in and out of the tub, however, was regarded as both something new and fun for the resident and something that was unfamiliar and seemingly undignified for the family members.

Families also perceived the strain on the resident as they were taken from their beds, with the help of the lift, into the tub room and back. Family caregivers questioned the benefit of such transfers with regard to the residents' resulting energy loss due to such activities.

Residents' decline also marked the importance for private space for difficult transitions/negotiations to occur in. Management of the quality of what is seen, and more specifically of who can see into the room, became very important from the perspective of the family caregivers. A family member described the importance of 'proper socialization', and of her husband having a private room, because she felt that with decline, there emerged a sensory vulnerability and a resistance to being seen by strangers:

It's important for my husband to have a private room, otherwise the resident is on display. The other thing is that, I am very mindful not to look into the room of people as I walk by, but this is not the case with other people. I feel like family members need to be socialized on how to behave in this environment. Sometimes, someone is having a bad day, and so it doesn't help the situation to feel like someone is invading their space. This is an issue.

Residents' decline also marked their reduced energy levels, and highlighted their difficulty absorbing what might be labelled as 'push media,' information that is pressed onto the resident in the form of small talk, questions or even constant presence by family members and friends:

People struggle with visitors. They don't have energy for visitors. Visitors don't know how to talk to the dying- we hear that a lot. They say things like- they are making small talk with me, and I don't have the energy for that. So part of our work is to help families educate the visitors. Families are more aware of what the needs are of the resident. We're talking about the people who don't come in every day to Hospice. To educate the friends and friends of friends as to what the needs are of the resident.

With reduced energy levels of residents and limited distraction artifacts for the visiting family and friends, tensions ensued as family and friends were said to try to extract meaningful moments from the declining residents through spoken word and through visual presence. These sensory qualities were not always welcomed, however, and resulted in negative experiences for the residents.

What proved to be a predominately positive experience for residents was mediated by the taste of food during meals. What became increasingly apparent through the many statements from all of the interviewed parties, was that with decline, reduced energy levels and shrinking personal and sensorial world, food took on immense significance:

If you are bedridden, aside from TV and food, and family, what is there? Food becomes very important.

The transition to pureed food, however, took away many of the valued qualities of the meal ritual. The presentation of the food became fundamentally different, with the appearance (sight), smell, texture and taste altered dramatically. The transition from solid food to pureed food with decline was also seen as a moment where something else was taken away, further reducing a sense of self:

...There is also the difficult transition of going from solids to liquids/puree. If the resident is cognizant enough, that is usually very difficult for them, they have a hard time. It happens when they are having difficulties swallowing and chewing. One resident is having his liquids thickened which is because he chokes when he drinks. It's the breakdown of muscles and your swallowing mechanism gets to a point where it can't handle normal textures. The residents feel infantile. It's one more thing that has been taken away from you.

The sensory system was impacted by residents' decline, and by the difficult transitions, such as requiring the lift and pureed food. Objects and services mediated sensory perceptions defined the experience of care.

5.4 Design

Statements about design of the environment were closely related to dialogue about shrinking personal world and sight, with the design elements at the hospice having the potential to house personal items, either facilitating or hindering how services are delivered and contributing to or reducing a sense of comfort.

Sentiments about the design of the hospice were mostly positive, with comments about the feel of the hospice ranging from “Boutique design”, to the fact that there is a lot of privacy and that “the room does not look like a hospital room.”

One family member described the private experiences that were facilitated in a public space through the design of the hospice:

It's the design. Its that its brand new, soothing colours. The black floors are very chic. You do feel like you are going into a private space that's yours, even though its not a private space, it's a public space to some extent. Because you are sharing it with other residents.

The public qualities of the space were apparent however, and were defined by the quality of sound in the rooms that travelled between the private rooms. One resident described hearing her neighbour passing, which to her was not a disruptive occurrence, but the sounds presented the narrative of what was going on in the space, even if residents never met face to face.

I think I made it very good here. That is the second lady who passed away (next door). To be honest, I see myself (see myself passing?), but then it goes away. It's just at the moment, when I hear it.

The sounds of active care were also audible through the shared washroom doors that did not close fully. Also, the design of the hospice washrooms did not take into account the bedridden condition of most residents. One family member expressed her concern and suggestions for improvement:

In our case, my husband is bedridden. Some residents do share a bathroom, and if you have diarrheal or other issues, and if you have to go, but you don't have a lot of energy to go to the other public washroom—in fact there is no public washroom on the main floor, it's been converted into a nursing station. It may have been a better idea to give everyone a toilet and a sink and then have a few common shower areas that could be used to be used to shower residents.

My husband has never showered in that space (in the room). I think it's problematic because of the way it's been constructed. It slopes into the bathroom areas as opposed to into the shower areas. So it doesn't drain properly. It's a hazard, because if the nurse is there, she would slip. They are great bathrooms, but they are not functional.

The figure that shows concentrations of the time spent for 'personal care during the day' in the shared washroom is supported by the above statement. The use of the showers was not common, whereas the use of the tub room appears more common and more desirable, with bed baths possibly most common for bedridden residents.

Statements revealed that families wanted to be close to their loved ones, and have commented both on the design of the chair that is in the private room as well as the Family Room which is located in the basement of the hospice building. Both the chair and the family room were designed to allow families to spend time at the hospice, and to spend the night. One family member commented on the distance between the private room and the family room:

I would not care to sleep down here, as comfortable as that couch looks, because that sort of defeats the purpose of staying. I would not be with her, I might as well go home.

The design did not take into account people's need for proximity and closeness to their loved one. The sight and touch of the resident was relayed as important, even at night. Poor access to the resident undermined the experience for family members.

Another family member who echoed the sentiment about proximity and closeness to the resident also commented on the usability of the reclining chairs in the room. She took it upon herself to bring in furniture that is designed for comfort in small spaces:

I stay over. They have those chairs that recline. But the chairs do not recline fully. The first night that we came, I stayed over to help with the transition. They have the family room, but the point is that you want to be with your loved one. I

purchased folding military cot that collapses and an overlay that I tuck in. You can buy those sofa chairs; that would be a more optimal choice for the space. So you get your sofa for the day, and if you do want to stay over, it's a very easy conversion. So I had to go through a bit of a production to be comfortable. It's just that I don't think they realize that those chairs do not go flat.

Design of the furniture and access to lighting in the context of themes Decline and Shrinking Personal World were alluded to as incongruent with the needs of the residents. The reach-ability of residents who were in decline was significantly limited, and even if they brought personal items from home (technology, books, clocks), the placement of these items and access to items on the bed side table was limited. A resident described the poor design of the bed side table in her room:

Obviously I would like the computer closer, but there is no place nearby, so I have to ask for it when I need it. I think the beside table could be better designed so that it is more usable to the patient. This is as far as I can reach and the bottom cabinet of the bedside table is useless to me. So there is a lot of stuff in that top drawer and on top, so I think designing or having something to hold the patient's belonging within the arms reach, would be better.

The experience of having satisfactory proximity and access to personal items was undermined by the inability to touch or even see personal items from the position of lying in bed.

5.5 Services

Statements about staff commitment and quality of care through service ran throughout the manuscripts. Residents and family caregivers expressed complete appreciation for the attentive and compassionate service offered by the professional staff:

The staff always approached the residents in an attentive and compassionate way, giving them the ability to choose and control things around them wherever possible. They used communication strategies to determine how much control residents wanted to have over every day things. One of the hardest things for the residents was said to be watching their independence deteriorate as their bodies did, so that the ways in which things like meals were delivered took on meanings of control and choice.

The first statement below was by a staff member and the latter was by a volunteer; both spoke to the importance of offering choice as part of their service model:

I remember asking one of the volunteers to ask [the resident] if she would like us to serve her meals to her in the pottery and dishes that she brought herself. And she was very touched by that, and expressed with a lot of gratitude for our asking her if she wanted for us to use her items and not ours...that meant a lot to her.

...

So it's not much in the world we can control, but when we stop controlling our bodies, it gets harder and harder. So if we could give them control anywhere we can it would be helpful. Even silly little things like when we serve them breakfast, to have the jam on the side of their toast so that they can control how much they want. Any small measure of independence and them making their choices is very important. Also the staff here is very cognizant of this when they are doing any kinds of personal care. 'first thing I am going to do is raise you in the bed..okay?' so making them participate in the process and making them feel less like things are done to them. It's also giving them some measure of boundaries and dignity. When someone is dressing you and washing you, so any little thing that we can give back to them becomes meaningful.

One family caregiver described the importance of technology facilitating her husband's transition into hospice care. Wireless connectivity within the hospice allowed him to retain some of his daily activities like using his iPad:

The fact that my husband has been able to have access to his iPad because they have wireless here, Netflix, full cable; I think having the ability to replicate his home environment was a big part in making the transition easier.

In these examples, choosing allowed for residents to preserve their preferences with regard to the kinds of objects they wanted to eat from (which includes the familiar site of the dish, the feel of the dish and the weight of the dish) and the way their bodies were being cared for by the staff through touch.

Control for residents who were more 'well' seemed to be more important, although they often relinquished it for expediency. One resident described the bathing/personal care process as more efficient if she just let the staff do the work. She opted to not interfere for the sake of efficiency, but actually wanted to do more things for herself:

Resident: Because everything is done for you. You can ask and get it...if they have the time. You don't have to do anything, really, if you don't want to, for yourself. If you can do it, then you can do it. But if you can't, then they help you. You are not alone.

Interviewer: What kinds of things do you still do for yourself?

Resident: at the moment, I do nothing. When I go into the shower, they shower me. In the bath, they give me a good bath. And then wipe me up. Actually I have less, and not much to do. That is another story. They do everything, I shouldn't do anything.

Interviewer: do you want to do more?

Resident: Yes, I want to. But, too many hands- makes it impossible to go. So they do it quicker, so okay. Then I read my paper, and watch tv, talk on the phone.

The experience of independence and general ability would have been facilitated through support during the bathing process instead of the drive for efficiency around time and process.

Massage therapy was identified as a service that offered a multisensory experience for residents, where through scented lotions and touch, residents were able to relax and quickly fall asleep:

We have a massage therapist that comes in to see the resident. [She] comes in, puts on the soft music, she closes the door, and puts a note 'do not come in' on the door. And when you go into the room afterwards, the smell is out of this world. Calming smell- with mint. It makes it cool, and they love it. When she finishes, and you go in, you want to stay in that room. For them, they want to relax and sleep right away- they love it.

Services needed by residents' whose physical well-being was declining were also represented heavily by the statements, and highlighted the need for constant staff vigilance when the ability to exert strength for everyday things becomes difficult:

Depending on the person's mobility- reaching for the phone can be very difficult. When things really deteriorate, people can no longer push bells, and staff are be constantly checking in.

With rapid decline of residents, families were often spending long hours at the hospice. The staff and volunteers were cognisant of their presence and supported them by offering meals. One family caregiver described her experience of being supported while at the hospice:

And the staff would offer me some food too which is great. Because lately I have not been cooking because I am not at my own house

Staff commitment to preserving a high quality of service was evident through the following statement where a volunteer explained the importance of understanding the palliative journey of each unique resident by adapting the way in which the information about residents' changing preferences and needs gets recorded:

There is another form that has prepared, because a number of us had expressed the fact that we have a hard time keeping up with where the residents are in their decline and that we don't know what we need to know....so now there is one page sheet for each resident which is filled out when they come in. And each morning, the first resident care volunteer is asked to sit in on a staff meeting as those two shifts change. So they are talking about patients and the resident care volunteers make notes on that sheet. So that we can tell, by looking at that, that so and so has stopped eating, and so and so does not want any sauce on his pie.

5.6 Sight (quality of what is seen)

Statements about Sight and Service are heavily interconnected with statements about Decline and Shrinking Personal World. For those residents who are bedridden, mostly what they have sight of on a day-to-day basis is their room, which includes the television, their personal items, the traffic through the door, including visitors.

For those residents who were more alert, there was consideration for the kind of sensory information they gathered from their surrounding environment. For instance, if a resident was identified as more responsive and more alert, there was an effort to broaden their landscape of perception by offering them an opportunity to have a better view. One

volunteer explained that by being a communication channel, she was able to vouch for a resident to be relocated to a room with a better view in order to improve the quality of experience:

People are occasionally moved to one of the rooms with a view. If it's evident that they are more alert and are open to things around them, their surroundings. Those rooms are definitely seen as prize rooms because they have a view.

People range very much, and I guess alertness is the key. But some people are evidently more aware of their surroundings. Whether it's a sense of loss of just noticing where they are living now and what the qualities of it are. Those would say things like 'it's not much but I can see a little sunlight out the window.

There was one person who expressed some interest in that aspect of her room, and then one of that back rooms became available and she was given the opportunity to move.

If people have made any kind of comment about things like the window or the view, then it's picked up. And those rooms have qualities of view.

Family members expressed the challenge of the limited sensory world that their loved ones were experiencing. Sensory experience that lies at the intercept of Sight and Personal items revealed the possibility of positive distraction for the resident. One family caregiver expressed his dedication to helping his mother to be able to see and read, as reading was his mother's favourite pastime:

And it's not like we are not mindful of her plight....We took her to the optometrist. And as a result of that effort, she said she could not move her arms because of the sheer effort of that trek. And as far as the benefit of the appointment, the guy was promoting laser surgery...which is out of question. He has changed the prescription for one eye and maybe she can resume reading. That would be very meaningful, because right now she does not have access to a whole lot.

Display of flowers in each of the resident room was also appreciated by residents. It was described as a small gesture to widen the sensory world of the resident.

6.0 Research Challenges

Several challenges emerged when conducting a design study in a residential hospice care environment: hearing the voices of residents and recording sensory data.

6.1 Hearing the Voices of Residents

It was challenging to obtain the perspectives and the opinions of the hospice residents. The voices of residents are most critical but these were not always accessible due to constraints of rapid (physical and cognitive) decline. The context of the hospice as the site for research and design also presented the challenge of distinguishing the perspectives of the hospice residents from those of family caregivers who were more able to communicate. The views of family caregivers, patients and staff are all necessary in order to define the sensory landscape of varied perceptions, and the data collection and analyses kept these differing perceptions in mind when piecing together the design qualities of this space.

Future research in this field must be mindful of including the perspectives of both more and less vocal participants. The challenges in accessing the perspectives of patients who are seriously ill are considerable, and cannot be overcome even when a good relationship is preserved with key staff members who identify the residents who are more able to communicate. The needs and perspectives of living and the dying participants were sometimes different and those differences were articulated by interviewing all of the stakeholders involved.

6.2 Recording Sensory Data

Observations and interviews at the hospice provided written information; where words were often not enough to capture the sensory realities fully. Paula Gardiner⁸ has put forth a framework that may help capture the sensory information in a way that would

⁸<http://hdl.handle.net/1807/16822>

help subsequent readers experience the moment as it happened in that research moment.

Capturing sensory data in what Gardiner calls a 'sensory transcript' is a way to record the holistic sensory experience and awareness that is experienced by the researcher at the research site.

Interview data that was accessed from audio files did not fully capture the sensory realities of the interview . For instance, the expressed enthusiasm or pain of a participant, along with the things they were touching, the smells in the room and the noises in the hall were not captured. The transcript data included just the spoken words and did not carry the fullness of a holistic sensory translation.

Furthermore, most of the interviews were conducted in the Family Room downstairs in the hospice basement. With only a few interviews conducted in an environment like the private room of a resident. The availability of the Family Room provided the needed privacy, but took away from being embedded in the sensory happenings of the hospice. What was necessary to do, in turn, was to record the remembered observations post interview, given that photography of the resident's room was not part of the research protocol.

A written observation like the one below captures the objects and processes that happened during the interview. Furthermore, capturing this content is important for knowledge translation and information dissemination, because the feeling of the interaction is better conveyed through a narrative.

6.3 Observation Narrative

A had an oxygen line that ran through the room and into the washroom. The line was very long, bunching around her walker. The washroom door was left ajar. She was sitting up in her wheelchair, facing the TV, unable to really rotate her head to look at me.

She made an attempt. She had multiple wool blankets folded and placed into the wheelchair for back support.

She also had a few oxygen tanks on a dolly on the right side of her bed. Those were to be used for taking the oxygen outside with her when she went for walks. She was still waiting for her daughter to take her out.

The bed looked perfectly put together. She had not yet used the bed that day.

Someone had passed recently next door and they were cleaning out the room. Noises of vacuum and general cleaning could be heard through the ajar door.

The room smelt of lavender. A had just gotten a massage from the massage therapist that comes in once a week.

Half way through the interview, Ola walked down the hall, and when **A** saw her, she raised her arms and called out to her. She kept calling her name until Ola stepped in to say hi. They had made a connection and both seemed content with the interaction.

A was a former nurse caregiver, so the sense I got was that she did not want to bother people with her demands. She would just accept things.

In her room, she has 3 photographs, and 1 wooden/clay piece on the wall that resembled 2 hands in prayer. There were 3 chairs in the room. And a fridge with German sweeties from Costco. **A** is German.

There was a lot of noise in the hallway during the interview, because of the construction/remodelling going on in the building. The renovation guys have no concept of sensitivities of residents, as they roll the mob buckets down the hall; a noise that was amplified by their working boots.

At the end of the interview, A asked me to open up the door because it was getting very hot in the room.

7.0 The Journey Diagram

This is an iteration of data that is more contextual, and allows for the insight into design opportunities as assessed from the views of the four stakeholder groups: residents, family caregivers, professional staff, and volunteers. This section builds on the co-occurrence diagram presented earlier, but shows the positive and negative qualities of the relationships that have been identified.

By identifying the main areas (called touch points) where people come into contact with the artifacts and services and where their subjective experience is shaped, we can begin to identify where the desired emotional and sensory connection needs to be established. By understanding the areas of patients' palliative journeys holistically, we can begin to design for human experiences rather than just systems or processes.

Below are four tables that highlight the points of tension/pain from the views of residents, professional care givers, volunteers and staff with regard to the needs of residents and their families within the hospice environment. Following that is a holistic representation of the patient journey including the positive and negative qualities of their experiences (Figure 14).

Most salient statements were plotted on a table that shows the major activities (admission, settling in etc.) against the POEMS framework. The latter holistic representation condensed the POEMS framework into People, Care Processes and Environment in order to plot the journey activities against a more concise vertical. Some of these 'pain points' are common between all four groups (i.e. temperature inconsistency in private room, shared washroom situation, aesthetics of pureed food etc.), and are therefore considered critical points for intervention. Prominent issues as expressed by the four participant groups are highlighted in pink followed by a more holistic representation ('Journey of Care Over Time') that offers a visualization to facilitate dialogue.

Overall, most statements were captured from the professional staff, volunteers and family members, with the least number of statements gathered from the residents themselves.



Volunteers

Admission	Getting to Know	Settling in	Personal Care During the Day	Meals	Receiving Visitors	Passing Time	Personal Care During the Night	Passing
One other comment that I saw is the 3rd floor which is unfortunately is not seen by the family. They walk up the stairs to the second floor, but its up and around the corner.	Some of the breakdowns, especially for the residents who have to have the set-up. Making sure that the things that would be there as well.	Sometimes it is hard to decide whether something is done for the comfort of the resident or for the comfort of the family. It is hard to know what the resident wants at an event for the staff and residents. It is very repetitive, but it is a nice touch that the staff have wanted to have.	Family can be tricky. I think it is really in that personal care than having a daughter or granddaughter change your level. But that is my personal view.	One of the resident thing for the residents is walking their bodies. So do not touch in the ward. We can control, but when we help, we have to be careful. Some of the residents are not in control. Some of the residents are not in control. Some of the residents are not in control. Some of the residents are not in control.	There have been residents who wanted to visit their family. Some of the residents are not in control. Some of the residents are not in control. Some of the residents are not in control. Some of the residents are not in control.	It is a nice one. I would want to check. Some of the residents have been in the ward. Some of the residents have been in the ward. Some of the residents have been in the ward. Some of the residents have been in the ward.	This starts in the morning with the residents. Some of the residents are not in control. Some of the residents are not in control. Some of the residents are not in control. Some of the residents are not in control.	
I don't think anything needs quite the same. I think it is a nice touch that the staff have wanted to have.	For what it is, the space is nice. It is a medical bed. The bathroom has medical facilities. I think it is a nice touch that the staff have wanted to have.	Everybody brings a resident in and giving me as one possible problem. They decided to give a private space rather than give everyone a private washroom. In fact, not everyone is being the same. I don't know how often the showers are.	I get a little disappointed to see the provider reports that they planned. And I can't quite really if other side who is having better nursing attention.	The dinner is not perfect. It is a little bit of a disappointment. But it is a nice touch that the staff have wanted to have.	The rooms are not huge. They are not as big as the rooms in the other side. They are not as big as the rooms in the other side. They are not as big as the rooms in the other side.	Also, all of the rooms have been in the ward. Some of the residents have been in the ward. Some of the residents have been in the ward. Some of the residents have been in the ward.	We have residents who are not in control. Some of the residents are not in control. Some of the residents are not in control. Some of the residents are not in control.	
There is another form that we have. It is a nice touch that the staff have wanted to have.	There is another form that we have. It is a nice touch that the staff have wanted to have.	Everybody brings a resident in and giving me as one possible problem. They decided to give a private space rather than give everyone a private washroom. In fact, not everyone is being the same. I don't know how often the showers are.	You have probably seen the other side who is having better nursing attention.	They have probably seen the other side who is having better nursing attention.	They have probably seen the other side who is having better nursing attention.	They have probably seen the other side who is having better nursing attention.	They have probably seen the other side who is having better nursing attention.	They have probably seen the other side who is having better nursing attention.
We have been working in a situation with one resident. And that is not good. It is a nice touch that the staff have wanted to have.	There is another form that we have. It is a nice touch that the staff have wanted to have.	Everybody brings a resident in and giving me as one possible problem. They decided to give a private space rather than give everyone a private washroom. In fact, not everyone is being the same. I don't know how often the showers are.	Diagnosis of the skin is very common. We do have a frequently rub skin, which is something that I think the residents enjoy. It is like a massage - very relaxing.	There is also the difficult situation of going into the kitchen to ask for help, even if it is as simple as a glass of water. This is more of a public hygiene matter - is not really a matter of public etiquette.	They have probably seen the other side who is having better nursing attention.	They have probably seen the other side who is having better nursing attention.	They have probably seen the other side who is having better nursing attention.	They have probably seen the other side who is having better nursing attention.

Figure 13: Journey Map from the perspective of Volunteers

7.1 Summary of Existing Opportunities for Design from Journey Diagrams Decline

Socialization and Education

- 1) Issues about socialization and education for family and friends who visit the hospice regarding i) proper etiquette including noise levels by visitors ii) decline of the resident and their changing capabilities iii) bringing personal items that the residents might not want in their room; and
 - a. Educating staff about the sensitivities of residents (aromas, tobacco smell, noises in hall)
- 2) Challenges to keep up and record residents' decline and changing abilities/preferences. The forms that are updated by volunteers might not capture rapidly changing decline details.

Services

- 1) Number of staff for night shifts and kitchen duties
- 2) Aesthetic issues regarding pureed food
- 3) Control with regard to everyday tasks and bodily care processes (residents want more control)
- 4) Helping with difficult transitions (into hospice and around the facility into unknown areas like the tub room)
- 5) Positive distraction functions in order to empower volunteers and to help them do more with regard to calming aggravated residents
 - a. Positive distraction for families who are in a state of waiting and with sometimes unresponsive residents

Shrinking personal world (Sight, Personal items, Design of private room)

- 1) Balancing the need to uphold rules and regulations while establishing a feeling of a 'homey' environment.' eg. kitchen situation, security situation
- 2) Furniture design, and specifically the chair in the private resident room
- 3) A sense of time in the private room (clocks have been requested)
- 4) Washroom doors that would provide proper sound insulation between rooms
 - a. The overall situation of the shared washroom and poor usability/design of shower
- 5) Inconsistent temperature in the private rooms. Currently, the doors are used to regulate temperature in private room
- 6) Brightness of above lights is inappropriate for residents who may be bedridden and facing the ceiling
- 7) Management of visual access into private room (tension between regulating temperature and being seen by strangers in the hallway)
- 8) Proximity and access to personal items
- 9) Use of family room

8.0 Democratizing the design process: Using narrative scenarios as inputs to idea generation exercises for a futures workshop

This section describes the use of design methods that invite dialogue about the artifacts and processes in the hospice care environment that negotiate comfort for residents and their families. The intension is to co-design solutions that are based on the participant insights highlighted above in the journey diagrams. By using a highly participatory idea generation exercise as part of a futures workshop, the goal is to engage participant groups to promote alternatives to the current situation. A breakdown of how such a workshop might be organized is described in more detail below.

The connection between designers and these participant groups is required in order to develop appropriate design alternatives that are desirable and feasible in the context. Furthermore, the development of an empathic relationship between these two groups is necessary in order to develop a shared design language (Saunders, 2008). Empathic relationships improve both the designers' understanding of the domain they are working in and the issues they encountered. To achieve this connection, the use of participatory design techniques will be proposed as a way to foster respectful engagement with participants in order to generate ideas regarding the optimization of the sensory qualities of the hospice environment for the residents and their families.

A recent abstract by Lindsay and colleagues (2012) is a starting point for understanding how empathic relationships can be used to bridge gulfs in experience. The authors' approach was not to introduce new methods, but rather to give details of their approach to framing participatory design to create empathic relationships between participants and designers.

Elizabeth Saunders has developed a visualization of design research approaches (2008), where participatory design zone spreads across both the research-led and the design-led approaches on the right side of the map.

Saunders defines participatory design as an approach to design that attempts to “actively involve the people who are being served through design in the process to help ensure that the designed product/service meets their needs” (2008).

The generative design method is meant to empower people to generate and promote alternatives to the current situation. The design language is generative in the sense that with it, people can express an infinite number of ideas through a limited set of stimulus items. For the purposes of this study, the presentation of the ‘Holistic Journey of Care over time’ visualization along with narrative scenarios would be presented as prompts for discussion.

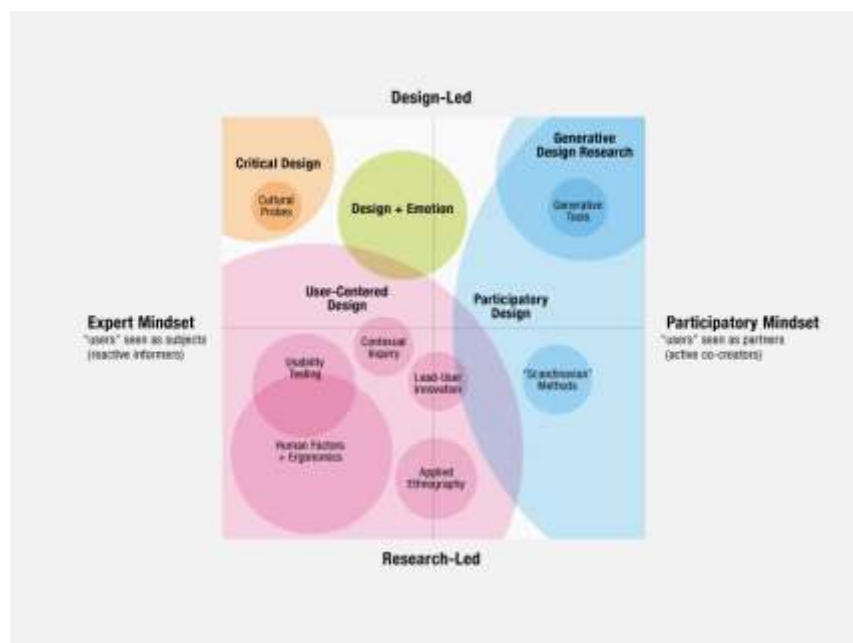


Figure 15: Landscape of Design research (Elizabeth Saunders, 2008)

Narrative Scenarios

The scenario method of foresight is a tool for thinking about the future and could be incorporated into the generative design toolkit. The purpose of this section is to develop a plan for inviting new ways of thinking about the existing sensory realities and about

what is possible in the future. The purpose is not to provide some sort of factual knowledge of the future, however, but to guide strategic decisions through dialogue.

Foresight work uses a highly varied array of research methods. Rafael Popper developed a diamond-shaped array of foresight methods (Figure 16) to help characterize and contrast each with regard to how it falls within the diamond with regard to creativity, interaction, expertise, or evidence. Popper positions scenarios as a highly creative, qualitative method (Popper, 2008). The following section describes the future(s) workshop phase in which narrative scenarios are most useful.



Figure 16: The Foresight Diamond (Popper 2008)

8.1 The Future(s) Workshop

The future workshop as a technique builds upon existing participatory design techniques to propose a way of encouraging participants to postulate the future of various systems, and for the purposes of this research the system is the sensory engagement in the

hospice care environment for improved quality of life. Such workshops can be used for a number of different contexts and are useful for generating commitment and ownership towards the discussed topics.

The future workshop as a method according to Jungk and Müllert (1987) involves the following phases:

1. The Preparation phase (30 minutes): The rules and the scheduled course of the workshop is determined with participants. As a first step, the preparation of the room for the workshop is completed. Whiteboards, paper, pencils etc. should be available. The participants should be seated in an open circle to be able to interact and go to the white board at any time to visualize the discussed ideas.
2. The Critique phase (40-50 minutes): Here, the problem is investigated holistically (but abstractly) during a visualised brainstorming session regarding research results. The exploration of the problem would also include the assessment of the 'Holistic Journey of Care over Time' visualization, where the holistic experiences of residents and their families are shown.

All ideas are written on cards (visualised insights) and grouped accordingly to topics, with the groups titled. After this, a selection of the relevant points can be evaluated.

3. After discussing the problems identified in the research, the future workshop does not immediately search for the solution. All participants would be asked to consider the narrative scenarios of the experience of care in order to draw out an exaggerated picture of future possibilities. As a first step, the participants would be asked to focus only on the Utopian quadrant titled "Be our Guest." This is the so-called Fantasy phase, which is followed by the exploration of the other phases.

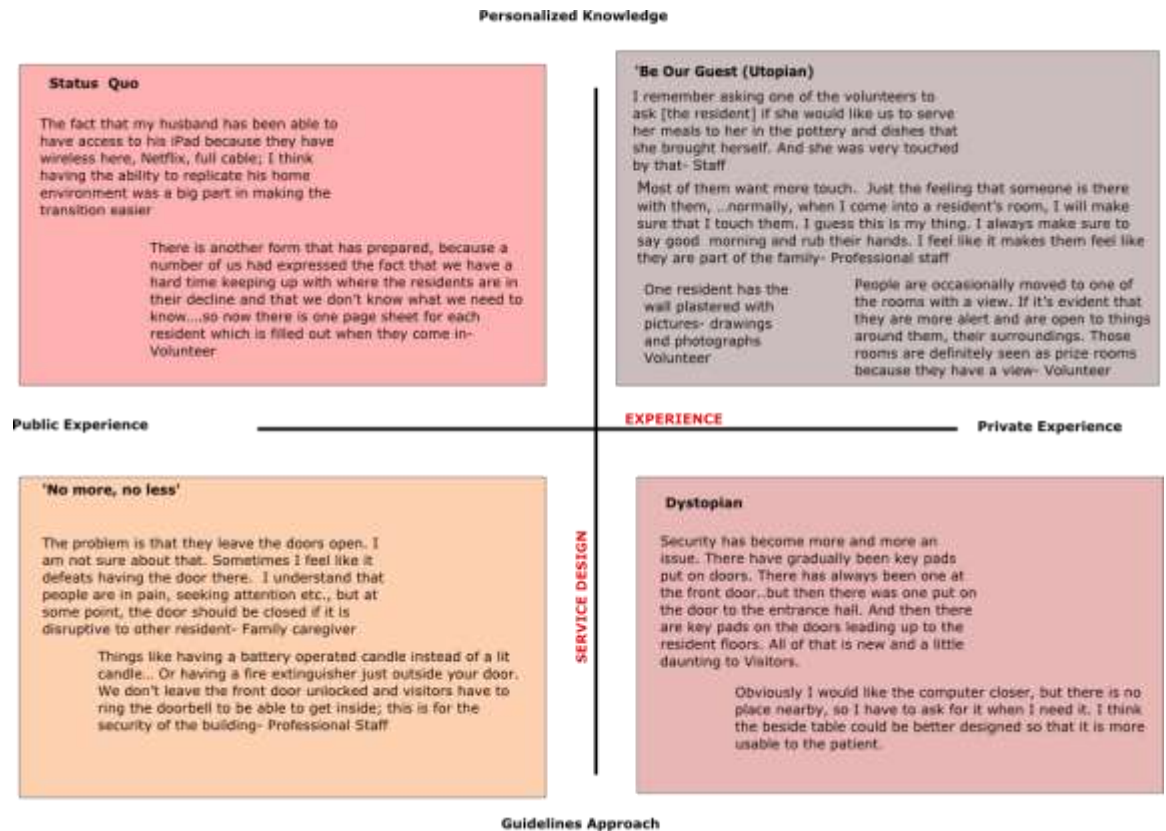


Figure 17: Matrix of four possible futures with quotes to guide discussion

Participants would be given narrative scenarios that focus on the sensory experiences of residents and their families. The narrative scenarios are part of the generative toolkit and would mark the beginning of abstract dialogue with the participants on the research results.

The participants would also be offered senses based interventions that are future oriented in order to stimulate discussion (Table 2).

Senses based interventions that are future oriented

The following examples of senses based interventions would be used as inputs to idea generation exercises for future workshops with the hospice.

Senses based intervention category 1: Choice for Comfort

Summary:

Gaining the ability to choose the degree of exposure to sensory information can serve as a positive distraction for people who are seeking a degree of control for comfort.

Description:

Time spent within a private room can limit the extent to which stimuli like sounds and sight can provide positive distraction for residents and their families. Introducing choice of positive distractions can empower and enhance the mood of residents, giving them back some control over their atmosphere.

Examples:

- The Disambiguation Room- Creation of spaces and areas within hospitals and rehabilitation homes to help soothe and provide calm for patients and their families.⁹
- 'Tomorrow is another day' by Mathieu Lehanneur- Drawing on the inevitable death of the patients of the ward, the device projects a clear image of the weather that is to come the following day, offering them the opportunity to be in a way, 'a day ahead of real time itself.'¹⁰
- Technologies to Combat Isolation, TAG Lab¹¹
- The Caring MR Suite- Patients can personalize lighting, music, images and video to enjoy during their MRI scan- with a tap of the suite's iPad. The variety of preprogrammed themes along with the option to create custom content makes for a more pleasant experience.¹²

⁹ <http://humanrooms.com/what-we-do/>

¹⁰ http://www.mathieulehanneur.fr/projet_gb.php?projet=168

¹¹ <http://taglab.utoronto.ca/projects/technologies-combat-isolation/>

¹² <http://www.pdcbiz.com/products/mr-experience/>

Implications:

Hospice is not comparable to home, but hospice can introduce a different kind of experience. The choice offered to residents and their families to orchestrate and personalize their space would enhance the mood for all users.

Senses based intervention category 2: Design for preferred (behavioural) outcomes**Summary:**

When designing at atmosphere of care that houses the living and the dying, the effective management of expectations is key.

To effectively manage expectations, there has to be design that first signals the preferred behaviour in the context.

Description:

Information about preferred behaviour (ie. socialization, reduced anxiety, positive mood), can be embedded into other media other than written documents. The environment, including artifacts and demonstrated physical interactions, can carry much of the information about preferred behaviour within a built environment over time.

Examples:

- Multisensory room/Snoezalen to reduce anxiety among patients with dementia and other neurological disorders, Baycrest.¹³
- “Luminous textiles” LED-embedded wall panels by Philips- Creation of dynamic spaces with the power to engage and attract, surprise and delight.¹⁴
- Ambient Orb to- a frosted-glass ball that glows different colors to display real time stock market trends, traffic congestion, pollen forecasts, or any other Ambient information channel: weather, windspeed, pollen, and more¹⁵.
- Philips Nebula Bedroom Environment - to address the aggravation patients experience at night- meant to enrich the experience of going to bed. The aim is to create an atmosphere in the bedroom that encourages rest.¹⁶
- JILLIES Medical Treatment Wear- allows women to experience privacy, comfort

¹³<http://cdhaf.org/2011/08/baycrest-apotex/> and

http://www.baycrest.org/documents/Baycrest_Matters_090909.pdf

¹⁴http://www.lighting.philips.com/main/application_areas/luminous-textile/bring_spaces_alive.wpd

¹⁵<http://www.ambientdevices.com/about-us/consumer-products>

¹⁶http://www.phelanassociates.com/philips_nebula.htm

and style during medical treatment. Blouse replaces hospital gown for dignity and comfort.¹⁷

- INATE-Eating with memory. Stimulation tableware for people suffering from Dementia¹⁸
- Project SMART: Sensory Motor Adaptive Rehabilitation Technology: Smart-e-Pants- Underwear combats the problem of bed sores by sending a mild electrical current to the wearer's backside every 10 minutes.¹⁹

Implications:

Embedded information can guide the ways in which visitors socialize within the hospice space, and can influence the mood and comfort of residents in a hospice environment. Information can also be relayed through different lighting qualities and temperature qualities that signal preferred traffic patterns through space.

Senses based intervention category 3: Measurement

Summary:

Measurement for a more precise delivery of service

Description:

Measurements of experience and satisfaction within hospice care can be informed by institutional level metrics (performance measurement) as well as measurement of emotions (mood) of residents and families in response to quality of care.

Examples:

- CareData Pro: CareData Pro is a user-friendly online data tracking and benchmarking system for hospice providers. Powered by Midwest Care Alliance, CareData Pro is offered in three modules to enable hospices to assess quality and identify areas to improve performance.²⁰
- Affectiva Q Sensor 2.0 is a wearable, wireless biosensor that measures emotional arousal via skin conductance, a form of electrodermal activity that grows higher during states such as excitement, attention or anxiety and lower during states such as boredom or relaxation. The sensor also measureless temperature and activity.²¹

¹⁷ <http://www.jillies.com/>

¹⁸ <http://www.neelima-design.com/category/design/>

¹⁹ <http://smartneuralprostheses.med.ualberta.ca/teams/pressure-ulcer-prevention-and-detection>

²⁰ <http://www.caredatapro.com/about.php>

²¹ http://www.affectiva.com/q-sensor/?gclid=CN2_toa8g68CFY0BQAodDnWI4g

Implications:

People have a hard time seeing the consequences of their actions. By capturing more data around the sentiments/mood as responses to care quality, the hospice would have a real-time feedback model that would help everyone be more aware of the consequences of their actions.

Senses based intervention category 4: Presence**Summary:**

Establishing physical presence bridges gaps in connection

Description:

Presence solutions can bridge gaps through location based technologies (i.e. technology to allow presence in a remote location) as well as devices that introduce a tactile solution for additional sensory information and distraction for greater sense of connection.

Examples:

- VGO's robotic telepresence solution is way to establish a physical location/physical presence in a distant location and to bridge the distance between friends and family members.²²
- Devices to soothe and support- Robot designed after a baby harp seal.²³

Implications:

Visual and tactile solutions can effectively broaden the private worlds of residents with the introduction to a wider variety of stimuli. Tactile and visual innovations can be effective distraction solutions for times family is not able to be present.

Table 2: Senses based interventions that are future oriented

All ideas are collected and put into an 'all ideas' store, regardless of their practicality.

At this time, participants will be asked to divide into several groups and would be provided with some low-tech materials like coloured pencils and paper, post-it notes,

²² <http://www.vgocom.com/productsandservices>

²³ http://www.nytimes.com/2010/07/05/science/05robot.html?_r=1

sticky paper, etc. The facilitator would ask the groups to select some of the ideas produced during the first session and to demonstrate the way in which the senses-based artifact or process would be used in the hospice context through simple props.

4. Implementation phase (30-40 minutes): At this time, the ideas found are checked and evaluated in regard to their practicality and feasibility. The whole group is asked to produce a set of requirements for each idea based on their understanding of the needs of residents and the family caregivers in the hospice.

The description of this exercise would involve a dialogue about what foresight is and how it can be used by the stakeholders.

The scenario method of foresight is a tool for thinking about the future, but it is not a tool for predicting the future. Prediction is possible for continuous, cyclic or simple systems, but not in a replicable fashion for social systems or any domain where surprises may change the course of events. When the future is uncertain, we must prepare for multiple plausible futures, not just the one we expect to happen (Bishop et al, 2007).

Scenario analysis allows us to do two things: it sharpens our strategic plans by helping us realize our long-term goals and fears; and it helps us identify the direction a system may be moving toward. An accurate prediction of the future is not necessary, but what is necessary is sufficient contrast between the scenarios to provide the broadest possible canvas for discussion.

Narrative scenarios are meant to be used in phase 3 of the workshop. Typically, the scenarios are developed using a straightforward method. A scan for senses based interventions that are future oriented were identified (shown in Table 2), and the identification of the two of the most critical and uncertain drivers were chosen to form the axes of a 2X2 matrix (Bishop et al, 2007). Figure 18 shows an example of a matrix for this purpose.

The narrative scenarios should serve to start a dialogue between designers and participants about the experiences of residents and their families as these are mediated by the sensory qualities of the artifacts and processes within the hospice environment. The narrative scenarios, along with the senses based interventions should be used as inputs to phase 3 of the idea generation exercises of the future workshop with the hospice.

8.2 Critical Uncertainties

In order to stretch our thinking about the future of hospice care, two axis of critical uncertainties have been identified as a starting point for group discussion. These are based on current tensions as identified in research. As it is common in scenarios development, the uncertainties were crossed in a two by two matrix in order to formulate the permutations for creation of the scenarios. This axis would be presented to the participants to generate discussion.

In the process of identifying the critical uncertainties, a discussion around what is certain and the assumptions around how those certainties are presently showing themselves can illuminate existing knowledge and perception points among stakeholders.

The development of the scenario matrices would be explained to the participants as a method of crossing senses-based intervention with more abstract conceptions of privacy, service design, identity and experience within the hospice. The participants would be invited to iterate these axis.

The axis below would be introduced as a starting point to represent the two exploration topics: service design and experience.

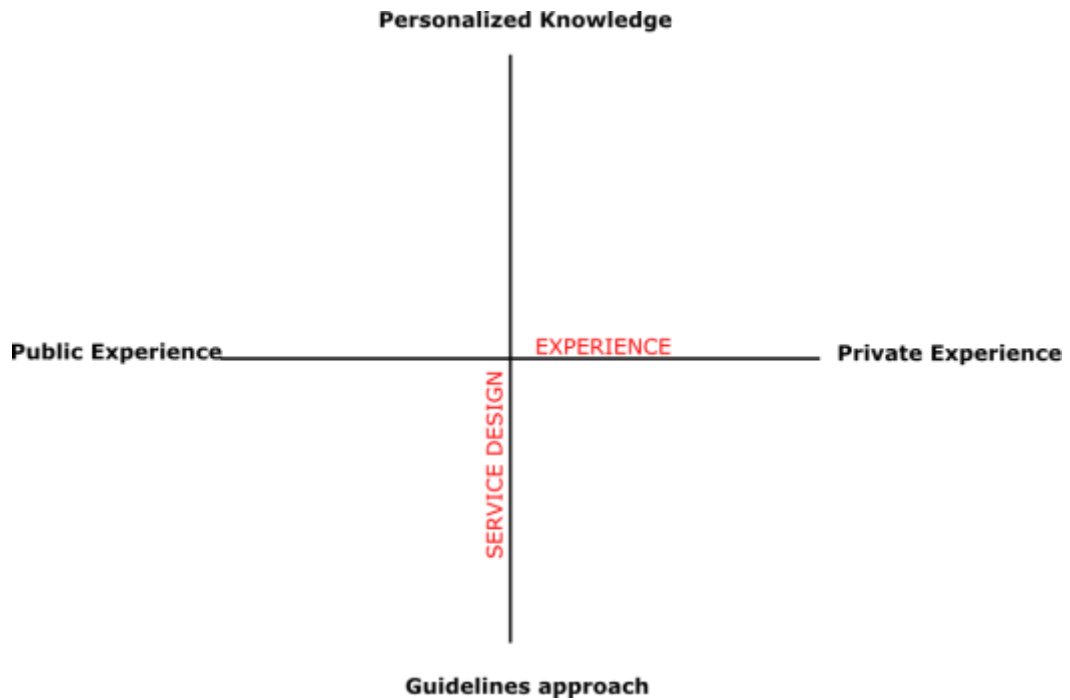


Figure 18: Matrix of critical uncertainties

Personalized Knowledge- Guidelines Approach

The personalized versus the guidelines continuum represents the tension at the intercept of flexible personalized care and a standardized model of care. The vertical axis describes some of the capabilities for including varied channels of information in the care of a resident and the degree of patient engagement in defining their own experience. The personalized care model enhances access to the sensory world for residents by allowing staff to offer unexpected services, while the guidelines approach to care limits the extent to which staff can offer access to the sensory world because no additional measures can be taken to stimulate the experiences of residents. The guidelines approach puts the onus on families and friends to deliver more tailored care.

Private experience-Public Experience

The private experience-public experience continuum offers a way to think about events and the extent to which services are perceived. The private experience can be made possible through appropriately coordinated sensory experiences in the environment that are in tune with individual preferences. The extent to which meaningful conversations and family gatherings can be had, and the needs of the resident tailored at critical journey points (transitions into hospice, preferences for food, odours, tactile, personal objects, and the kinds of things a resident might like to look at while in hospice). When the quality of care is highly responsive, it offers a private experience to the resident.

The public experience is a collective experience that is not tailored. The collective experience involves the inclusion of the experiences of all residents and their families, in a non-personalized more general/common approach to care. The quality of experience is better than it would be in a hospital environment, but the service is not designed to facilitate difficult transitions for residents or to uniquely support the private needs of residents and families.

8.3 Four Narrative Scenarios

After some discussion of the axis, the participants would be introduced to the concept of narrative scenarios as a way to design in a participatory manner. The participants would be introduced to a persona (Janet) what would encourage them to think more abstractly about a user, her needs and the needs of her loved one. The narrative approach is intended to help overcome some differences between the varied participants, and would dissuade them from referring to specific examples, as they would be encouraged to refer to the experiences of “Janet.”

Persona: Janet is a 45 year old woman who is a working professional. She has 2 small kids, both under the age of 8, and her husband is often travelling for business. Janet

knows that her mother would prefer to remain in her home among her familiar things, but given the circumstances, that arrangement is no longer possible. She is declining, but is still responsive and still likes to have visitors. She is also a private person.

Janet and her mother have always been close, and so when it came down to deciding on a hospice for her mother, Janet wanted to spend some time visiting and exploring the kind of care her mother would be receiving in various hospice care environments.

Personalized knowledge- Private Experience-Utopia

Janet was pleased that her mother was going to be able to get the most out of each day through the hyper-personalized, intuitively crafted care and constant ideation and innovation offered at the Kensington hospice.

After speaking with one of the volunteers, Janet was made aware of all of the personalized considerations that were extended by the staff and by the volunteers to help residents feel comfortable. The staff explained that they often went above and beyond, introducing many options to the residents. As an example, they would ask residents who brought in their own dishes from home whether they could “serve meals to {them} in the pottery and dishes that {they} brought.” The volunteer continued, saying that “people are occasionally moved to one of the rooms with a view. If it’s evident that they are more alert and are open to things around them, like their surroundings. Those rooms are definitely seen as prize rooms because they have a view.” Janet was overjoyed, realizing the tailored care that her mother would be receiving would allow her to remain herself.

Janet was also reassured that all of her mother’s personal items that she was planning to bring in (ie.pictures, lotions, cosmetics, hobby items, personal bed linen, relaxation items like candles and music) would be integrated into care processes by staff and volunteers.

Guidelines Approach – Public Experience- No more, no less

Janet entered the Heritage Hospice where she noticed an air of public and collective experience, with little attention given to patient privacy. After looking into a few rooms, she noticed that there was little attention given to personalization or tailoring of care. She noticed there were many limitations, with signs posted all over the place, indicating security measures that are being taken. She overheard one of the family caregivers in the room making a comment about noise in the hospice: “The problem is that they leave the doors open. I am not sure about that. Sometimes I feel like it defeats having the door there. I understand that people are in pain, seeking attention etc., but at some point, the door should be closed if it is disruptive to other resident.” The family caregiver was reminded by one of the staff of the institutional responsibility and the need to ensure safety as well as comfort: “Things like having a battery operated candle instead of a lit candle... We don’t leave the front door unlocked and visitors have to ring the doorbell to be able to get inside; this is for the security of the building.” There was a clear focus on the more public experiences than the private experiences of the residents. It seemed like everyone got the same level of attention and the same quality of service- no more, no less.

The information pamphlet indicated that personal items like perfumed lotions were not encouraged. She also read that families were welcome to bring their loved ones foods from home, but were not able to store anything in the communal fridge, due to food handling regulations.

Guidelines Approach – Private Experience- Dystopia

Janet continued her tour of the hospices in her area and discovered another urban hospice- Lighthouse Hospice. Her first impression was that this hospice was understaffed, and families are required to be present to assist with feeding and bathing. Due to the deficiency in staff, it seemed like no extra measures were being taken to

address the unique needs of residents, and more effort was directed at security rather than comfort measures. Janet overheard some volunteers discussing the changing security situation: "Security has become more and more an issue. There have gradually been key pads put on doors. There has always been one at the front door..but then there was one put on the door to the entrance hall. And then there are key pads on the doors leading up to the resident floors. All of that is new and a little daunting to Visitors." Janet was not put off by the two doors through which she had to be buzzed in by the volunteer at reception, but imagined it would become a nuisance if she were to visit every day. She also noticed that many of the residents did not have personal items with them- in fact they had very little beside them. She figured that those who did bring in personal items were quickly discouraged after they had to wait too long for the staff to pass their personal items to them. She overheard one of the residents telling her husband that she wished for better access to her things: "Obviously I would like the computer closer, but there is no place nearby, so I have to ask for it when I need it. I think the beside table could be better designed so that it is more usable to the patient."

She felt like without her books and pictures, her mother would experience a significant loss a loss when moved to this more restrictive hospice environment.

Personalized Knowledge- Public Experience- Status Quo

Janet also stopped in for an information session at the Southern Ontario Hospice.

When she entered, she noticed the place was buzzing with volunteers. They seemed like they knew everything about the residents- including what spices they liked on their toast. Janet felt like if her mother was admitted to this hospice, that she would be exchanging much dialogue with the volunteers about her mother's daily changed. She overheard one of the volunteers expressing their efforts to develop a better system for recording information about residents' preferences: "There is another form that has prepared, because a number of us had expressed the fact that we have a hard time keeping up with where the residents are in their decline and that we don't know what we

need to know....so now there is one page sheet for each resident which is filled out when they come in.” Janet understood the degree to which the volunteers were committed to the residents and their family caregivers. It seemed like the private experiences of residents were constantly negotiated by the presence of volunteers.

Janet decided to spend some time in the common area where she got an opportunity to speak with a family caregiver of one of the residents. Her name was Anna. Anna expressed some satisfaction with regard to her husband’s smooth transition from home to hospice, mainly due to the fact that her husband could remain connected through Wifi- “The fact that my husband has been able to have access to his iPad because they have wireless here, Netflix, full cable; I think having the ability to replicate his home environment was a big part in making the transition easier

Janet figured her mother would likely bring her iPad because she has always liked the connection to the wider world through BBC news podcasts. Janet figured that she too would bring her laptop and do some work. Her expectations of the space accommodating her work needs were quickly dismissed, since there the space was not really designed for people who needed quiet work time while supporting their loved ones.

Janet noticed some security protocols, but the space still seemed home-like and comfortable.

9.0 Discussion

This work describes the sensory needs of residents and their families at the Kensington hospice, with many of the statements suggesting what might be lost in a move to a hospice. Based on the data gathered from a single hospice facility, the findings indicate the multiple dimensions of the experience and sensory perceptions of residents, as gathered through the points of view of family caregivers, professional staff and volunteers. The inclusion of the views of multiple stakeholders was key to understanding fully the sensory needs of the residents, while informing the future(s) workshop to be held at hospice.

The intention of this research has been to understand the personal losses for residents who enter a hospice and decline, and the ways in which some of the qualities of artifacts and experiences can mediate those losses. This study has brought attention to importance of the design of a hospice facility, along with elements of service design that broaden the sensory landscape for those whose worlds are getting smaller due to decline, as a inseparable element of hospice atmosphere.

The visualizations below show the extent to which sensory perception is a function of place; and that by prolonging the quality of life of residents (until death) through continued sensory stimulation and exposure to a larger sensory world we might control the extent to which the quality of life is negotiated with rapid decline at the later stages of the illness trajectory.

Figure 20 shows that with the initial introduction into the hospice environment, the unfamiliarity of surroundings might decrease the quality of life for residents and their family caregivers. But as they get accustomed to how things run at the hospice, and gain a sense of familiarity, along with introductions of sensory information, residents and family members might experience an increase in quality of life.

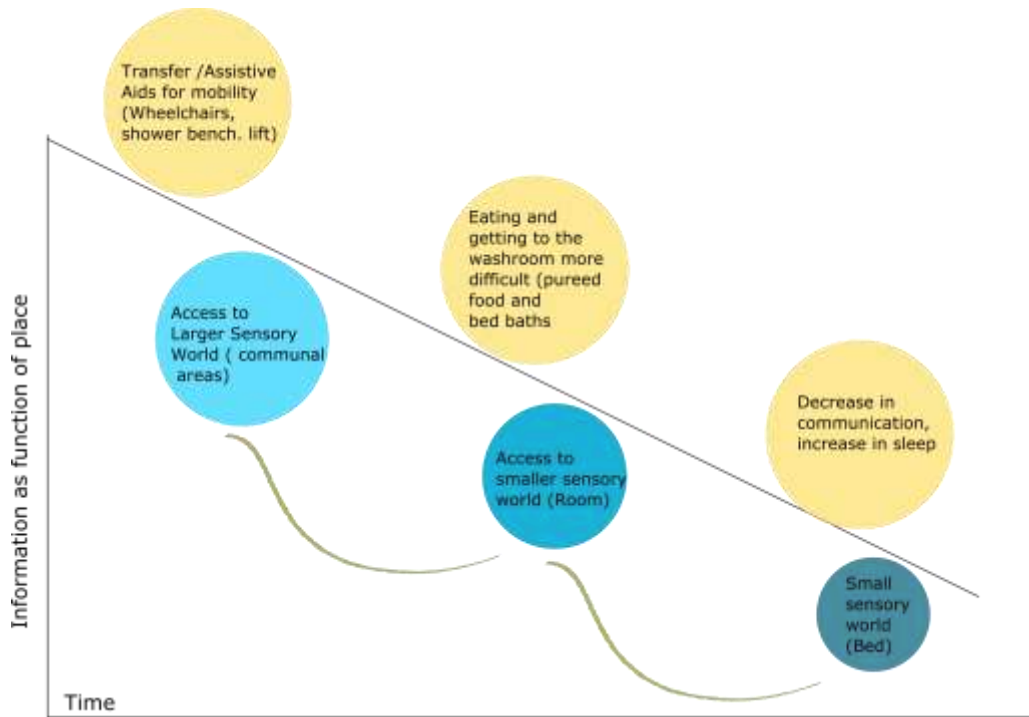


Figure 19: Residents' decline as it connects to the extent to which sensory perception is a function of place

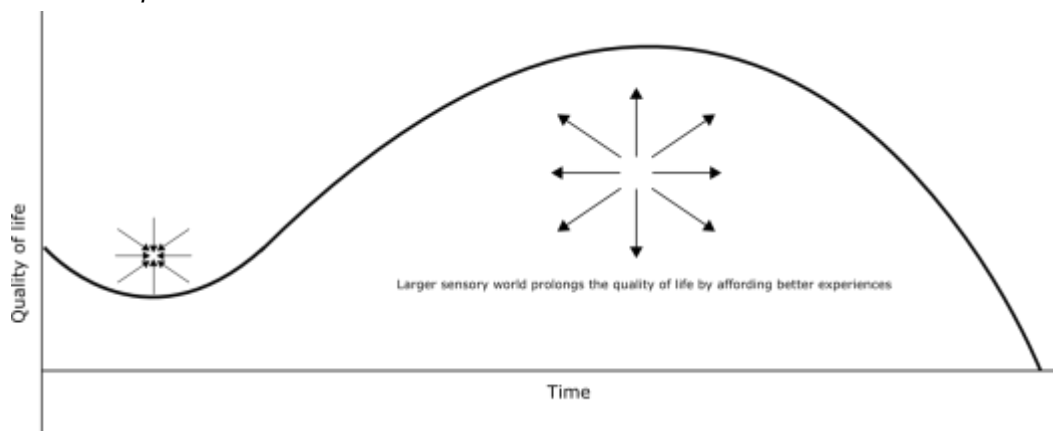


Figure 20: Prolonging the quality of life of residents (until death) through continued sensory stimulation

Bathing, massage, and the ritual of food (save for the issue of the pureed food) were all positive experiences, defined by the touch, sight and taste around those activities. These

experiences allowed residents to participate in a larger sensory world. For most of the activities that were mediated by touch, and managed quality of what is seen (seeing or being seen), the experiences were positive.

The presence of family caregivers appeared to be an important element in shaping the sensory worlds of the residents. The family caregivers orchestrated many of the artifacts and processes the resident was exposed to and they were the ones that often expressed their appreciation of the “boutique’ and intimate feeling of the hospice. Often the quality of light in the private rooms of residents was juxtaposed with the overall ambiance that was achieved through other qualities like the wooden floors, quilts and flowers in the room. Lighting is a common issue in other medical settings like operating rooms and intensive care units. Privacy is also a common issue in other care settings, but the negotiation of privacy at Kensington hospice is superior to the provision of privacy in a more general setting like a palliative care ward in a hospital.

The presence of caregivers defined the experiences around communication, personal care processes (whether the lift would be used), and the concentrations of sensory information (noises, room temperature, and traffic in the hallways). The family’s presence in the hospice introduced an element of normalization which was seen as both beneficial (bringing in familiar objects, spending time, managing care processes) and sometimes insensitive (bringing in objects that a resident might not want in their room, inviting residents to continue to do social activities like going out for dinner and opera without understanding their disease progression).

Residents’ choices in one or more sensory experiences that emerged from the journey maps and the holistic journey visualization, highlight the fact that end of life can be a ‘healthier’ journey when preferences are granted, attitude understood and values respected.

From the point of view of the hospice volunteers, the intercept of ‘passing time’ and ‘objects’ was presented as an area where the resident would benefit from having more control over their environment. Statements about the furniture in the room, the overhead lights, the tension between communal versus private experiences of residents and their

families, and access to a sense of time, highlighted key areas that would enhance the experience for residents and their families. Volunteers stated that the number one complaint they have received has been about the noise, with sight (view) a close second. Volunteers also expressed concern about smells in the hallway and the differing temperatures of the floors that carry the smells of various things, like those generated by people being sick.

The types of food that were pureed was a big concern among volunteers. The volunteers voiced the concerns of residents as they transitioned from solid foods to pureed foods. The number of foods that were pureed was concerning for the volunteers, and the undistinguishable state of the blended food was described as unappetizing, marked by the changed texture. The smell of the food appeared to gain more importance, with spices like cinnamon adding more sensory dimension to the pureed food. Since the volunteers spent much of their time in the kitchen, (preparing or serving meals to residents) they were very vocal about this particular journey activity, stating this area of service is currently understaffed. The volunteers did not differentiate between the preparation of meals that were pureed and non-pureed, but did point to the kitchen design as ill equipped to handle the number of people behind the counter as well as the volume of dishes that required better appliances for speedier cleaning.

The shared washroom situation appeared to be of concern for most interviewees.

For the professional staff, 'personal care during the day,' 'receiving visitors' and 'settling in' were journey categories that highlighted many tension points (or pain points) with regard to facilities (shared washroom and lack of 'proper' shower) and socialization and education of families and visitors around disease progression. Staff highlighted the need for appropriate furniture to accommodate 2 specific needs: 1) Furniture to accommodate families sleeping over and 2) seating to accommodate larger groups of families who are present at critical times like when a resident is actively dying. One professional staff member used the word 'shlepping' to vocalize her frustration with constantly moving seating around to accommodate the needs of family members within the residents' rooms.

Statements regarding education for visitors about noise, duration and frequency of stay, communication patterns (no energy for small talk) and expectations about personal care processes that required assistive technologies like lifts were noted. Professional staff expressed how hard it is to manage family expectations regarding the residents' physical and social abilities in light of disease progression.

Professional staff were very much aware of the transitions that residents were making. One major transition was into the hospice itself, with residents appearing fearful of the new institution. Another transition occurred within the hospice concerning the physical deterioration and reluctance to be social, even if cognitively and physically aware. A noted third transition was towards having pureed food served instead of solid foods. All of these transitions involved changes in sensory perceptions for the residents, whether it was regarding food presentation and texture or regarding bodily deterioration/changes in self which began to limit the sight of the resident, and specifically the extent to which they wanted to be seen by strangers.

For the family caregivers, choices about sensory experiences emerged in discussion about the journey activities 'settling in,' 'passing time' and around POEMS categories 'objects' and the 'environment'. Caregivers described the production they went through to get comfortable in the space, by bringing in items like cots to sleep on during the night. This highlights their presence and their want for comfort for their extended stay at the hospice. Caregivers described the challenge of a shared washroom when both residents needed to use the facilities. The use of the shower was said to be minimal.

The private room was described as important in order to avoid incidents where residents would feel on 'display.' Family caregivers also talked about their role in managing the extent to which strangers see the resident and expressed the need for greater socialization for visitors with regard to noise and behaviours like peeking into the room which were referred to as 'invasions of space.'

Family caregivers expressed the need to 'pass time' in an area other than the resident's room and to do work. They also expressed concern about noise during the activity of 'passing time;' with concerns generally rooted in the design of the room and specifically

the door. With the washroom doors not closing fully and the room door being required to stay open for air circulation and temperature regulation, the family members expressed concern about creating private experiences.

Overall sound was raised as an issue multiple times, often called 'intense' and 'disruptive.'

The concerns of the residents were also mainly around the journey activity areas of 'settling in', 'passing time', but also around 'personal care during the day.'

Residents expressed their sensitivities to aromas and noises in the hospice, and preferred to have their personal items closer to them. One resident's dislike for people 'taking their time to look in' was considered the result of their poor socialization around what is preferred behaviour in hospice environment, and was perceived as an invasion of privacy. The design of the door of the space sometimes introduced unwanted experiences (noise, being seen by strangers in the hall, smell).

One resident expressed her frustration with not being given the opportunity to do more things for herself with regard to personal care.

The experiences of the hospice residents are very intertwined with those of the family members. It also appears that the more families are able to locate themselves in the environment (Edvardsson et al. 2005) the more residents are able to do this as well. The idea that there is *somewhere* to be for the family emerged from the statements of family caregivers and indicated their sense of ease within the environment which welcomed them. The presence of family caregivers also informed the type of sensory information (sounds, smells) that entered the private space of the resident. Family members often worked to bring in familiar objects and to preserve the sensory world of the resident. For family members, the hospice becomes what Ray Oldenburg called "the third place," an anchor of (community) life that is neither a workplace nor a home (2002).

Family members often felt that they could provide something special to the loved one, which often included their favourite food and objects like photographs of favourite memories and grandchildren.

Some of the cultural modifiers, like language differences and socialization differences (loud noise in hallway, large families in the resident's rooms, sensitivities and ability to find voice to speak up), defined the perception of a hospice care environment for residents and for families and defined the extent to which private experiences were able to be contained in private spaces.

For example, the private sounds that travel between the rooms of the residents via the shared washroom door become more public.

Originally, the experience of sound within the room was localized and considered a private experience in a private space as seen below:

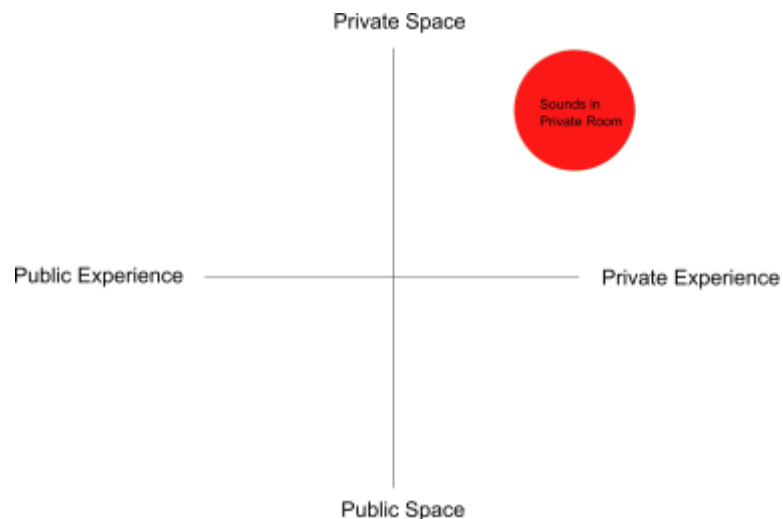


Figure 21: Private sounds in the hospice room

But with the quality of sound from a) passing neighbour b) personal care of neighbour c) visitors with the neighbour, the residents' experiences are transposed into another quadrant where the sounds in the private room become more public:

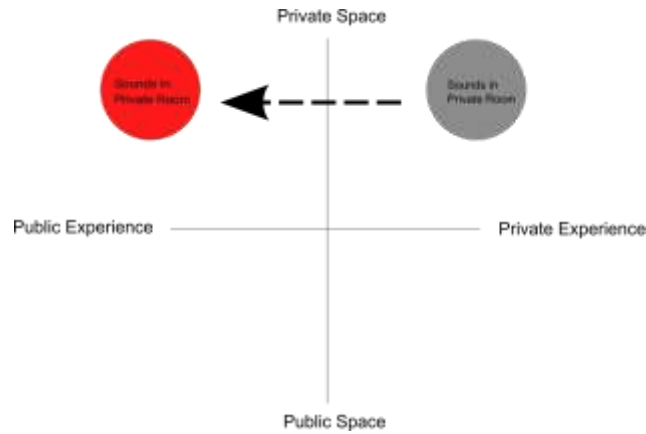


Figure 22: Private sounds transposed into a different quadrant

Similarly, residents' experience of having a bath in the Tub Room is transposed into the private experience in a public space quadrant, because the experience is mediated by personalized service of touch, smell and sight within that seemingly more public space.

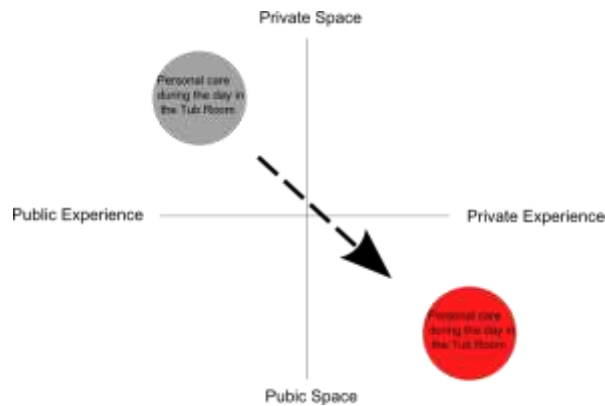


Figure 23: Bathing experience transposed based on sensory perception

A third example is access to personal items. When a resident brings in items from home, they expect to have access to those items. Typically things like laptops, books and clocks are brought in. Yet the bedside table is currently not designed to hold many personal items. Therefore, access to personal items is made possible through a request

for staff members to pass items from the window sill, making the private experience more public through staff involvement.

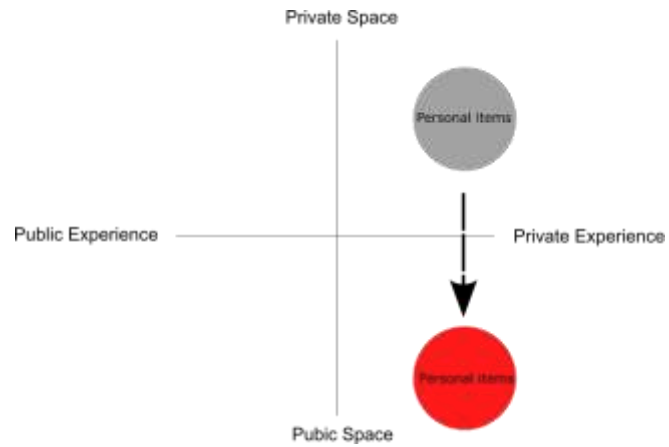


Figure 24: Access to personal items transposed into a more public quadrant

10.0 Recommendations

The synthesis of findings is helpful for introducing a dialogue centred approach to discovering opportunities for design and innovation in a hospice care environment. It is hoped that a feasible development regarding ways in which we can begin to broaden the sensory world of the residents at the Kensington hospice will be realized after a future(s) workshop is held with the participants. This empathic approach to design will create trust between designers and hospice participants, and will ensure that a common language is achieved both in the discussion and in the design.

11.0 Conclusion

This research was intended to start the conversation about the importance of sensory perceptions of artifacts and services in palliative care.

The goal of this project was twofold; 1. to understand and categorize the highly individual and dynamic sensory experience needs of residents and their families in the residential hospice care environment and the perceived responsiveness of services and artifacts to their needs; 2. To suggest a generative design process for participatory design of artifacts and/or services to better address the needs and desires of residents with regard to their experiences in the hospice space.

The experiences of people who use hospice care are all defined by moments of final closeness with a person who is approaching the end of life. How best to preserve the value of interaction and communication for difficult moments shapes not only the real time experiences, but also facilitates the transition for families who must move on and continue life after their loved one passes.

Residents' perception of *care quality* appear to be highly dynamic and informed by the events that occur within the hospice as well as those that preceded the transition into hospice care. This was described by the statements of the resident who did not consider noises in the hospice to be a bother, based on her previous experiences of noise in the hospital setting. Furthermore, the interrelated nature of perceptions, and specifically the information gathered from the service cues in the environment by residents and their families, shapes the perception of quality of care and the extent to which the dimensions of the sensory world are defined.

Perceptions about the quality are as much connected to the professional care offered, including psychosocial care, as they are to the spatial environment within which care is offered (Rasmussen et al., 2000, Rasmussen and Edvardsson 2007). This was shown to be evident in the hospice care environment, where the services offered by staff (around

meals, managing difficult transitions, personal care, and education) were important for supporting the sensory needs of people in the environment.

The focus on a more vulnerable population within a niche setting, such as a residential hospice, allowed for a vertical and highly specific research focus that can be translated into other contexts. These include the sensory needs of children in palliative care and their family members, the sensory needs of young adults (19-39) in palliative care, and the waiting experiences of people who are making difficult transitions around death and dying. All of these areas of research require an empathic process for both the investigation and analysis of data. Further, considering the whole person (along with their holistic journeys) in the context of palliative care required experimentation with new design methods and frameworks for the analysis of data (as well as the presentation of the data to a participant group to generate solutions) in order to address the ways in which sensory needs of residents and their families might be optimized.

12.0 Future research

The development, testing and evaluation of interventions for improving the experiences of the care environment for the recipients of care would be a natural next step.

13.0 Appendices

13.1 Appendix A: Qualitative Consent form for the Patients and Caregivers



Princess Margaret Hospital
University Health Network

UNDERSTANDING SENSORY EXPERIENCES IN PALLIATIVE CARE
INTERVIEW STUDY

Principal Investigator: Dr. Gary Rodin,
Head, Department of Psychosocial Oncology and Palliative Care,
Princess Margaret Hospital
416-946-4504

Co- Investigators: Oksana Kachur, MDes Graduate Student, Ontario College of Art and Design (OCAD) University; Kate Sellen, Principal Advisor, OCAD University; Job Rutgers, Advisor, OCAD University

INTRODUCTION:

You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the study staff to explain any words you don't understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

PURPOSE:

This study seeks to understand and address the sensory needs of palliative patients and their families.

There is little known about specific sensory characteristics that are important to patients in a hospice or palliative care setting. These may be related to sight, hearing, taste, smell, and touch, but may also include patients' sensitivity to temperature, their perception of pain, etc. This study seeks understand the qualities of the hospice environment that are most important to patients and their families. Therefore, by understanding the qualities of care environments like the Kensington Hospice, the design of optimal environments for patients and their families can be better informed.

You are invited to take part in this interview study to help us better understand what traits are most important for patients who are in a hospice or palliative care environment.

Learning about care-environment qualities can help us put together future tools to help aid in the understanding of the sensory experience for palliative patients because there are currently no existing tools available.

PROCEDURE:

The interview questions are about your experiences as a patient or (primary) caregiver to a patient who is currently at the Kensington Hospice care environment.

The interview will be audio-recorded and will last approximately between 10-40 minutes. You will determine the length of the interview.

RISKS/BENEFITS:

There are no known risks associated with taking part in this interview. You may stop the interview at any time, and you can also choose not to answer any questions that you do not feel comfortable answering. The knowledge that we gain from completing this research study may not directly benefit you. However, it may benefit patients who will be residents of the Kensington Hospice or another hospice in the future.

VOLUNTARY PARTICIPATION:

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your care (or your loved one's care) at the Kensington Hospice. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying "pass."

CONFIDENTIALITY:

Interviews will be audio recorded and then transcribed. As with all information that is collected for the study, audio-recordings will be kept in a locked and secure area or on secured UHN network computer servers by the research team, and the transcribed data will be stored for 10 years after study completion, after which the transcripts and other study data will be destroyed in accordance with the Research Ethics Board guidelines. Only the study team will be allowed to look at patient records.

Representatives of the University Health Network Research Ethics Board may look at the study records and at the personal health information of patients to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines.

All information collected during this study, including the personal health information of patients, will be kept confidential and will not be shared with anyone outside the study unless required by law. Excerpts from the interviews may be used in presentations and reports. Interview data will be used towards a Major Research Project of student researcher, Oksana Kachur.

Your name, or any other detail that may reveal your identity, will not appear in any reports, publications, or presentations that may come from this study.

You will be asked to avoid using any personal identifying information during the interviews; however in the event that personal identifying information is accidentally released, it will not be transcribed. All audio recordings will be deleted once transcribed and verified for accuracy by the research team.

If you decide to withdraw from the study, the information that was collected before you leave the study will still be used in order to help answer the research question. No new information will be collected without your permission.

In no way does signing this consent form waive your legal rights nor does it relieve the investigators, or involved institutions from their legal and professional responsibilities. You do not give up any of your legal rights by signing this consent form.

QUESTIONS ABOUT THE STUDY:

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Dr. Gary Rodin (Principal Investigator) at 416-946-4504, or Oksana Kachur (Masters student) at 416-340-4800 ext. 2976.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board, at the Research Ethics office number 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

CONSENT:

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

Print Study Participant's Name

Signature

Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent

Signature

Date

13.2 Appendix B: Qualitative consent form for the Professional Staff and Volunteers



Princess Margaret Hospital
University Health Network

UNDERSTANDING SENSORY EXPERIENCES IN PALLIATIVE CARE

INTERVIEW STUDY

Principal Investigator: Dr. Gary Rodin,
Head, Department of Psychosocial Oncology and Palliative Care, Princess Margaret
Hospital
416-946-4504

Co- Investigators: Oksana Kachur, MDes Graduate Student, Ontario College of Art and
Design (OCAD) University; Kate Sellen, Principal Advisor, OCAD
University; Job Rutgers, Advisor, OCAD University

INTRODUCTION:

You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the study staff to explain any words you don't understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

PURPOSE:

This study seeks to understand and address the sensory needs of palliative patients and their families.

There is little known about specific sensory characteristics that are important to patients as they approach the end of life. These may be related to sight, hearing, taste, smell, and touch, but may also include patients' sensitivity to temperature, their perception of pain, etc. This study seeks to understand the qualities of the hospice environment that are most important to patients and their families as the patient approaches the end of life. Therefore, by understanding the qualities of care environments like the Kensington Hospice, the design of optimal environments for patients and their families can be better informed.

You are invited to take part in this interview study to help us better understand what traits of care environments are most important for patients as they approach the end of life.

Learning about care-environment qualities can help us put together future tools to help aid in the understanding of the sensory experience for patients at the end of their life because there are currently no existing tools available.

PROCEDURE:

The interview questions are about your experiences as a professional care giver to patients who are currently at the Kensington Hospice care environment.

The interview will be audio-recorded and will last between 10-40 minutes. You will determine the length of the interview. The interviews will be audio-recorded and will take place at the Kensington Hospice

RISKS/BENEFITS:

There are no known risks associated with taking part in this interview. You may stop the interview at any time, and you can also choose not to answer any questions that you do not feel comfortable answering. The knowledge that we gain from completing this research study may not directly benefit you. However, it may benefit patients who will be residents of the Kensington Hospice or another hospice in the future.

VOLUNTARY PARTICIPATION:

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your position or employment at the Kensington Hospice. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying "pass."

CONFIDENTIALITY:

Interviews will be audio recorded and then transcribed. You will be asked to refrain from disclosing any personal identifying information during the interview. However, if you do release personal identifying information, this information will not be transcribed and will not be used as study data.

As with all information that is collected for the study, audio-recordings will be kept in a locked and secure area or on secured UHN network computer servers by the research team, and the transcribed data will be stored for 10 years after study completion, after which the transcripts and other study data will be destroyed in accordance with the

Research Ethics Board guidelines. Only the study team will be allowed to look at the study data. All audio recordings will be deleted once they have been transcribed and verified for accuracy by the research staff.

Representatives of the University Health Network Research Ethics Board may look at the study records to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines.

All information collected during this study, including the personal health information of patients, will be kept confidential and will not be shared with anyone outside the study unless required by law. Excerpts from the interviews may be used in presentations and reports. Interview data will be used towards a Major Research Project of student researcher, Oksana Kachur.

Your name, or any other detail that may reveal your identity, will not appear in any reports, publications, or presentations that may come from this study.

If you decide to withdraw from the study, the information that was collected before you leave the study will still be used in order to help answer the research question. No new information will be collected without your permission.

In no way does signing this consent form waive your legal rights nor does it relieve the investigators, or involved institutions from their legal and professional responsibilities. You do not give up any of your legal rights by signing this consent form.

QUESTIONS ABOUT THE STUDY:

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Dr. Gary Rodin (Principal Investigator) at 416-946-4504, or Oksana Kachur (Masters student) at 416-340-4800 ext. 2976.

If you have any questions about your rights as a research participant or have concerns about this study, call the Co-Chair of the University Health Network Research Ethics Board, at the Research Ethics office number 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

CONSENT:

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

Print Study Participant's Name

Signature

Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent

Signature

Date

13.3 Appendix C: Study Notice



Princess Margaret Hospital
University Health Network

Principal Investigator: Dr. Gary Rodin,
Head, Psychosocial Oncology and Palliative Care Program, PMH
416-946-4504

Student Investigator: Oksana Kachur,
Master of Design (MDes) Candidate in Strategic Foresight and Innovation,
Ontario College of Art and Design University
416-340-4800 ext. 2976

Understanding Sensory Experiences in Palliative Care

RESEARCH STUDY

Who is conducting this study?

This study is being conducted by Dr. Gary Rodin, Head of the Psychosocial Oncology and Palliative Care Program at Princess Margaret Hospital, in collaboration with researchers at the Ontario College of Art and Design (OCAD) University. This study has received University Health Network Research Ethics Board approval.

What is the purpose of the study?

This study seeks to understand and address the sensory needs of palliative patients and their families. There is little known about specific sensory characteristics that are important to patients in a hospice or palliative care setting. These characteristics may be related to sight, hearing, taste, smell, and touch, but may also include patients' sensitivity to temperature, their perception of pain, etc. This study seeks to understand the qualities of the hospice environment that are most important to patients and their families. Therefore, by understanding the qualities of care environments like the Kensington Hospice, the design of optimal environments for patients and their families can be better informed.

What does this study involve?

This study will take place between October-December 2011 and involves general observations of the Kensington Hospice environment, and interviews with staff, patients and family caregivers of patients at the Kensington Hospice. Participation involves one interview of 10-40 minutes in duration that will be audio-recorded and transcribed for research purposes. Study participation is voluntary and all collected information will be kept strictly confidential.

How do I find out more about the study?

If you are interested in finding out more about this study or would like to participate, please contact Oksana Kachur (Masters' student researcher) at 416-340-4800 ext. 2976.

Thank you very much for your consideration.

13.4 Appendix D: Interview Topic Guide

Introduction

This interview is being conducted as part of a study to develop insight and strategies for addressing the unique sensory needs of patients in palliative care environments. My aim is to understand the sensory environment as experienced by patients and to attend to the highly individual and dynamic nature of the sensorial needs of patients in a hospice setting.

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 10-40 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 would like to audiotape our conversation. I assure you that all your comments will remain confidential and secure and will not be discussed with your:

Interview group 1: family members or friends or health care providers

Interview group 2: other professional care-giving staff, the patient or their care givers

Interview group 3: the patient or the professional care-giving staff

If you agree to this interview and the tape 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-taped interview, this information will not be transcribed and it will not be used as study data.

Opening Question for the Patient

Can we start by you telling me a bit about your experiences since your arrival at the Kensington Hospice (Probe: what environment are you coming from?)

What have been some of the benefits of your relocation to this hospice? (Probe: contact with others, beauty of the space, the food, being seen and heard?)

What would be some things that you would miss if you had to be moved to another facility?

General Questions

What were some of your expectations of the environment when you first arrived at the hospice? Have they been met? (or not met?) Exceeded? What would you say has been the most unexpected aspect of your stay?

Have you taken the time to notice the space around you since your arrival? The atrium, the garden, the windows? What sorts of things do you notice changing around you?

How has the look and feel (aesthetics) of this environment affected your general mood?

Does this space/place help you feel comfortable, and does it give you pleasure?

What do you remember about your home? What sorts of objects do you associate with every day life? Do you see any items around you now that remind you of home?

Is there anything that you brought from home? Were you asked what items you preferred around you? How did you decide where to place these items?

Do you make requests for your family to bring certain items that make you feel good?

What things have you noticed that foster positive feelings? (Probe: images, laughter, smiling, sounds and gestures that diminish worrisome thoughts?)

How have behaviours and interactions of people around you influenced your level of comfort? What have you noticed about their pace, movement, gestures and approach?

Where in the hospice do you feel relaxed or at ease? Why? What would help you feel more relaxed or at ease?

Where would you like to be when your family visits? What's special about that place?

What every-day processes and activities contribute to feelings of comfort? Is anything missing?

What is your perception of time? Would you request, for instance, a clock to be put into your room? What other visuals and smells indicate time changes for you?

If you had a magic wand, what would you have happen to the environment you are in right at this moment?

Opening Question for the Professional Care Worker (Including Volunteers)

POST PATIENTS' ARRIVAL AT THE HOSPICE

What have been some of your experiences in this care environment since the patients' arrival? What have been some of the most noticeable differences in staff as compared to previous care environments you may have worked in?

General Questions

What objects or processes have you noticed that have helped preserve the dignity,

integrity and control for patients in this Hospice environment?

How might you discover the intricate details of a patient's preferences? (For instance, if they like the curtains open or closed, window open or closed, whether they want to engage in dialogue or to remain quiet)

What have been some of the items that patients normally bring with them when they arrive at the Hospice? What do patients seem to find comforting to them?

What have you noticed about the places where patients prefer to visit with their loved ones? What is different about this/these place(s)?

In what ways would you say the well being of the patient and their (primary) care givers is interrelated? What sorts of interventions would help both groups?

What do you think have been the advantages and disadvantages of this Hospice's location?

Are there any changes you would suggest to improve the environment of this Hospice? For the patients? For the family care givers? For the professional staff?

Opening Question for the (Primary) Care Giver

How do you generally feel when you arrive at the Hospice? What aspects of the building draw you in?

Do you feel comfortable when you are here? Are you always eager to leave? How do you make sense of this for yourself?

Who else do you/have you brought with you? Children? Grandchildren? And what have been their reactions to the space?

General Questions

What changes have you noticed in the patient since their arrival at the Kensington Hospice?

Is the environment comfortable for the patient? What every-day processes and activities contribute to feelings of comfort for the patient? Is anything missing?

What have been some of your memories of the environment after your visits with the patient? What do you bring or take away? What do you see and hear? What do you show them and what do they show you?

Where does the patient prefer to be when you visit? In the bedroom, in the sitting area, in the garden, etc.? Why do you think this is the case?

Do you think the home-like environment has made a significant improvement to the quality of life for the patient? Why?

What do you think have been the advantages and disadvantages of this Hospice's location?

Are there any changes you would suggest to improve the environment of this Hospice? For the patients? For the family care givers? For the Hospice staff?

Before completion (Patients, Primary Caregivers, Professional Staff)

Probe: Is there anything else that you would like to add? Are there any important issues related your experiences at the Kensington Hospice that we haven't talked about and that you would like to share with me?

Probe: How have you felt about taking part in this interview? Were there any questions you felt I should not have asked? Were there any questions you felt I should have asked that I didn't? Is there anything you would like to ask me about the interview?
Thank you very much for your participation in this interview.

13.5 Appendix E: Table of Codes

Title of Code	Description
SENSES	Touch of objects, touch through services
Child code: TOUCH	
Child code: SMELL	
Child code: SIGHT	Quality of is seen, seeing and being seen
Child code: TASTE	
Child code: HEARING	
JOURNEY	
Child code: Admission	
Child code: Getting to know	
Child code: Settling in	
Child code: Personal Care during the day	
Child code: Meals	
Child code: Personal Care during the Night	
Child code: Receiving Visitors	

Child code: Passing	
Child code: Passing Time	
Door	Open/closed Curtain Privacy Identity Sense of control Intrusion Design
Physical Comfort	Mattress Position
Choosing	Own Ownership Permission Mode of medication Meals
Shrinking Personal World	Options shrinking (options, spaces) Immediate access Meal together Neighbour passing Neighbor Proximity (closeness) Going for walk Mobility Inward time Vigilant
Technology	Phone call button iPad TV
Food (Preferences)	Timing for food Smell and temp of food Breakfast State of meals-puree
Other care environments	Hospital No room for residents Home care Busy

Passing	Die at home Place to die Neighbour
Sense of time	Timing (schedule)- whose schedule is it? Sense of days Time passing Enough time Routine Time spent
Rules and Regulations	Set Rules and Procedures Bend rules and accommodation
Aesthetic	Wood Newness
Everyday tasks/events/things	Independence Clothing Accessibility to Amenities
Communication	Topics of conversation Stories Language barriers Feedback
Music	Piano Noises Radio
Humanization	Offering food to family Reducing burden on caregivers Welcoming environment- Somewhere to be Qualities of hotel
Kitchen as hub of house	Hub for gathering
Change in self	Self image Looking your best Cosmetics Rituals (make-up) Taking good care (massage) Overwhelming attention Mirror
Confusion	Mood changes Falling Familiarity and knowing Aggravated

Normalcy	Preserving activities (like before) Getting away from- talking about something else Religious rituals
View	Window Dust and dirt
Continuation of life	Coming to terms New social networks/friends Getting work done (actively working) Break space Reality Work as coping mechanism Practicality of living/working
Personal items	Settle in Things from home Blanket from home (not alone) Need vs Want for personal item Photos Replicating the home environment Homey Sense of Home Insistence for settling in
Public Space	Great room Family space
Anticipation (Events)	Baby shower Bath Participation Decorations Getting ready
Privacy	Intrusion Private space Visual access Dignity
Lights	Brightness of lights (above lights used by staff) Side lamp
Smell	Fresh air Garbage
Transition	Sense of loss (with transition from home) Moving/transitions
Tactile	Texture (of personal items)

Sounds	Variety of sounds travelling through space
Staff Commitment	Always there Spending time Negotiation of family expectations Confidence in staff Trust Nurse reports Interaction with staff
Temperature	In room
Voice (Ability to speak up)	Management of Pickiness Difference/Pluralism
Sharing space	Washroom
Sensitivity	Socialization around dying in public place Disregard for others Disruption Other people Public Waiting experience
Resident centred-ness	Focus on the resident
Sense of Guilt	Sense of Burden Sense of worry Guilt
Family space	Space for family Family room Visitors
Caring	Voice-(positive,soft speech) Psychosocial intervention Supportive staff Getting to Know (preferences and needs) Attention (response to needs) Emotional intelligence
Identity	Feeling of safety Sense of self

Motivation	Giving back Having the means Staff motivation
Decline	Peaceful passing Degradation Bedridden Illness Trajectory Duration of residency Duration of active dying Energy (loss of strength) Tired Sleep Night gown
POEMS	
Child code: People	
Child code: Objects	
Child code: Environment	
Child code: Messages	
Child code: Services	
Presence (enabling though)	Getting used to things Connectivity between patients and family Spoiling Family waiting in patient room More presence with decline Conversation Moments Little things Gifting Helping and desire to help Little things
Design	Shower Flexible environment Hallway Workarounds (eg. cot in room) Resources

	Room Chair Bed Bed-side table Furniture Door
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13.6 Appendix F: The original unfiltered coding matrix



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