THE ROLE OF DIGNITY IN DEATH AND DYING

HOW MIGHT WE OVERCOME STIGMA AND ENCOURAGE THE AGING POPULATION TO ACTIVELY PARTICIPATE AND PREPARE FOR DEATH AND DYING?

Submitted to Ontario College of Art and Design University in partial fulfillment of the requirements for the degree of Master of Design in Strategic Foresight and Innovation-
Toronto, Ontario, Canada

April 2015

KRITTIKA SHARMA

DECLARATION

I hereby declare that I am the sole author of this major research project (MRP). This is a true copy of the MRP, including any required final revisions, as accepted by my examiners. I authorize OCAD University to lend this MRP to other institutions or individuals for the purpose of scholarly research. I understand that my MRP may be made electronically available to the public.

I further authorize OCAD University to reproduce MRP by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

ABSTRACT

The idea that one's own competence provides a secure sense of identity is extremely crucial for the patients. Encouraging a clear and empathic line of communication can determine a patient’s state of mind- whether they feel empowered to experience a sense of wellness or unspoken concern, shame or guilt which may lead to a feeling of illness. By having ongoing conversations devoid of stigmatized words, **The Suitcase Project** is a sensory based cultural probe designed to assist in the enquiry, reflection and preparation for a good death. In the long run, it intends to reach out to health seekers of all age groups, encouraging meaningful conversations and serve as a preparation tool for the inevitable forthcoming event.

ACKNOWLEDGEMENTS

This project has one name on the cover but would have impossible to achieve without the unending support of my family, the guidance of my advisors, the insightful conversations with my interviewees, and my inspiring SFI colleagues.

Thank you to my family in India for your invaluable encouragement.

Thank you to my advisors, Katherine Sellen and Helen Kerr for the constant support of your academic guidance, wisdom, enthusiasm and kindness.

Thank you to Dr. VN Shrikhande, Dr. Devi Shetty, Dr. Alka Ganesh, Elaine Moralee, Debbie Emmerson, Dr. Kate Whitehead, and Dr. Anita Walani for being so generous with your time for the interviews. Thank you to the wonderful healthcare teams at Kensington Hospice, Toronto, Canada and G. Kuppuswamy Naidu Memorial Hospice and Arya Vaidya Pharmacy, Coimbatore, India.

Thank you to Josina Vink, for your enthusiastic mentorship and motivation, Kelly Kornet, for contributing to the paper with your beautiful illustrations, and William S Georg, Laura Dempsey, Jill Sharrock, Ron Memmel and Nihal Ahmed for being my constant inspiration.

DEDICATION

Children perceive their parents to be superheroes. I was inspired to follow the path of innovation in healthcare because of my father. Despite having setbacks in his health, his positive mind, curiosity and determination to live a life of quality makes everybody marvel at him. My mother has played a pivotal in ensuring his speedy recovery and bringing hope back into all of us. Their attitudes deeply shape and inspire me. To my Dad & Mum, for being the best thing that has ever happened to me.

To my beautiful Dadi[1], who started a very profound conversation about a good death a few years ago. It would be an honour to come back and pursue round 2!

---

[1] Grandmother in Hindi

CONTENTS

LIST OF FIGURES

INTRODUCTION

> *"No one pitied him as he wished to be pitied. At certain moments after prolonged suffering he wished most of all (though he would have been ashamed to confess it) for someone to pity him as a sick child is pitied. He longed to be petted and comforted. He knew he was an important functionary, that he had a beard turning grey, and therefore what he longed for was impossible, but he still longed for it."*- Extract from The Death of Ivan Ilyich, by Leo Tolstoy: VII[1]

My line of enquiry within the system of healthcare began because my family has been in close contact with it in the past few years in India. That there are so many advantages with new technologies and the advancement of medicine cannot be denied. However, the downside of this advancement is an erosion of the all-important human factor. In these past few years, many doctors have admitted that their professions are not equipped to handle the humane and empathic aspect within their area of expertise. Medicine school does not allot adequate time discussing how to have difficult conversations and does not focus on fostering a compassionate environment for the people that they serve[2] [3].

In an attempt to explore the role of dignity in healthcare, the project focuses on understanding palliative care and how one might acknowledge and enhance the quality of life of patients during their end of life experience. There has been a shift in the concept of care from families and community into the hands of healthcare teams as medicine today can prolong or redirect life and so, as a society, we see 'life-saving' as a form of care[4] [5].

---

[1] https://ebooks.adelaide.edu.au/t/tolstoy/leo/t65d/chapter7.html

[2] http://www.theatlantic.com/magazine/archive/2014/11/doctors-tell-all-and-its-bad/380785/

[3] Information gathered during the interview with Dr. Shrikhande

[4] http://atulgawande.com/book/being-mortal/

Due to a rise in the aging population, the healthcare system is overburdened and overwhelmed by the change within demographics. Never in the history of mankind have people's life spans increased at this rapid pace[6]. From the healthcare teams perspective, it is challenging to attend to so many people and give them the quality time that they deserve. This has begun and will become more prevalent as the population ages and enters its end of life chapter.

> *"As we medical students saw it, the failure of those around Ivan Ilyich to offer comfort or to acknowledge what was happening to him was a failure of character and culture. The late-19th century Russia of Tolstoy's story seemed harsh and almost primitive to us. Just as we believed that modern medicine probably could have cured Ivan Ilyich of any disease he had, so too we took for granted that honesty and kindness were basic responsibilities of a modern doctor."*-
> Gawande (2014)[7]

Current end-of-life care research increasingly suggests that Canadians prefer to die at home or in their home communities (i.e. in long-term care facilities) instead of in hospital settings[8]. While there are many existing opportunities like the creation of care plans or wills that demonstrate a rationalized kind of planning[9], there are limited options (e.g., like hospices) to pre-plan and prepare one's private choices that demonstrate a sense of self[10]. "In Jungian theory, the Self is one of several archetypes, which are predispositions of responding to the world in particular ways. The Self signifies the coherent whole, unifying both the consciousness and unconscious mind of a person. The Self, according to Jung, is the most important and difficult archetype to understand.

---

[5] http://www.ted.com/talks/peter_saul_let_s_talk_about_dying
[6] http://atulgawande.com/book/being-mortal/
[7] http://atulgawande.com/book/being-mortal/
[8] http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf
[9] http://www.attorneygeneral.jus.gov.on.ca/english/justice-ont/estate_planning.asp
[10] Information gathered during the interview with Dr. Devi Shetty

It is realized as the product of individuation, which is defined as the process of integrating one's personality[11]." The paper, A Quality End of Life from a Palliative Care Patient's Perspective by Gourdji, I., McVey, L., & Purden, M. (2009) speaks of how palliative care strongly believes in providing quality of life care to everyone. It is found to be extremely challenging but crucial to recognize the subjective perspective of patients in order to cater to their needs and die a good death. Due to a lack of conversation about individual dignity and sense of self, many of the patient needs are dealt with on the spot by caregivers and healthcare teams, after the patient's admission. It could range from tangible (e.g., specific clothing material to help with the pain of bed sores) to more intangible requirements (e.g., understanding and managing the role of visitors). By this time, having that discussion on choice is perhaps too late.

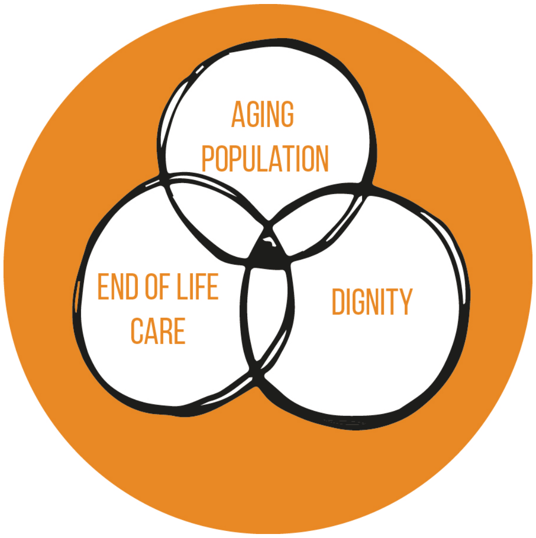
Several researchers have presented reports that involve interviewing patients in long-term care settings in order to study and better define what constitutes dignity and quality of life in end of life journey. Examples include "Dignity" by Baillie (2008), a study that 'investigated the meaning of patient dignity, threats to patients' dignity, and how patient dignity can be promoted, in acute hospital settings.' The paper "Research Sensitivities to Palliative Care Patients" Addington-Hall, J. (2002) states ethical concerns regarding interviewing palliative care patients and whether it is 'ethically sound to ask them to participate in research and risk 'depriving' them of energy and time that they could be using to complete 'unfinished business' and to be with their family.

---

[11] http://en.wikipedia.org/wiki/Psychology_of_self

SETTING THE CONTEXT

The intersection between the role of dignity for the target audience, the aging population in the setting of palliative care was the foundation identified in order to delve deeper into the research question.



Target Audience: The Aging Population

"In any society, the problem of old age and (problems of poverty) are immense. Old age problems have become more prominent because people are living for longer times."- Dr. VN Shrikhande, M.B.B.S (Bom) 1953, F.R.C.S (Eng) F.R.C.S Edin 1959

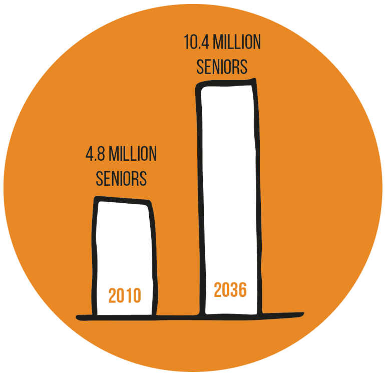
Statistics suggest that 41% of Canadian seniors are dealing with two or more select chronic conditions. About 45% of provincial and territorial governments' health care expenditure in 2009 was spent on seniors, yet this group accounts for only 14% of the population. Seniors are more frequent users of several sectors of Canada's health care system and utilize it in varied ways and with a different intensity as compared to other age groups[12].

The Organization for Economic Co-operation and Development (OECD)[13] defines seniors as age 65 and older, allowing for comparability across member countries, although there is some variation. Among researchers and others, however, there is no true consensus on this definition. Some argue that rising life expectancies worldwide

---

[12] http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf
[13] http://www.oecd.org/health/

mean that age 65 can no longer be regarded as the start of older age. They also assert that, since seniors age differently, combining all people age 65 and older into one cohort results in a group so diverse there is no longer a common experience across it. Comparisons are made with younger adults and, where possible, with subgroups of the age 65 and older cohort—those age 65 to 74, 75 to 84, and 85 and older[14].



In 2010, about 14% (4.8 million) of Canadians were seniors (those age 65 and older). By 2036, this proportion will rise to about 25% (10.4 million). In 2011, the first members of the largest birth cohort in Canada's recent history—the baby boom generation—turned age 65. As a result, the aging of Canada's population has accelerated[15].

---

[14] http://www.oecd.org/health/

[15] https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf

An Introduction to End of Life Care

"Within the hospice what we do here is actually very nice because we can bring families together so that husbands can still be husbands, and wives still wives and not caregivers so it creates a moment of reuniting that relationship whereas when they were in the house, maybe the ill person was in their home, where the husband was no longer the husband, he was the caregiver to his wife. I can remember one gentleman who was touring here, thinking maybe his wife can come here and when I mentioned that concept to him, that you can become a husband again and we will do the care giving and we will partner with you but you will be the husband again, he started to cry. Like the relief for him knowing that he could return to the husband role, was a gift and that's what we can do. It's lovely." - Debbie Emmerson, Kensington Hospice, Director of Hospice Care

End-of-life care as defined in a recent Canadian Institute for Health Information (CIHI) report refers to care for people in decline who are deemed to be terminal or dying in the foreseeable (near) future. Modern end-of-life and palliative care was conceptualized in the later half of the last century in the United Kingdom, focusing upon the role of analgesia, the concept that pain is multifaceted with psychological and physical components, and endorsing the important role that family and friends play for dying patients[16].

---

[16] http://www.cahs-acss.ca/wp-content/uploads/2013/08/End-of-Life-Care-in-Canada.pdf

The choices for end of life care can be broadly categorized into two options: inpatient care and home care. While statistics suggest that while most people would prefer to die at home, a majority of them die in inpatient care facilities[17].

Hospice Palliative Care

According to the Canadian Hospice Palliative Care Association (CHPCA), hospice palliative care is aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, advanced illness or are bereaved.
It is a special kind of health care for individuals and families who are living with a life-limiting illness that is usually at an advanced stage. The goal of palliative care is to provide comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. While an important objective of palliative care is medical interventions for pain and other symptoms, palliative care meets not only physical needs, but also psychological, social, cultural, emotional and spiritual needs of each person and family[18].

Home Care

End of life care can be delivered in the comfort of people's homes and communities. Saint Elizabeth[19], a prominent home care provider in Canada explains the healthcare team who may be involved in this process:

---

[17] https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf

[18] http://www.chpca.net/family-caregivers

[19] https://www.saintelizabeth.com/Services-and-Programs/Services-for-Families-and-Indiviuals/Palliative-Care.aspx

Nurses who provide at-home care. During a visit, a nurse will assist with pain and symptom management. This may include monitoring pain and comfort, giving medications, linking back with other members of the health care team, and sharing information about managing pain. The nurse will also provide psychological social support, such as talking about end-of-life planning, listening to concerns, and providing links to additional support services.

Occupational therapists who can help with safety and equipment needs.

Personal support workers (or community health workers) who can provide personal care, such as bathing or dressing.

Physiotherapists who can assist with mobility, and in some cases, pain management.

Social workers who support families in working through their emotions by providing coping and stress management strategies and linking them to additional services (e.g., financial supports, compassionate care benefits.)

Spiritual care providers.

Long-term Care Facilities

Long-term care facilities provide living accommodation for people who require on-site delivery of 24 hour, 7 days a week supervised care, including professional health services, personal care and services such as meals, laundry and housekeeping.

Long-term facilities-based care is not publicly insured under the Canada Health Act. It is governed by provincial and territorial legislation. Across the country, jurisdictions offer a different range of services and cost coverage.

Hospitals

According to a report by the Departments of Medicine and Critical Care Medicine, Sunnybrook Hospital, Toronto, Ontario, Canada, hospitals provide end-of-life care for 70% of Canadians and 10% to 15% of patients are admitted to the intensive care unit (ICU) on their final hospital admission[20]. While there is access to palliative care health teams, the focus is largely on pharamalogical treatment.

---

[20] http://www.cahs-acss.ca/wp-content/uploads/2013/08/End-of-Life-Care-in-Canada.pdf

End of Life: Cross Cultural Issues and Global Stigma

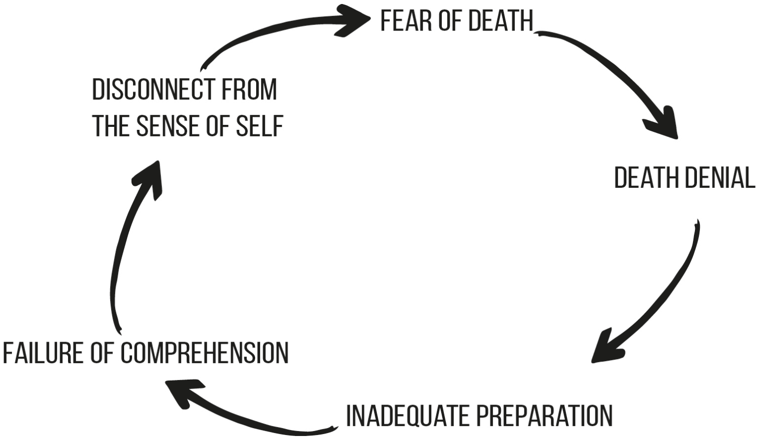


Fig. 1: Death Denial- A Reinforcing Loop

Death is a universal phenomenon. Yet, globally, large sections of societies have a death denying culture. By keeping it taboo and giving it a forbidden quotient, it quickly establishes fear and misconceptions. Technology and modern day medicine can keep a terminally ill patient comfortable, but can also prolong and deflect death. Death is seen as a personal apocalypse so the focus is more on defeating it, thereby leaving little room to prepare for the journey with oneself and loved ones involved.

"You know some of our people who come here, families and residents, they don't want to talk about it. They know it's happening but well... I don't know if it's denial because they know it's happening and they feel like if they don't talk about it, what's coming soon then maybe it won't come. There are some people, some faiths and some cultures that you talk about death and it's going to happen. So you don't talk about it and it's still going to happen."- Debbie Emmerson, Kensington Hospice, Director of Hospice Care.

Philosopher Stephen Cave[21] explains how the human race has always built associations pertaining to immortality. In his talk, he addresses four stories that societies have told themselves about death throughout culture and time in the hope of living forever. The stories are that of elixir, resurrection, the existence of the soul, and leaving a legacy. Today, there is an additional notion that science can cure death, giving modern societies another channel of hope for immortality. This behaviour connects to the Terror Management Theory (TMT)[22] [23] that was proposed in 1986 by social psychologists Jeff Greenberg, Tom Pyszczynski and Sheldon Solomon. The theory was inspired by the writings of cultural anthropologist, Ernest Becker. The theory proposes a basic psychological conflict that results from having a desire to live but realizing that death is inevitable, thereby producing terror. According to TMT, cultures are symbolic systems that act to provide life with meaning and value.

While it is understandable that the conversation about death is hard to start, the existence of fear and stigma possibly leaves patients feeling helpless and, furthermore, tends to create a lack of understanding in the process being adopted. The experience of a dying loved one is known to be traumatic. Additionally, the right and access to information can often be hard to navigate within the existing complex system of healthcare. During my interview with Palliative Pain and Symptom Management Consultant Dr. Anita Walani, she spoke of a personal experience regarding a difference of opinion with reference to treatment for a dying loved one. Since she knew the system

---

[21] https://www.ted.com/talks/stephen_cave_the_4_stories_we_tell_ourselves_about_death?language=en

[22] http://www.tmt.missouri.edu/

[23] http://en.wikipedia.org/wiki/Terror_management_theory

(and her rights, mainly due to her profession) she was able to make more informed decisions. But due to the complex navigation and scattered availability of information, the common man tends to suffer.

> *"You become a doctor for what you imagine to be the satisfaction of your work, and that turns out to be the satisfaction of competence. It is a deep satisfaction very much like the one that a carpenter experiences in restoring a fragile antique chest or that a science teacher experiences in bringing a fifth grader to that sudden, mind- shifting recognition of what atoms are. It comes partly from being helpful to others. But it also comes from being technically skilled and able to solve difficult, intricate problems. Your competence gives you a secure sense of identity. For a clinician, therefore, nothing is more threatening to who you think you are than a patient with a problem you cannot solve."*- (Gawande, 2014)

The wider association of palliative care is death and dying. While this understanding can be considered fair, it simply scratches the surface of what palliative care supports. Another pattern that some of the interviewees pointed out was that many caregivers (especially, children) try and 'protect' their parents or aging loved ones from the reality of their terminal condition, resulting in the lack of personhood or sense of choice. In some cultures like the Eastern ones that lean towards being more family oriented, many aging individuals depend on their caregivers to make the choices. Cultures that are more individualistic like the Western ones tend not to endorse that conversation with loved ones despite being raised with so many choices and what could be called a more expansive upbringing of the sense of self[24].

> *"Even in birth, we do it with our mother. School, university, marriage or having your own children or anything, everything we do, we don't really do alone. I mean we can go shopping alone but there's people around and you're telling someone about your shopping expedition. But death you do alone. Nobody's going with you. When you die, you die alone. And so it's really*

---

[24] Information gathered during the interview with Debbie Emmerson

nerve-racking and scary and the thing that you're doing alone is you don't know where your trip is." - Debbie Emmerson, Kensington Hospice, Director of Hospice Care

Retired palliative care nurse, Elaine Moralee expressed during our interview that there is a prominent future for end of life care providers due to an increase in chronic conditions, terminal illness and current rise in the aging population.

An Introduction to Dignity

Universally, illness is considered as an occurrence and almost everyone can empathize with what it feels like, how the sense of self seems altered and how in those moments, one feels a sense of isolation. Illness makes patients vulnerable and put in an alien setting, can influence the dignity of a person. While researching definitions of dignity, dignity can be understood as having multiple interpretations that include varying subjective components of mental, physical and emotional states of mind.

Expert Lennart Nordenfelt identified four concepts of dignity in 2003[25].

1. menschenwurde (dignity that all humans have equally)
2. merit (due to position in society or earned through achievements)
3. moral stature (dignity due to moral deeds—a virtue)
4. dignity of identity (integrity of body and mind)

In a later paper, Nordenfelt and Edgar (2005) acknowledged that dignity of identity is most relevant in the context of illness as disability restricts autonomy and threatens personal identity. The themes 'dignity as merit' and 'dignity as moral stature' are of questionable relevance to healthcare because nurses should treat all patients with respect for dignity, regardless of perceived merit or moral status[26].

---

[25] https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

[26] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

In 2008, Lesley Baillie carried out a case study regarding patient dignity in an acute hospital setting in the United Kingdom[27]. It was a qualitative, triangulated single case design study that consisted of 24 patients and one ward's staff. The objective was to investigate the meaning of patient dignity, threats to patient dignity and how patient dignity can be promoted in acute hospital settings. While the results gathered consisted of several subjective interpretations of dignity, the key themes identified were "feelings (feeling comfortable, in control and valued), physical presentation and behaviour."

Reports of studies all over the globe, contributed to the secondary research. The most common element was that there were several definitions and interpretations of dignity. The complexity and the very nature of dignity taken alongside the subjective nature of various illnesses, required a qualitative approach in order to gain clarity and propose recommendations. The reports reinforced the fact that presence of dignity is a universal requirement and has an impact at personal, community and systems levels. To know more about the Related Works on Dignity, refer to the APPENDIX B: ‘Related Works on Dignity,’ page: 133.

---

[27] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

METHOD

Based on the nature of the research question, **"How Might We Overcome Stigma And Encourage The Aging Population To Actively Participate And Prepare For Death And Dying?"** and its context (aging population, palliative care and dignity), the process of gathering information was determined by the process of problem finding, framing and solving and is expanded upon with the help of the illustrated framework and brief summary given below.

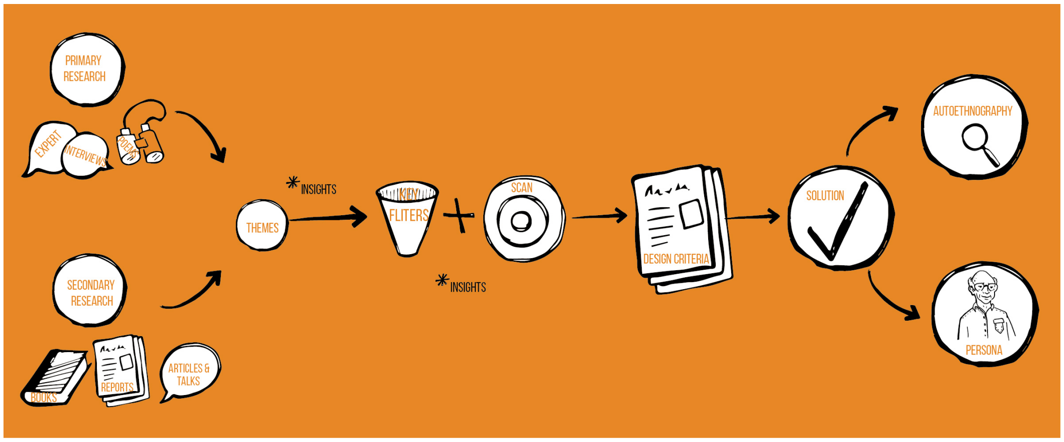


Fig. 2: Method

Primary Research

The primary research was conducted in both India and Canada as it provided an opportunity to understand and experience perspectives of different healthcare models.

A. Expert interviews

Participants: Due to considerations connected with research ethics and time limitations, only experts were interviewed for the project. While the preliminary discussion began with 15 experts, only 7 were selected and interviewed in detail based on the nature of the research question. The experts were categorized by:

- Physicians working directly in palliative and geriatric care- 5
- Non- physicians working directly in palliative care- 1
- Physicians that have been significant change makers in the health care system who had not specialized in palliative/ geriatric care- 2

Purpose: To investigate the identified research question in more depth with providers of medical expertise and care.

B. POEMS

POEMS is a qualitative research method that comprises of 5 parts: People, Objects, Environments, Message and Services. This method was used as an observational framework when visiting the hospices in India and Canada.

Purpose: To gain an understanding through the direct observation of the natural setting.

Secondary Research

A. Books
B. Reports and case studies
C. Articles and talks

Purpose: To gain a deeper understanding of the context relevant to the research question, to learn from the existing knowledge, findings and perspectives from active experts involved in the complex system of healthcare.

Process

After gathering the primary and secondary data, the next step involved identifying and analyzing the themes that emerged from the research. This was carried out by finding recurring themes as well as keeping Nordenfelt's concept of dignity as the foundation of the research paper. From the 28 themes identified, 4 key elements were established.

A scan was then conducted to determine, analyze and gain insights into existing innovations within the ecosystem of dignity from a systems, community and personal standpoint.

The 4 key elements and subsequent scan helped build the design criteria. The rationale of the design criteria was to identify and contain specific goals that the solution must follow in order for it to succeed. This culminated into the creation of a proposed recommendation.

The proposed recommendation was finally delineated into understanding its purpose, approach and anticipated scale of impact.

Due to ethics restrictions, an autoethnographic approach was used to test the proposed recommendation. The purpose of this social research method was to participate, describe, evaluate and document the experience in order to familiarize oneself and test the solution.

A persona was then created to further ground the recommended solution. The intention of the persona was to portray a realistic representation of the intended user of the proposed solution. Additionally, the solution was tested on the persona.

EMERGING THEMES AND KEY ELEMENTS

After the primary and secondary research was gathered, they were clustered into themes based on the research question and 28 themes were collectively identified. This was carried out by finding recurring themes as well as keeping Nordenfelt's concept of dignity as the foundation of the research paper. From the 28 themes identified, 4 key elements were established.

EMERGING THEMES FROM THE PRIMARY RESEARCH

Semi- Structured Interviews

Due to the research sensitivities around conducting research with terminally ill patients and their caregivers, only experts were interviewed for the purpose of the research. The primary research was conducted in both India and Canada as it provided an opportunity to understand and experience perspectives of different healthcare models. The intent was to understand their points of view regarding their experience and interpretations of the role of dignity. The questions were composed in an open- ended format with the objective of allowing the interviewees to take their own course in the conversation. Most of the experts were given the questions prior to the interview being conducted. All the experts used the questions as a general framework and spoke about the topic in the way that they encountered and utilized it, thereby sharing a wide array of rich information and interpretations. The interviews were conducted in person, on skype and email. The groups of experts can be divided into the following categories:

- Physicians working directly in palliative and geriatric care- 5
- Non- physicians working directly in palliative care- 1
- Physicians that have been significant change makers in the health care system who had not specialized in palliative/ geriatric care- 2

As some of the experts were not involved directly in palliative care, the questions were designed to elicit an understanding of the role of dignity in the context of healthcare; thereby addressing two key components of the research question: the role of dignity and long stay patients. It was observed in the interviews that the experts predominantly viewed long stay patients as terminally ill patients and defined long stay as 30 days or longer.

Questions for the experts:

1. I am looking for stories about patients/ caregivers and what they do to maintain dignity, sense of self, familiarity or/and privacy. Would you be able to share anything related to this?
2. What feels like care, in relation to sensorial interventions for long stay patients? How is care perceived?
3. Are there particular ideas that stood out for you? In what way does it impact the patient?
4. How do these innovations/ ideas impact your role?

All the interviews were transcribed manually and the following results were collated and analyzed based on the recurrence of themes as well as significant components of their successful experiences and practices.

1: Lack of Urgency in Planning the Needs of the Aging Population

While there are many experts addressing the rise of the aging population and the issues that it brings with it, there are incremental steps being taken to implement how this shift in demographics is going to impact individuals, communities and systems.

> *"It is inevitable that today we are bragging about the demographic dividends that we have (…) but it's a matter of time that all of them will grow old. Eventually we'll have a huge number of elderly population and when a country sells more of the elderly diapers than the newborn baby's diapers, then the entire dynamics would change. Now as a country, we are not at all prepared for that transformation because we always do things late. The requirement of an elderly, weak, sick person is dramatically different."*- Dr. Devi Shetty, Chairman and Founder, Narayana Health

2: Global Stigma Surrounding Death

There is fear and stigma surrounding the subject of death and dying, globally. By being fearful, there is an absence of conversation and preparation, thereby making the process of end of life taxing and less understood for patients, caregivers and healthcare teams. While some cultures believe that talking about it means that one brings it upon oneself and family members, other cultures choose to avoid it completely, thereby dealing with it only when it actually happens.

"When I was in Qatar last year on a project there were people who didn't want to hear about it, didn't want to talk about it and patients, they didn't want to have anything to do with dying even though death was very close. So it's not just in India or here, it's a global problem but it is a scary thing."- Debbie Emmerson, Kensington Hospice, Director of Hospice Care

“It doesn't bear out in studies as far as I know that people decompensate. I think it’s a cultural perception that it's something that is too difficult to talk about. I often wonder if that's because it's too difficult for people who are close to the dying person to hear and it's too difficult for people who love them to discuss it with them. Because then a person has to face their own fears about the loved one who is dying. It can be challenging because it’s not a conversation that you have everyday and because it's hard to have a conversation that you know might make somebody cry.” - Kate Whitehead, B. Sc., M.D., CCFP (EM). Palliative Care Physician, Grace Hospital

3: Hospice Model of Care Strives to be More Patient- Centered

Death is a universal phenomenon that connects us irrespective of race, status and gender. However, the ever-changing nature of choice and personhood is hard to capture and even more challenging to implement. Within the different departments of healthcare, palliative care is more successful in allowing and providing varying degrees of choice. Almost all the experts interviewed felt that choice is an important ingredient that should be provided and that many healthcare institutions are gradually moving towards addressing it.

> *"We listen to our patients and families. In hospice palliative care we have the model to guide hospice palliative care. It's from the Canadian Hospital Palliative Care Association and it is what guides palliative care practices in Canada and you'll see that the patient and family are in the center and it is always best practices for the patient and family. It is not just the patient, it is always the patient and the family so in hospice palliative care I think we do a great job of it and not so much in other areas of medicine but can it be improved even in hospice palliative care? Yes."*- Dr. Anita Walani, BScN, RN, M.Ed(c), CHPCN(c), Palliative Pain and Symptom Management Consultant, Toronto

4: Rise in Patient Awareness

While, it is difficult for the system to customize dignity due to the subjective nature of circumstances affecting individuals, there are more and more people educating themselves about healthcare and their rights within the healthcare system. Choices may be restricted due to the capacity constraints and over burdened institutions, but "choosy people[28]" will demand more from the system. The concept of wellness must be addressed through the creation of thoughtful products and services, not merely by throwing money at the problem by allocating a budget head.

> *"At some point in the future hospitals will be graded by patients. Today a patient has very few hospitals to choose from. When there are adequate number of hospitals, then a patient will have the authority to decide which hospital he wants to go. Then a hospital that does all these things will score over the others because healthcare will become a commodity. It will lose its uniqueness that it has today. When it becomes a standard protocol driven care, then all these things matter."*- Dr. Devi Shetty, Chairman and Founder, Narayana Health

> *"In the future we're going to see a lot of educated people who are going to be the family members who are going to be asking some tough questions to the health care professionals because currently the baby boomers like my mom wouldn't ask questions about my grandmother's care, she'd say whatever the doctor says is right. But for us we would say no this is our parent. So you tell me why you're doing what you're doing and tell me what is the alternative to that and why I shouldn't choose the alternative and go with you. The choice is more on us and that's a good*

---

[28] Two or three experts used the phrase "choosy people" with respect to the informed and educated patients and caregivers.

thing but as healthcare professionals that's a change in mindset for us that's going to be difficult to switch."- Dr. Anita Walani, BScN, RN, M.Ed(c), CHPCN(c), Palliative Pain and Symptom Management Consultant, Toronto

5: Interpretations of Dignity Amongst Stakeholders Involved

Care and dignity are essential for the sense of self however, from the healthcare systems' perspective, these terms they are interpreted differently. For physicians and nurses, care relates to complex components that include ensuring that patients are being diagnosed, monitored and cured (or, in many cases, exploring treatments to manage symptoms in the case of chronic illnesses) and the measurement of quantitative metrics of success e.g., reduction in the number of deaths on the operating table. These elements are supported to the best of their ability. Providing care as it is being understood by the healthcare systems can, in itself, be a monumental task.

> *"You see, we're so overwhelmed with the fact that we are the healers and we are the people who can save life. For us, saving lives is a big thing. Everything else doesn't matter. But for a patient, it's different."*- Dr. Devi Shetty, Chairman and Founder, Narayana Health

6: The Lack of Soft- Skill Training for Heathcare Teams

Often, doctors and nurses are not trained to have the end-of-life conversations as their success measurement criteria are quantitative and not, qualitative. The advancement and progress of technology drives the acquisition of hard skills, taking the focus away from the growth of soft skill; values like human touch and caregiver-patient conversations that are extremely important elements in the healing process.

"Who will teach values when everyone is so busy? Medicine is about observation and coming to conclusions therefore medicine is a science and practice is an art. Mathematics is not art. Mathematics, physics, chemistry are hard skills which can be taught. You can't teach soft skills but some people inspire other people to follow you. Then the message can go forward and that's why good doctors are few."- Dr. Shrikhande, M.B.B.S (Bom) 1953, F.R.C.S (Eng) F.R.C.S Edin 1959

"In today's modern medicine we really don't need to touch the patient because when a patient is sitting in front of me, he has undergone ECG, echo, angiograms, CT's, MRI's, possibly everything. Now, my checking his pulse rate or listening to his heart through stethoscope, which is the crudest instrument doesn't make any sense but when I talk to the patient, I always put my finger on his pulse so I get to know what the pulse rate is but more than that, I am touching him. Touch is the most intimate relationship you can have with the other person. You may try to put in a lot of words with all kinds of flowery languages but nothing would convey as strong as a touch. Then I examine him. That act of examination involves touching and listening right? Then when I finally give my advice to him, I always like to put my hand on his shoulders so I'm influencing him. One, by my word, the other is my facial expression, looking at his eyes and third is the touch right? You see, the art of healing is not about prescribing medications. These medicines are standard medicines; every textbook gives what the treatment is. But why some doctors succeed in treating the patients' problem, why others fail because it is not just about

prescribing medications or doing the operation. It's about his confidence that what I am telling him is what he can trust and that will solve his problem. His confidence in my ability to cure him does 50% of the job."- Dr. Devi Shetty, Chairman and Founder, Narayana Health

Key Insights from the Expert Interviews

- **The designing and planning for the requirements of an aging population pressing needs for the existing healthcare system.**
- **The acquisition of soft skills is not given adequate importance in the existing healthcare system.**
- **While there are successful innovations being created within the healthcare system, their scale of impact is still limited to a small group of persons.**
- **The patient is the most vulnerable stakeholder and yet, he/she is not the focus of the components of care and conversation due to the fragmented structure of the existing healthcare system.**
- **Care and dignity are interpreted differently for all the active stakeholders involved in the healthcare system.**

POEMS

There were two hospices that were visited in the course of the research period: Kensington Hospice in Canada[29] and Raksha- The Hospice in India[30]. The investigations were based on POEMS (People, Objects, Environments, Message and Service), a qualitative observation method. Examinations included looking at empty patient rooms, facilities provided (meals, clothing, gowns, last wishes) and structure of the building (use of light and nature and sound). The goal was to observe actively but in a non-intrusive manner. The purpose of using the POEMS method was to gain a better understanding of the physical space where experience of death and dying is most prominent in a healthcare context.

It must be acknowledged that there were some restrictions in terms of where the photos could be taken, as there were patients, doctors and nurses present (for example: the washrooms and kitchen area in the Indian hospice).

---

[29] http://www.kensingtonhealth.org/

[30] http://www.gknmhospital.org/cms51.html

1: Atmosphere

The healthcare teams were extremely friendly and gentle in both the hospices. While there was a sense a calm maintained in the Canadian hospice, the Indian hospice was more informal and laughter could be heard frequently. The focus was clearly on symptom management however, there seemed to be a huge conversational aspect in the interaction between patients and nurses in the Indian hospice.

2: Facilities

Fig. 3: Top and Bottom Left- Patient Room in Kensington Hospice, Canada; Middle and Top Right- Patient Room in Raksha, India; Bottom Right- Detail of the Dedication of the Room Donation (Photographed by Author)

The Canadian hospice had more facilities compared to the Indian hospice. The rooms seemed more private and there was more area to navigate through the space and individualize it. The Indian hospice rooms were smaller, less private and divided by sturdy separators. Caregivers who had lost loved ones there donated most of the elongated, cubicle-like rooms. Dedications were put up on most of these doors. Additionally, there were adequate cloth dividers available to give patients and their caregivers further privacy. The Canadian hospice rooms had private washrooms whereas the Indian hospice had a communal layout for the washrooms.

3: Common Spaces

Fig. 4: Common Area (Living Room, Dining Room and Kitchen) in Kensington Hospice, Canada
(Photographed by Author)

The Canadian hospice had a prominent community space (living room and kitchen set up) while the Indian hospice had a kitchen at the back where the meals were cooked and brought personally to the patients. The Indian hospice had a long hallway between the patient's bedrooms and contained a television set along with basic furniture. However, most of the patients and caregivers were in their rooms.

4: Ventilation and the Role of Nature

Fig. 5: Top Left- Outdoor Area, Raksha, India; Bottom Left and Right- Detail of Roof and Indoor Spa, Kensington Hospice, Canada (Photographed by Author)

The ventilation was more than adequate in both the hospices. Due to the low roof structure, the Indian hospice did not have as much sunlight as the Canadian hospice. However, it was surrounded by lush greenery and patients and nurses were seen stepping out to utilize it. There was a playground, temple and a preparation room at the back of the hospice. Due to the weather and location, the Canadian hospice did not accommodate for open surroundings but as it was a heritage building, it had high ceilings, aesthetically pleasing woodwork and abundant sunlight. It seemed that for the purpose of the weather conditions and symptom management it contained a single-person spa located inside the premise.

The architectural structures of both the hospices appeared sound for the weather conditions and their locations.

5: Location

Fig. 6: Top Left and Center- Entrance, Kensington Hospice, Canada; Top Right and Bottom: Entrance, Raksha, India (Photographed by Author)

Both hospices were located close to the city centre. While the Canadian hospice was situated in a residential neighbourhood, the Indian hospice was situated in a quiet lane close to its primary hospital.

6: Location of Nurses Stations

The Canadian hospice had the nurses' stations on a lower level, creating a medical- free atmosphere around patients' rooms. The Indian hospice operated on a single floor allowing patients, caregivers and the healthcare team to be within close proximity to one another.

7: Appearance of Patients

While most patients in the Indian hospice wore loose fitted, light clothes, some were wearing hospital gowns. For cultural reasons, the women were seen improvising by wearing the sari petticoat below the gown to cover their skin. One of the patients (pants and a sweater) seen in the Canadian hospice was dressed in what was assumed to be the patient's own clothing.

Key Insights from the POEMS Method

- **Both the hospices displayed a balance between a patient- centered and a healthcare- oriented understanding of space and facilities, successfully creating a space for the use of both, soft and hard skills.**
- **While they serviced the needs for patients requiring end of life care, the atmosphere was calming and positive, quite different to the usual stresses normally surrounding death and dying.**

EMERGING THEMES FROM THE SECONDARY RESEARCH

Books

Reference books were researched from the perspective of stakeholders- primarily healthcare physicians, systems thinkers, caregivers and patients. All books were based on field experience and adopted an enquiry-based approach towards the design of a more efficient system. It provided the research question with concrete examples, stakeholder involvement and a wider context of the complexities of global healthcare systems.

1. Being Mortal- Dr. Atul Gawande[31]
2. Design for Care- Dr. Peter Jones[32]
3. The Year of Magical Thinking- Joan Didion[33]
4. Illness- Havi Carel[34]
5. Extracts from An English translation of the Sushruta Samhita[35], based on original Sanskrit text. Edited and published by Kaviraj Kunja Lal Bhishagratna[36]

---

[31] http://atulgawande.com/book/being-mortal/

[32] http://rosenfeldmedia.com/books/design-for-care/

[33] http://www.npr.org/templates/story/story.php?storyId=4956088

[34] http://www.independent.co.uk/news/people/profiles/havi-carel-my-10year-death-sentence-440805.html

1: The Broken System of Healthcare

The overall healthcare system is fundamentally broken. It primarily focuses on illness and is far removed from supporting health and wellness in society. Ironically, the present complex system can be navigated either by an expert or a patient. Health and Wellness seekers are not necessarily the target audience.

> *"We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well- being. And well being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way."*- (Gawande, 2014)

> *"We've created a multitrillion-dollar edifice for dispensing the medical equivalent of lottery tickets- and have only the rudiments of a system to prepare patients for the near certainty those tickets will not win. Hope is not a plan, but hope is our plan."*- (Gawande, 2014)

---

[35] http://en.wikipedia.org/wiki/Sushruta_Samhita

[36] https://archive.org/stream/englishtranslati00susruoft/englishtranslati00susruoft_djvu.txt

2: Care Towards Patients

It is essential to enquire- what do patients value and what do they expect from the healthcare system? From the diagnosis up until end of life, a significant amount of time is spent in finding the most comfortable and effective cure, lifestyle changes and managing financial matters. As a chronically ill person's world grows smaller, physically and mentally, it may seem overwhelming to have a drastic reduction in choices.

"Illness or disability is not an external mark of indiscretion. Nor is it a foreign and detachable part of the ill person. It is intimate and personal, yes, but at the same time it is visible, objectively perceived feature of my body."- (Carel, 2008)

3: Death as a Failure, not a Process

In societies that are reluctant to talk about aging and death, the inevitable process is often treated as a failure. The advancement of medical science and technology has found ways to prolong and redirect death thereby making the act and process of dying more clinical and impersonal.

> *"Technological society has forgotten what scholars call the 'dying role' and its importance to people as life approaches its end. People want to share memories, pass on wisdoms and keepsakes, settle relationships, establish their legacies, make peace with God, and ensure that those who are left behind will be okay. They want to end their stories on their own terms."-*
> (Gawande, 2014)

4: The Healthcare System as an Experimentation Ground

Illness is private, subjective and complex to customize but there is proof that it is a possibility. Many examples of innovations that attempted to bring dignity into the healthcare settings were primarily successful because they focused on delivering the human element. In Gawande's book Being Mortal, he highlights the success of an experiment at the Chase Memorial Nursing Home conducted by Dr. Bill Thomas[37] where plants, animals and children were introduced into the hospital setting. It brought a sense of purpose into the lives of the patients that previously suffered from the 'Three Plagues' of nursing home existence, a term created by Dr. Thomas that comprises of boredom, loneliness and helplessness. While the introduction of these elements brought other logistical complications, it was successful in contributing to a positive culture and developing a sense of responsibility among the patients.

> *"Researchers studied the effects of this program over two years, comparing a variety of measures for Chase's residents with those of residents at another nursing home nearby. Their study found that the number of prescriptions required per resident fell to half that to the control nursing home. Psychotropic drugs for agitation, like Haldol, decreased in particular. The total drug costs fell to just 38 percent of the comparison facility. Death fell 15 percent. The study couldn't*

---

[37] http://usa.ashoka.org/fellow/william-thomas

say why. But Thomas thought he could, "I believe that the difference in death rates can be traced to the fundamental human need for a reason to live.""- (Gawande, 2014)

5: The Complexity of Care

Care is intricate- with its numerous definition, interpretation and implementation models. The role of care differs for patients, caregivers and healthcare teams. Perhaps the broad distinction is that while care is personal and individualized within the circle of care for the patient, the healthcare teams support care by providing medical expertise.

> *"The verb care has acquired different meanings in different health and caring professions, and each profession related to health and human development may subscribe to a different definition and view of care. When settling these differences in meaning and not just discourse, the problem becomes ontological, a question of the reality of caring. This is not simply a conversion of meanings from one field to another. The very meaning of care and caring differs between providers (health practitioners) and between providers and recipients (patients). Design has not yet taken a clear stand in the matter of care. Perhaps we recognize that we cannot own the core when we ourselves still live and work at the periphery."*- (Jones, 2013)

6: Social Stigmas Surrounding Aging and Illness

Society treats illness and aging as malfunctions and breakdowns whereas there should be a focus on understanding that the needs differ. Awareness and education is crucial for the unwell and aging. Similarly, the general public also needs to be made aware and sensitized regarding the needs of this population.

> *"Adaptability takes place on physical, psychological, social and temporal levels. The changes occur simultaneously on several levels and often blend into one another… The tension between the body as active and passive, subject and object, capable and unable, presented with an obstacle and overcoming it, is present in adaptability."*- (Carel, 2008)

7: Holistic versus Specialized Healthcare Models

Unlike traditional medicine, non- traditional medicine like Ayurveda, an ancient Hindu form of medical practice believes that treatments and the path to wellness are achieved by attending to a person holistically (mind, body and spirit) and not separately. Chronic illnesses impact mind, body and spirit and this holistic compilation is hardly addressed in traditional practices of medicine.

> *"Though it is customary and convenient to group apart such phenomena as are termed mental and such of them as are exhibited (...) in society, under the heads of Psychology and Sociology, yet it must be allowed that there are no absolute demarcations in Nature, corresponding to them, and so in the entire Science of Life, psychology and sociology are inseparably linked with Anatomy and Physiology, nay, more, with Pathology and Hygiene and above all with Treatment. In short the Biological Sciences must deal with whatever phenomena are manifested by living matter in whatever condition it is placed. Life in health as well as Life in disease, therefore, fall within the scope of Biology— even life exhibited (...) in Society is not exempted from it."*- (Kaviraj Kunja Lal Bhishagratna, 2008)

Key Insights from Books

- Due to medical advancements, death is viewed today as a failure of the medical process rather than a natural occurrence. This increases society's lack of acceptance of death.
- Around the globe, best practices are not being borrowed from one another.
- Providing Care is a complex matter. The current system finds it difficult to customize Care to suit individual needs. Although there have been successful small and medium scale interventions, the challenge is to create a scalable model that remains relevant and successful in future.

Reports

The reports aligned to the research topic comprised of studies that explored the meaning of patient dignity in long term and hospice settings, interactions with patients and health care teams, alternate therapies like the effects of music, pets, nature and alternate environments on terminally ill patients. The studies were conducted globally and primarily used qualitative approaches to analyze their research. To view the summaries of the reports, refer to APPENDIX B: ‘Related Words on Dignity,’ page: 133.

1: Numerous Interpretations of Dignity

Many of the studies explored attempted to capture an understanding of the meaning of dignity and quality of life that terminally ill patients define and try to live by. While several studies showed a focus on communication, personal connections and conflict resolution, there continues to be a profound and key human drive to feel needed and relevant despite being rendered differently abled due to illness, pain and frailty.

"Life without giving is not life… I think most if not all religions will emphasize this aspect of justice and compassion and so forth… I believe that human beings have this drive toward giving and serving… When we have a chance to reflect (on) what's going on in our lives, we do realize that we need to be of service."

"It makes your life good… to try your best to help other people… It's very good to have the feeling that you're able to help the others… even if I am now tired and sick and stuff, I feel very happy if I can help somebody else."- (Gourdji, I., McVey, L., & Purden, M. 2009)[38]

---

[38] Extracts from interviews conducted in the paper Quality end of Life From a Palliative Care Patient Perspective

2: Research Sensitivities Towards Terminally Ill Patients

While most researchers have used observation and interview based formats to interact with patients in long- term care facilities in order to better understand the role of dignity, some researchers have mentioned that while the information obtained is meaningful, the process can be detrimental to the patients and caregivers due to their limited time with one another. Additionally, the ethical concern is that the patients themselves may not be able to directly benefit from the recommendations based on the research.

> *"Questions have therefore been raised about whether it is ethically sound to ask them to participate in research and to risk 'depriving' them of energy and time that they could have been using to complete 'unfinished business' and to be with their family. There is no possibility that these patients will benefit from the research (...). Again, it has been argued that research in palliative care may therefore be unethical as patients have no opportunity to benefit."-*
> (Janssens & Gordijn 2000)

3: Making Patients Active Stakeholders

While aging is an experience, it might prove to be advantageous to leverage a human-centered approach. By including and giving patients responsibility towards their healthcare plans, the patients are allowed to actively participate and in some cases, have a voice in their wellbeing. Today, with the rise in patient awareness along with the advent of smart technology, patients are more capable than they, themselves and or the healthcare systems think. Furthermore, an aging patient as an active stakeholder could support the creation of empathic tools like aging suits[39] thereby, helping to create better products and services for stakeholders and protocols within the system.

> *" "We regard patients as co-players in their own treatment because we know that their self-care is of utmost importance in the treatment of their disease," says Claus Duedal Pedersen, head of the department for Clinical innovation at OUH.*
>
> *An early study shows that the intense communication between hospital and the patient at home has nearly halved the readmission rate without affecting the mortality rate."*- (Patient's Journey, 2012)[40]

---

[39] http://agelab.mit.edu/agnes-age-gain-now-empathy-system

[40] Extract From A Guide to Patient Journey

4: The Role of Humour

While the process of dying can be trying and emotionally taxing on caregivers and the extended circle of care, research suggests that humour plays many roles in the patient's journey. Examples include the use of humour as a state of acceptance, ease of interaction between nurses and fellow patients, to decrease embarrassment and the threat of the loss of dignity.

> *"Some patients described using humour to counteract threats to dignity. Two patients considered that a loss of dignity was inevitable in certain situations: Mrs. U considered that having her 'bottom wiped' was a loss of dignity which staff could not prevent and Mr. C felt similarly about having a urethral catheter."* - (Baillie, L. 2008)

Key Insights from the Reports

- **Dignity has many interpretations to a patient, depending on the way their state of being is viewed by them, their caregivers and healthcare teams.**
- **Perhaps, interviewing patients in palliative care is a step too late to create positive impact for them and their caregivers.**
- **A focus on actively involving the patient (and their caregivers) could assist in the improvement of healthcare system practices.**
- **Dignity has a spectrum ranging from physical appearance and capabilities to mental and spiritual manifestations. While it may be hard to design for each component, the soft skill training for healthcare teams will enable the staff to recognize and communicate based on the individual's need.**
- **Humour in death and dying may help relieve some of the stress and anxiety about the condition of the self.**

Articles and Talks

This section contains insights and claims from various stakeholders within as well as on the periphery of healthcare in the form of articles and talks. The articles and talks helped the understanding of the relevance of the research question from the perspective of multiple stakeholders – observations, experiences, research and growing innovations in the field.

1: Smart Textiles for Health and Wellness

While technology has brought radical advancements to medical science, it is diverging towards the creation of smart products and services in the textile industry of which many are targeted towards health and wellness and can be managed on a patient level. Examples include self-monitoring wearable's (t-shirts etc), bandages that detect healing and infection through colour changes, clothing that monitors temperature etc.

> *"The global market for smart fabrics and interactive textiles is projected to reach $2.6 billion by the year 2017, according to a new report from Global Industry Analysts Inc. Companies like Oryon Technologies (OTC.BB:ORYN) whose patented technology is trademarked as ELastoLite®; a thin, flexible, crushable, water resistant lighting system which was used in the movie TRON: Legacy and 3M's (MMM) Durel® Electroluminescent Lighting could be a driver behind this sectors growth.*
>
> *Patrick Williams, who is part of Nike's Apparel Innovation Team, was quoted earlier this year before the Smart Fabrics 2012 convention as saying, "There are several opportunities for smart textiles to become a regular part of our lives. As electronics and computing power continue to become cheap and ubiquitous, smart textiles will be integrated to a much higher degree than they are today."*- Marketwire, 2012[41]

---

[41] http://www.marketwired.com/press-release/smart-fabrics-to-reach-26-billion-in-5-years-1663061.htm

2: Shift in Family Dynamics

From a global perspective, societies have noticeably moved away from relying on elders for wisdom, rendering aging people voiceless and without a purpose. It is essential to understand and perhaps even redefine their role in a technology driven era with family dynamics changing so drastically. There is a need for individuals and communities to be more aware and address the changing demographics and family dynamics, without relying solely on the healthcare system.

"In contrast, in traditional societies without writing, older people are the repositories of information. It's their knowledge that spells the difference between survival and death for their whole society in a time of crisis caused by rare events for which only the oldest people alive have had experience. Those, then, are the ways in which older people are useful in traditional societies. Their usefulness varies and contributes to variation in the society's treatment of the elderly."- Jared Diamond, How Societies can Grow Old Better, Ted Talk[42]

---

[42] http://www.ted.com/talks/jared_diamond_how_societies_can_grow_old_better?language=en

3: Patient- Healthcare Team Relationships

While patient self-advocacy is on the rise, there is still a considerable amount of fear in the hierarchy between the patient and doctor. This leads to a breakdown in points of communication and an incomplete understanding of a patient's comprehension of their condition. This could lead the patient into engaging in another round of enquiries with a different healthcare team, abandoning treatment plans or simply going along without an exhaustive understanding, thereby affecting sense of self.

> *"To them, I was a relatively fit, often high-functioning young woman who had a long list of "small" complaints that only occasionally swelled into an acute problem, for which a quick surgical fix was offered (but no reflection on what might be causing it). To me, my life was slowly dissolving into near-constant discomfort and sometimes frightening pain—and terror at losing control. I didn't know how to speak to the doctors with the words that would get them, as I thought of it, "on my side." I steeled myself before appointments, vowing not to leave until I had some answers—yet I never managed to ask even half my questions."*- Meghan O'Rourke, Doctors Tell All—and It's Bad[43]

---

[43] http://www.theatlantic.com/magazine/archive/2014/11/doctors-tell-all-and-its-bad/380785/

4: Death as a Failure

Medicine can delay or redirect death but it is impossible to alter the very act of death itself. However, with the leaping advancements in medical technology, patients and caregivers often demand a ‘cure’ thereby making death a failure.

> *“So we have had tremendous success, and we kind of got caught up in our own success quite a bit, and we started using expressions like "lifesaving." I really apologize to everybody for doing that, because obviously, we don't. What we do is prolong people's lives, and delay death, and redirect death, but we can't, strictly speaking, save lives on any sort of permanent basis.”*- Peter Saul, Let’s Talk About Dying, Ted Talk[44]

---

[44] http://www.ted.com/talks/peter_saul_let_s_talk_about_dying

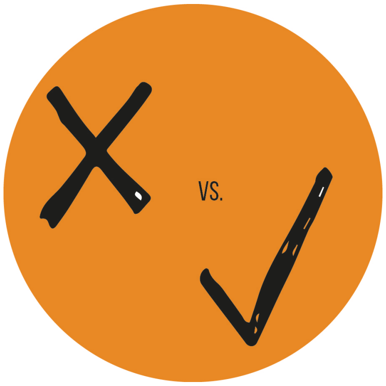
Key Insights from Articles and Talks

- **In many cases, dignity is a secondary focus for the healthcare team. The primary one is to ensure a cure or find one. This creates a strain in a patient- doctor relationship as it may result in a lack of empathy, thereby increasing vulnerability in patients. A patient’s voice often remains unheard.**
- **Patient advocacy and awareness is on the rise that may lead to more products and services that are empowering to patients and their loved ones.**
- **The focus on death as a ‘medical’ problem as opposed to embracing it as a natural, incurable phenomenon.**

THE KEY ELEMENTS

As the research indicates, there are numerous articulations of dignity. Upon analyzing the 28 themes extracted from the primary and secondary research, the following 4 elements were chosen as the prominent ones that seemed pertinent to the research question. They were identified based on the recurrence of themes along with keeping Nordenfelt's concepts of dignity central to the definition of dignity for the research question.

Dignity and Subjectivity of Illness (Illness vs. Wellness)



"I think that a lot of what makes people comfortable is individual, know what I mean? I think that what people are searching for within the institution is to be an individual within it. I think people feel very uncomfortable with being institutionalized because when you're in an institution you become part of a machine and a number within it. You're a number on an x ray or in a chart and I think it's difficult for humans to be that way. What I see a lot of people do who want to make an environment that's more comfortable for them is to bring in things that make them individual. A lot of people will bring in photographs of when they were younger or when they were well. A lot of people will bring blankets and pillows and their sweater that they were always wearing at home and that sort of thing but it's stuff that's very uniquely theirs."- Dr. Kate Whitehead, B. Sc., M.D., CCFP (EM). Palliative Care Physician, Grace Hospital

From an Individual's Perspective: Almost everybody has encountered illness and can empathize with the feeling of vulnerability resulting from being isolated and removed from a familiar, personal surrounding. Tolstoy's character, Ivan Ilyich is portrayed as wanting compassion instead of the expertise of a physician. Some patients may withdraw, while others may ask for additional assistance, however terminal illness requires a deep sense of compassion and empathy. It presents itself as a visible or invisible factor and plays a significant role in impacting the personhood of an individual.

Some of these factors include a sense of identity, keeping control, chosen isolation, feeling safe, relaxation, caring qualities and humour.

From a Systems perspective: Holistic treatments like Ayurveda focus on an approach that believes in viewing the patient as a whole person, i.e. understanding and acknowledging mind, body and soul. Personhood is embedded in the core philosophy of the ancient Hindu medicine system, thereby making healing and wellness the process and the main goal.

Tadd (2004) reported that loneliness, boredom, apathy, desperation and suffering, led to a loss of dignity for older people. Any of these factors can accompany hospitalization, particularly where it is long-term[45].

The psychological impact of living with fear and uncertainty, which can accompany both acute and long-term illness, has also been identified (Raholm and Lindholm, 1999) and Chochinov (2002) reported that fear of dying impacted on dignity. Nordenfelt (2003) elaborated on how illness threatens dignity, suggesting that illness itself leads to loss of a person's self image of having integrity, strength and autonomy. Thus the loss of dignity relates to the loss of an intact and functioning body[46].

> *"If you're treated well - not just like on a conveyor belt - just another one coming in - but as a person."* (Mrs. Y)[47]

---

[45] https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

[46] https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

[47] http://www.sciencedirect.com/science/article/pii/S0020748908002083

Healthcare trends suggest that technological advancements are enabling patients and caregivers to manage care in the comfort of their own homes. This may help patients feel more comfortable and empowered. By having familiar objects and memories surrounding them, which may be viewed as a contrast to the setting of long-term care[48].

In the case study, 'Patient dignity in an acute hospital setting: A case study' conducted by L Baillie in 2008[49], patients were asked to state the meaning of dignity. Words such as privacy, comfort and respect were key in their understanding of dignity. Some even commented on being in control of the situation. This may prove to be complicated as there are varying degrees in the ability of a patient to be in control. If they are unable to, then a family member or healthcare professional would usually takes over.

Emerging Insight: The importance and pressing requirement of soft skill training to accompany the hard skills imparted to the healthcare teams.

---

[48] http://www.saintelizabeth.com/About-Saint-Elizabeth/Media/News/January-2015/Samsung-Canada-and-Saint-Elizabeth-Team-Up-to-Expa.aspx

[49] https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

Dignity and Communication

On a global level, there is a demand on the healthcare system to provide efficient and effective care. With the number of terminally ill patients rising, the doctors are restricted for time. In most cases when they meet with their patient, they spend a substandard amount of time on a consult while browsing through the history and adding next steps towards the treatment[50].

Palliative care is a sector in healthcare that believes that time spent with patients and listening to them is extremely crucial in effectively discharging their role. It is this belief that makes hospice care extremely meaningful to patients and caregivers.

In my interview with Dr. Devi Shetty[51], global pioneer in medicine and founder of Narayana Hrudalayala[52], spoke about the benefits of India having a talking culture- a culture that constantly engages and interacts. This may be the answer to address social

---

[50] http://www.theatlantic.com/magazine/archive/2014/11/doctors-tell-all-and-its-bad/380785/
[51] Interview with Dr. Devi Shetty, Director and Founder of Narayana Hrudalayala, Bangalore, India
[52] http://www.narayanahealth.org/

isolation and an indicator of the importance of communication. A combination of distance and lack of interaction can magnify a sense of loneliness. This is a grave concern for caregivers especially when dealing with aging or ailing family members.

Emerging Insight: Patients with complex illnesses require interaction as their care is spread across the fragmented components within the healthcare system. Through engagement, patients can be active stakeholders in their own care as opposed to being a vulnerable and perhaps a passive receiver of care.

Dignity and Physical Appearance

"We do have hospital gowns. One of our staff members is a seamstress so she made hospital gowns for our residents so they're not the typical blue or hospital blue colour. They're made with different floral cottons and different patterns and so when you put one on you don't feel like it's a hospital gown, you feel like it's a blouse or a shirt or something even though it is a hospital gown. But she put a little lace around the collar and made it nice and so I think it was really one of things we thought was just so special. Yes, the practicality of the hospital gown is there but it's done with colour and design and I think it really helped. Because people with a life limiting illness (most of our patients have cancer) their body image is really changed and it's very difficult to look at yourself in the mirror and you're very very thin or your hair is falling out so using fabric that's not just traditional or using make up or trying to help them spruce up their appearance makes them feel better about themselves." - Debbie Emmerson, Kensington Hospice, Director of Hospice Care

Although it does not play a very prominent role in palliative care, a popular example in the healthcare system is the hospital gown and the lack of dignity that surrounds it. The traditional and widely used structure often exposes body parts, making patients feel uneasy and embarrassed. A patient first encounters a hospital gown during a visit to a doctor's office and the gown represents the first bump of reality of being ill. It also emphasizes a clear distinction in hierarchy between the healthcare team and patient thereby making illness the main focus.

In the study, 'Patient dignity in an acute hospital setting: A case study' conducted by L Baillie in 2008[53], an entire sub section is dedicated to understanding the patient's point of view of physical presentation. Here, some patients felt that being exposed made them uncomfortable. When asked to clarify the link between dignity and being presented appropriately, one of the participants stated:

"Not showing body parts."- (Mrs. O11)[54]

Patients' perceptions of bodily exposure can vary, for example, Matiti (2002) identified that older patients were more self conscious about exposure and she highlighted societal acceptance towards most of the male body being exposed publicly. Several studies have found that hospital gowns or nightclothes put privacy of the body at risk as they are ill-fitting and expose the back (Bauer, 1994; Denner, 2004; Matiti, 2002; Matiti and Sharman, 1999; Maxwell, 2000; Tadd, 2005; Walsh and Kowanko, 2002; Woogara, 2005). In addition, Matiti (2002) identified that as gowns are done up at the back they render patients helpless. Bodily exposure also extends to exposure of body products with publicly displayed urine bags being considered a loss of dignity (Volker 2004) and privacy (Bauer, 1994; Woogara, 2004). Thus there are a variety of ways in which hospital experiences result in bodily exposure and loss in dignity[55].

---

[53] https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

[54] http://www.sciencedirect.com/science/article/pii/S0020748908002083

[55] https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

While one might claim that the hospital gown is designed perfectly for healthcare teams to access patients during an emergency, a solution to reduce the risk of infection and is a cost effective solution to provide frequently changeable clothing, it is clear that the gown lacks a patient- centered approach, thereby making it lack the fundamental human element required in care- dignity and compassion[56].

> *"Dignity is about feeling that you have some being of your own and that you're not under pressure to do things, in relation to what tests are carried out on you, what you have to wear."* (Mr. O3)[57]

Many case studies suggest that patient dignity is closely connected to their physical appearance in hospital settings. It is also hard to be seen as a patient in front of caregivers, well-wishers and fellow patients. Retired palliative care nurse Elaine Moralee indicated how many patients are very concerned about their hair, makeup and attire. Dr. Alka Ganesh, consultant geriatrician, mentioned how using cultural inspiration from traditional garments may help to design better patient clothing. She explains:

> *"I personally favour an Indian women's hospital gown which is two piece. The lower part is a long loose skirt gathered at the waist with a tape. This is familiar to all as part of the traditional saree[58] underskirt. The upper half is a loose blouse without a front or back opening, and short sleeves. Most women would like a small piece of narrow material such as a Malabar towel to cover the chest. For examination purposes, the lower part can be loosened to expose the abdomen without exposing the upper half of the body; similarly raising a loose blouse to examine the chest, keeps the lower torso covered adequately."*- Dr. Alka Ganesh, Consultant Geriatrician, India

---

[56] http://www.huffingtonpost.com/2014/09/23/pants-hospital-gowns_n_5870410.html

[57] http://www.sciencedirect.com/science/article/pii/S0020748908002083

[58] A long, unstitched garment made from cotton or silk traditionally worn by women from South Asia

Emerging Insight: Illness can bring undesired physical changes that can cause a loss in dignity. Perhaps anticipated changes in the physical can be addressed in advance, with compassion.

Dignity and Dexterity

A sense of being in control creates a feeling of independence as it retains a sense of self. For many chronically ill patients, the lack of dexterity is a prominent part of their illness. Research suggests that bodies also become sensitive to touch, movement and temperature. It reduces the sense of control considerably, which can be additional and negative side effects to the illness itself[59].

By not being able to perform everyday activities autonomously, a person could feel extremely embarrassed and undignified. In long-term situations, this would mean requiring support on a regular basis, affecting one's personhood.

In Ayurveda, touch is an extremely important aspect of healing the body, mind and soul. Aside from the massages that are conducted for medical purposes, some Ayurvedic practices[60] demonstrate how certain natural fabrics or dyes have healing elements that

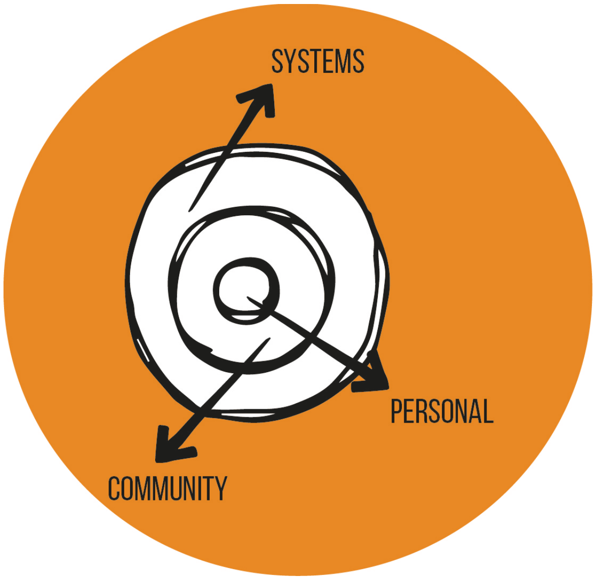
---

[59] http://ayuvastra.ie/
[60] http://ayuvastra.ie/

are known to make a patient more comfortable and positive with regard to pain and dexterity.

Emerging Insight: A sense of control is almost synonymous with the sense of self, it is perhaps the most challenging aspect to design and provide to patients.

EXISTING INNOVATIONS WITHIN THE ECOSYSTEM OF DIGNITY



After extracting 28 themes from the primary and secondary research and identifying the 4 key elements, the next step was to conduct a scan and identify existing innovations within the ecosystem of dignity. The investigation found that the innovations could be differentiated through their scale of impact from a systems, community and personal standpoints. It was divided in this manner in order to understand where the changes are happening and what value they are hoping to bring into the existing stigmatized culture surrounding death and dying.

			
(INDIVIDUAL, SYSTEMS LEVEL)	(INDIVIDUAL, COMMUNITY, SYSTEMS LEVEL)	(INDIVIDUAL, COMMUNITY LEVEL)	(INDIVIDUAL LEVEL)
BRINGING DIGNITY TO HOSPITAL GOWNS	HOSPITABLE HOSPICE	DEATH CAFE	PERSONHOOD IN DEMENTIA
EUTHANASIA AND ASSISTED SUICIDE		THE ORDER OF A GOOD DEATH	
MY GIFT OF GRACE			

Fig.7: Categories of Existing Innovations Within the Ecosystem of Dignity

Bringing Dignity to Hospital Gowns

For several decades, patients have complained about the form of the hospital gown. There have been incremental steps towards solving the distress and patients continue to feel stripped off their dignity. In a recent article, the gown was compared to the prison jumpsuit, reflecting how it reduces the sense of self, challenge one's identity, changes a power dynamic and amplifies the feeling of illness[61].

One might contend that the time spent in a gown is brief therefore, making the experience bearable during a checkup or a test. However, it is the first bump of reality when a person is being diagnosed with what might possibly be a life changing illness- more so for the patient but also includes the caregivers. In palliative care however, patients encounter the gown less frequently. In a hospital setting, several factors such as bed sores, lengthy hours spent horizontally, administering medicine, cleaning and

---

[61] http://news.nationalpost.com/2014/10/01/the-dreaded-hospital-gown-described-as-health-cares-prison-jumpsuit-often-imposed-on-patients-needlessly-study/

dressing a patient, emergency disrobing lead to the frequent and in some cases require an almost constant use of the gown. However, this physically and mentally strips off the patient's self-respect, making illness more noticeable to them, caregivers and other patients. To view the remaining examples identified, refer to the section, APPENDIX C 'Innovations in Gown Design,' page: 149

Observation: **The hospital gown is an excellent example of a piece of clothing where so many stakeholders are impacted by its form and function. Perhaps, it is due to the multiple needs that there have been incremental steps taken towards creating design solutions.**

Euthanasia and Assisted Suicide

"One of my greatest fears is to have to rely on others for all my needs. I do not want to live in a bedridden state, stripped of my dignity and independence. I have decided I want to die when I no longer have quality of life."- Gloria Taylor, Co-Plaintiff in the fight for the Right to Die[62]

Globally, euthanasia has been a burning debate for decades now. While countries like the Netherlands have been practicing it since 1973, it is treated as a stigma everywhere else. However, more patients are aware and are demanding dignity towards end-of-life or due to a terminal illness. While in most cases, it is due to a terminal illness, finances can also play a large role in making a decision[63].

In Gorsuch's book, "The Future of Assisted Suicide and Euthanasia," he "points out that the provision in law that a patient be "terminally ill" in order to qualify for assisted suicide has little rational basis in a policy that places such tremendous emphasis on personal autonomy. After all, if "choice" is the issue, and killing is determined to be an acceptable response to the problem of human suffering, what does dying have to do with it? Many people who are not terminally ill suffer more intensely—and for a far longer period—than do the terminally ill. This being so, why should they be refused access to "aid in dying[64]"?"

---

[62] http://www.dyingwithdignity.ca/
[63] http://www.discovery.org/a/4000
[64] http://www.discovery.org/a/4000

On the other hand, crucial questions arise and often relate to role of the circle of care. For instance, are medical doctors responsible because they have the ability and knowledge to prolong life?

Recently, 29-year-old Brittany Maynard chose to die with dignity, as she was terminally ill. It was executed by taking a lethal medication prescribed to her under Oregon's Death With Dignity Act.

> *"I am not suicidal," she wrote in an op-ed today for CNN. "I do not want to die. But I am dying. And I want to die on my own terms."*- Brittany Maynard[65]

In 1972 in Canada, suicide was removed from the criminal code and it has been legal ever since. However, it remains illegal for anyone to counsel, aid or abet another person to end his or her own life. On July 4th, 2014, in the Carter vs. Attorney General for Canada, the Supreme Court of Canada Ruled that Dying With Dignity has been given the right to intervene in the case of Gloria Taylor (Carter et. al. vs. Attorney General for Canada[66]). More recently, the Supreme Court ruled that Canadians have the right to doctor-assisted suicide[67].

Observation: **There is a rise in demanding dignity in terminal illness at a systems level. The individuals who are have been successful examples have conveyed the awareness to all the levels. This is a strong signal that indicates**

---

[65] http://www.cbc.ca/newsblogs/yourcommunity/2014/10/brittany-maynard-29-year-old-cancer-patient-explains-her-choice-to-die-with-dignity.html

[66] http://www.dyingwithdignity.ca/

[67] http://www.cbc.ca/news/politics/supreme-court-says-yes-to-doctor-assisted-suicide-in-specific-cases-1.2947487

shifts in policy and health care, where change is often slow due to the scale and complex protocols within the system. If it is carried out with a long-term goal for change, like the Canadian example, it has the chance to percolate into communities and individuals in a structured way.

Hospitable Hospice

Fuel For is a Singapore based company that has developed a vision for the Hospitable Hospice[68] of the future. The 7 concepts articulated support a more open, personal and easier-to-navigate end-of-life experience and 24 universal experience design principles provide the building blocks for creating future services and spaces.

It was in close collaboration with project partners Assisi Hospice, Dover Park Hospice and St Joseph's Home and Hospice. They attempted to understand the hospice sector in Singapore by conducting ethnographic observations, co-designing workshops and in-depth interviews with patients, families, care teams and experts. As a result, the Hospitable Hospice offers critical new thinking and a refreshing vision with which to re-imagine future hospices and end-of-life care services. The client was LIEN Foundation & ACM Foundation, Singapore.

Observation: **Here, there is an attempt to rethinking Hospital foundations from a patient, caregiver and healthcare centered manner. While it proposes transformational change, it will take time to attend to pressing concerns. Would it contain certain products and services that can be incorporated and tested within existing structures?**

---

[68] Extract adapted from http://www.fuelfor.net/

Death Café

At a Death Cafe[69] people, often strangers, gather to eat cake, drink tea and discuss death. The objective is 'to increase awareness of death with a view to helping people make the most of their (finite) lives.' The model was developed by Jon Underwood and Sue Barsky Reid based on the ideas of Bernard Crettaz. The concept has spread quickly across Europe, North America and Australasia.

A Death Cafe is a social franchise and a group directed discussion of death with no agenda, objectives or themes. It is a discussion group rather than a grief support or counselling session.

Death Cafes are always offered:

- On a not for profit basis
- In an accessible, respectful and confidential space
- With no intention of leading people to any conclusion, product or course of action

Observation: **While the death cafe attempts to bring people together and initiate the conversation about death and dying, it lacks a 'take-away.' The concern is that after 1-2 sessions, does it continue to build meaning and challenge stigmas or does it become redundant?**

---

[69] Extract adapted from http://deathcafe.com/

My Gift of Grace

My Gift of Grace[70] is a conversation game and was designed by The Action Mill. It is used around the world in hospitals, hospices and homes. In the box, there is an instruction sheet, 47 question cards and 24 thank you chips. During each turn, all the players have a chance to share their answers to the same question, trading chips as part of the game play. The cards cover many topics about living and dying well.

It can be played by families, co-workers, teams, strangers or a mix of any of these. There are no age restrictions or experiences that one needs to have before it is played. The game adjusts itself to the level of comfort of the players and to how long a group wishes to play, ranging from a short game of 20 minutes to a game that lasts for hours.

Observation: **The questions on the cards function as great prompts but the gamification aspect may not be appealing for individuals and family members. The idea of a game may be offensive or upsetting to those who are already death denying or have lost a loved in tragic circumstances. Perhaps, using it for training purposes might be the most beneficial use of it.**

---

[70] Extract from http://mygiftofgrace.com/

Personhood in Dementia

The aim of the Jayne Wallace's research was to use the fact that jewellery objects have the ability to accompany an individual through their experiences and act as anchor points to events in ones lives and consequently ones sense of self[71] [72]. "The hope is that the jewellery pieces will aid an empathic engagement with people who are living with memory loss as well as being tangible and reassuring aids for people with dementia in their recollections of who they are and what they have experienced."

> *"The common ground shared by art jewellers and philosophers of dementia care is the potential for the body to be seen as something intrinsic to self-identity. In contemporary jewellery the body is valued as a very special site for objects and as an emotionally intimate place. In philosophy of dementia care the body is considered in similar terms, as a unique aspect of someone's identity and means to communicate this. The role of the body becomes acute in dementia as something that can represent identity when other means, such as speech, have dissolved. Therefore there is great potential for jewellery objects to bring significant benefits to someone with dementia. Objects of this kind could make a genuine and profound difference to a dementia sufferer's internal and external representation of self and bring significant benefits in the maintenance of personhood. In this way such objects can act as agents for change in the way families or communities consider the maintenance of personhood in dementia."- Jayne Wallace*[73]

Observation: **There is such beauty and respect contained within this small-scale project. It has the potential to be adapted to a patient's wider circle of care. Moreover, it is a fine example of creating an activity between patient and caregiver that is a rare arrangement at a community or systems level.**

---

[71] http://www.digitaljewellery.com/jaynewallace/home.html

[72] http://vimeo.com/19431560

[73] http://www.digitaljewellery.com/jaynewallace/personhood_in_dementia.html

The Order of the Good Death

The Order of the Good Death[74] is a group of funeral industry professionals, academics and artists exploring ways to prepare a death phobic culture for their inevitable mortality. It was founded in January 2011 by Caitlin Doughty, a mortician and writer in Los Angeles, CA.

The Order is about making death a part of life. That means committing to understand fears and stigmas about death. Accepting that death itself is natural, but the death anxiety and terror of modern culture are not.

Observation: It is extremely humorous, entertaining and informative. However it is uncertain if the viewer has a participatory role. The team has academic and experience in the field of death and dying so there is a strong network base.

---

[74] Extract from http://www.orderofthegooddeath.com/

KEY INSIGHTS: A SUMMARY

"You'll be surprised it (Care Companion[75]) was launched about a year ago. Last month the British Parliamentary Commission on innovation rated Care Companion as the most innovative program in healthcare in the past one- decade. How much did it cost? It cost nothing, just the way of thinking. Now this will become a standard protocol all over the world. In the Western countries, the cost of creating an institution mechanism to take care of a sick patient after a heart surgery or a brain operation is very expensive whereas here you have somebody who is willing to care for the patient free of cost with lots of love and affection. All you need to do is to educate them and in 4 days, they are a captive audience."- Dr. Devi Shetty, Chairman and Founder, Narayana Health

When Dr. Devi Shetty mentioned the motivation behind Care Companion, it was clear that it seemed important to connect the social systems to the healthcare system. It also served a broader purpose of bridging the need to bring soft and hard skills together. Perhaps some components pertaining to end of life quality and care should be directed back to individuals and communities so that they are more empowered when the time comes to understanding their rights better and planning for the good death that seems to be a universal aspiration.

---

[75] For details, refer to APPENDIX D: Care Companion, page: 157

Based on reports that addressed the ethical concerns of interviewing palliative care patients, starting these conversations well before it is time, might be an effective way to conduct research during a more active phase with participants prior to their end of life stage. While it might generate multiple themes due to the frequent change in choice, through qualitative analysis it may create perspectives to inform caregivers and the healthcare teams anticipating the needs of patients.

"The designer role, while still a creative activity, leads by facilitation and co- creation with stakeholders in designing care service. They convene and lead circles of stakeholders, designers, care providers, and patients to collectively gain and visualize a deep understanding of complex issues."- (Jones, 2013)

"It's rare, very rare, it's far more rare than the request that somebody doesn't want to have that conversation or can't handle it and I think that that's true in the elderly."- Kate Whitehead, B. Sc., M.D., CCFP (EM). Palliative Care Physician, Grace Hospital

Based on primary and secondary data, one of the biggest challenges found is that illness is subjective thereby making it challenging to understand and provide for it. Healthcare teams have roles to play that support dignity, while the caregivers are somewhere between the patient and healthcare teams. They are "the people who are left behind" who live in the memory of the way their loved ones departed. In my interview with Palliative Pain and Symptom Management Consultant, Dr. Anita Walani, she spoke of how some caregivers often doubt their own actions and decisions and look for comfort in the healthcare teams for assurance of "doing the right thing."

Retired palliative care nurse Elaine Moralee mentioned that several people liked to personalize spaces and wanted a sense a comfort around them. Letters, photographs and music were the most prominent items. In some cases, a desire to see pets[76] was a priority and came up in conversations with two other experts.

There is value in understanding aging as a learning and seems to be a relevant insight with regard to how one designs for the needs of the aging population. They are a huge, undervalued resource and in order to design for their needs, an inclusive, co-creative approach may be beneficial to all stakeholders involved. By using a combination of empathy and self-reflection, these components could help design better products and services. A popular example is the AGNES developed by MIT. It is a suit worn by students, product developers, designers, engineers, marketing, planners, architects, packaging engineers, and others to better understand the physical challenges associated with aging[77].

Based on the insights gathered from the research, if one were to view it by using the formula for change- D x V x F > R[78] [79], it is clear that there is a sense of dissatisfaction in the way death is perceived and dealt with. There is evidence that an ecosystem of dignity exists and strives to address needs at a personal, community and a systems level. Perhaps the challenge is to address and test the resistance of the stigma in order to gauge and overtake it. This could explain why so many innovations lie closer to personal and community levels as the testing grounds are easier to permeate.

---

[76] Example: http://www.dailymail.co.uk/news/article-2827489/Pictured-prime-horse-loving-grandmother-dying-wish-favourite-animal-one-time.html

[77] http://agelab.mit.edu/agnes-age-gain-now-empathy-system

[78] Where:
D – Signifies the degree of dissatisfaction with the current situation.
V – The vision of what can be done and what is possible.
F – A plan of the first concrete steps that can be taken towards materializing the vision.
R – The resistance to change.

[79] http://www.brighthubpm.com/change-management/122241-gleichers-formula-a-scientific-approach-to-change/

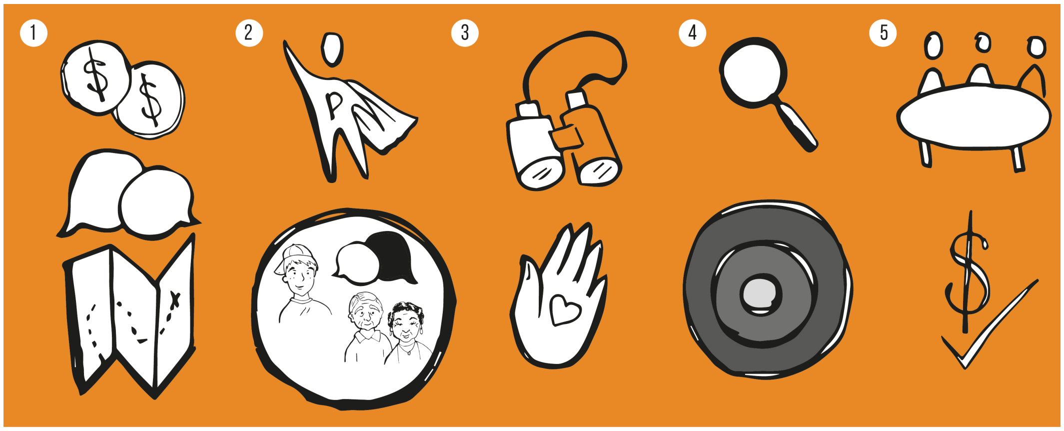
With trends that point to patient empowerment and patient- centered innovations as possible futures, it is crucial for all the stakeholders involved to be invested in healthcare. When one observes the values in Maslow's hierarchy[80], it is interesting to note that if the ultimate destination is 'self- realization', then why is it that we fail to prepare for the final, unknown destination and explore options about dying a good death? Why do not choices in life translate into choices in the act of dying? The lack of planning for death and dying is evident from the research gathered and depicts a short-term mindset towards the event, which lessens the priority towards preparation and planning. In a society crippled by the stigma and fear of aging and dying, it is crucial to help change the mindset of this inevitable process.

---

[80] http://www.simplypsychology.org/maslow.html

DESIGN CRITERIA

Based on the insights gathered and analyzed from the primary and secondary data and the scan on the innovations within the ecosystem of dignity, given below are the design criteria identified that may support a possible innovation in assisting with society's stigmatized approach to death and dying. The rationale of the design criteria was to identify and contain specific goals that the solution must follow in order for it to succeed.



1. Affordable, engaging and easy to comprehend.
2. Foster patient empowerment (and personalization) through collaboration- an opportunity to co-create with the aging population, thereby fostering healthy inter-generational collaboration.
3. To foresee vulnerability and design ahead of the need.

4. To find an effective way to explore and gain insights within the ecosystem of dignity.
5. Beneficial to all stakeholders.

PROPOSED SOLUTION

"Talking is one of the best forms of healing we grossly underestimate."- Dr. Devi Shetty,
Chairman and Founder, Narayana Health

In palliative care, death is managed in a unique manner. It involves actively listening and providing comfort to families that are facing extreme emotional trauma. Most importantly, it includes the priorities touched upon in the 4 key elements from the themes gathered from the primary and secondary research.

During the interviews, many of the experts referred to death as the last chapter and a final destination while discussing the importance of planning for it. The idea of a journey was an extremely powerful metaphor and I began to explore it as a concept for preparation. This also brought up the relation to society's acceptance- when is the right time? What might preparation mean to patients and loved ones?

The approach was to create a cultural probe. It is a technique used to inspire ideas in a design process. It serves as a means of gathering inspirational data about people's lives, values and thoughts[81]. This method of capturing data proved to be an appropriate tool for the proposed solution given below.

In an attempt to remove words like death, aging and illness, there is potential in substituting the fear and stigma and initiating a healthy discussion about end of life in order to preserve the sense of self. Dr. Anita Walani, Palliative Pain and Symptom

---

[81] http://en.wikipedia.org/wiki/Cultural_probe

Management Consultant and Debbie Emmerson spoke of how during the stage of end of life; nothing is necessarily a restriction (unless it is life threatening). Dr. Walani explained in our conversation:

> *"We do a lot of things in hospice palliative care. It's like why can't they have alcohol because we have people who are dying because they have liver toxicity and they drank their livers to death. So now does it make sense to tell them that they can't have alcohol? No, because at the hospice we have beer in our fridge and people can go in and pick up their beer. We had an Italian guy I remember and he didn't want to eat anything at this point. He said, "I'm dying anyways, I'm not eating but I want my bottle of wine." So he would have two bottles of wine every day and he wasn't drunk because that's what he was used to. He would sit there and he would talk to you but he would have his glass of wine in his hand and that's what kept him happy. The way we look at it in hospice palliative care is 'so what' at this point. Does it really matter if they have what they want to have? Is it really going to kill them?"*- Dr. Anita Walani, BScN, RN, M.Ed(c), CHPCN(c), Palliative Pain and Symptom Management Consultant, Toronto

What do you do when you set off on a journey?

You pack (a suitcase)

The Suitcase Project has been approached as a cultural probe, designed to initiate conversation between the patient and the circle of care in order to support personhood. By using a rather universal and relatable object like the suitcase, it hopes create a less intimidating ground for empathic engagement. The suitcase aspires to be a tangible conversational artefact that can help tell stories and ease the burden of conversation on death. It attempts to bring a ritualistic exchange with the connection to reflection and patient empowerment. This aligns closely with rituals like grave goods[82] and the baby bag for birthing[83] that enable preparation and meaning to the act of itself. In addition, it serves as a sensorial experience through the act of engaging with personal belongings and preferences. For instance, while a soft textured blanket is a physical object, it could contain emotional value for a person. By embracing an empathic approach, it allows for sensorial interaction, contemplation and conversation.

---

[82] http://en.wikipedia.org/wiki/Grave_goods

[83] http://www.babycentre.co.uk/what-to-pack-in-your-hospital-bag

The steps are designed to follow the pattern of:

Enquiry

Where the conversation is initiated by asking about what the suitcase for the final journey might contain. This may be done individually or in groups (e.g., families, healthcare teams, multiple stakeholder groups).

Discovery

Through conversation, the individuals or the group would learn about important aspects of personal choice. It could also be a reciprocal process and could be documented based on the requirements.

Co-creation

After gaining access to the information, it could be stored in a manner best suited to the individual or group. If there are items that are tangible then they could be stored separately. If they are not, then there can be an action plan framed on how to achieve it. For e.g., if the wish to access a pet were a non- negotiable item in the suitcase during the end of life, then it would be important to find out which hospices allow pets. By using the dialogic route, the participants would engage with the system of healthcare prior to being admitted and more importantly, as persons seeking information and not vulnerable patients.

Approach

"We consider the use of Design Probes as tools for design and understanding. As such, design probes are objects that are usually small in scale, whose materiality and form are designed to relate specifically to a particular question and context, posing a question through gentle provocative, creative means offering a participant intriguing ways to consider a question and form a response through the act of completing the probe creatively."- Wallace, J., McCarthy, J., C. Wright, P., & Olivier, P. (2013)[84]

Given that the very nature of probes is intimate and in order to understand the meaning of qualitative data gathered, it would be crucial to identify focus groups and facilitate a pilot project. This would enable evaluating the design criteria, observing how people use the probe and hopefully finding themes in their suitcases. From the hope of fostering effective communication and co-creation, this could help categorize the data into the ecosystems of dignity at a personal, community and systems level and create more focussed design solutions (products and services) for end of life care.

---

[84] Making Design Probes Work by Jayne Wallace, John McCarthy, Peter C. Wright and Patrick Olivier

Possible Outcomes

While facilitating this final journey, it may benefit patient and stakeholders involved, to begin communicating sooner, before the resistance becomes strong.

"Learning from empathy is a first step toward caring, by allowing us to understand how other people experience the situations we are committed to improving."- (Jones, 2013)[85]

---

[85] From http://rosenfeldmedia.com/books/design-for-care/

Patients

As mentioned earlier, dignity has numerous interpretations for different people. The items in the 'suitcase' could result in extending those conversations, thereby conveying meaning, sharing stories and celebrating life.

By discussing what patients want to carry in their suitcase, it could encourage them to be more aware and curious about their rights in end of life care. Often, while in the state of vulnerability, patients may not feel entitled to request for their choices. Asking and being aware may empower that sense of entitlement, thereby focusing on personhood. This sense of self could serve to individualize rooms, bedding and atmosphere and would be meaningful if patients were not in their own homes and in end of life care facilities. However, the suitcase could also benefit patients who would prefer to die at home by enhancing their surroundings with their preferences.

Caregivers

In many of the expert interviews, it was mentioned that while the process of death and dying is significant for the patient, it could have a long- lasting mental and emotional impact on caregivers. Additionally, there is a sense of guilt during the dying process as families may not have conversed freely about it, thereby having to rely heavily on improvisation and designing in the moment of care[86]. Through the proposed solution, they can be better prepared through conversation and co-creation and through the sense of knowing and doing, strengthen their bond and enrich the loved ones experience. It is important to note that The Suitcase Project does not intend to alter the sense of loss of a loved one, but to focus on the preparation for a good death instead.

---

[86] There are times when the situation is unavoidable. The proposed solution is not suggesting that this is a full-proof method to solve improvisation.

Healthcare Teams in Palliative Care

The choices can be discussed with the healthcare teams to help them be better acquainted with their patients and can even come into use at a time where the caregivers and patients may not be in the optimum frame of mind. By using it as a tool for communication, the palliative healthcare teams could gain a better understanding of personhood thereby creating an enhanced layer of value and access. This could mean that the families could truly rely on the healthcare team to ‘support’ care through meaningful communication and symptom management. In the diagram given below, one can observe the relationship between the dignity of a person and their decline in two long-term care settings. The Suitcase Project hopes to start the conversation about dignity before entering the active dying phase, thereby keeping personhood constant during the process of active dying and only tapering at the very end along with the departure of the person.

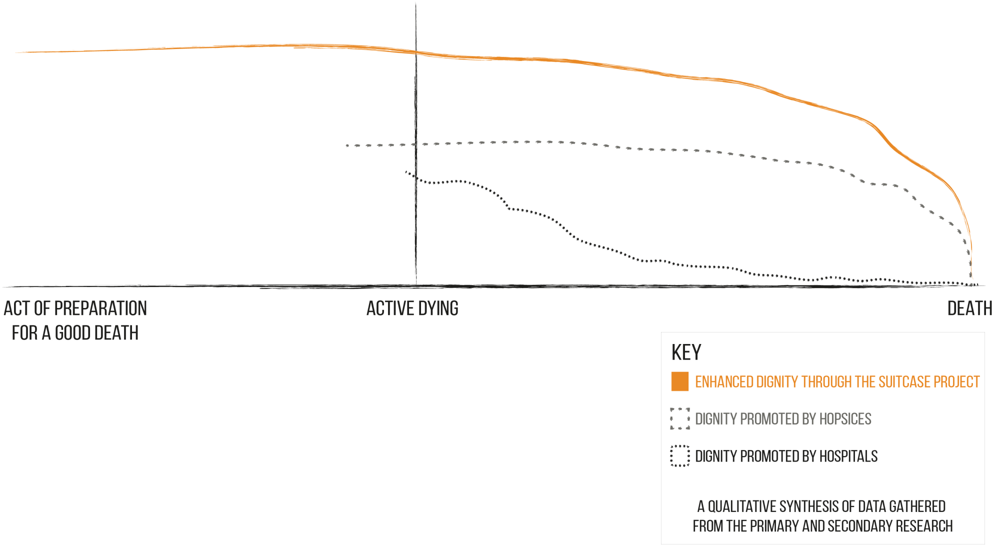


Fig. 8: Enhanced Dignity Though The Suitcase Project

Within the context of healthcare services, the suitcase could potentially be shared with the healthcare teams prior to the patient being admitted. It would help them anticipate what would make a patient comfortable. For example, having a patient's pet present to ease the transition or familiar music and items placed in the room for comfort. The concept of customized service could create a meaningful experience for patients and their loved ones, while it furthers the soft skill training for the healthcare teams.

Outside the Healthcare System

The patterns in the data could inform and create better design solutions (products and services) in palliative care. For e.g., new fabrics and linen to prevent bedsores, visual patterns or a language that show patient’s details and status (in pain, no visitors; want fresh clothes etc.)

Example: An Autoethnographic Approach

Due to ethics restrictions, an autoethnographic approach was used to test the proposed recommendation. The purpose of this social research method was to participate, describe, evaluate and document the experience in order to familiarize oneself and test the solution. It must be acknowledged that since I was physically away from home, certain items were found locally for the purpose of creating the suitcase.

While it was challenging to think about the contents of the suitcase, I restricted the number of items to 15. This helped me gather my thoughts and identify the most important physical and emotional needs for myself, as well as my state of mind for my caregivers and healthcare teams. For the purpose of the exercise, I envisioned my parents, brother and sister- in- law as the primary caregivers.

The intangible items posed in the form of questions are the important invisible components and they require research and coordination on a very practical and systems level.

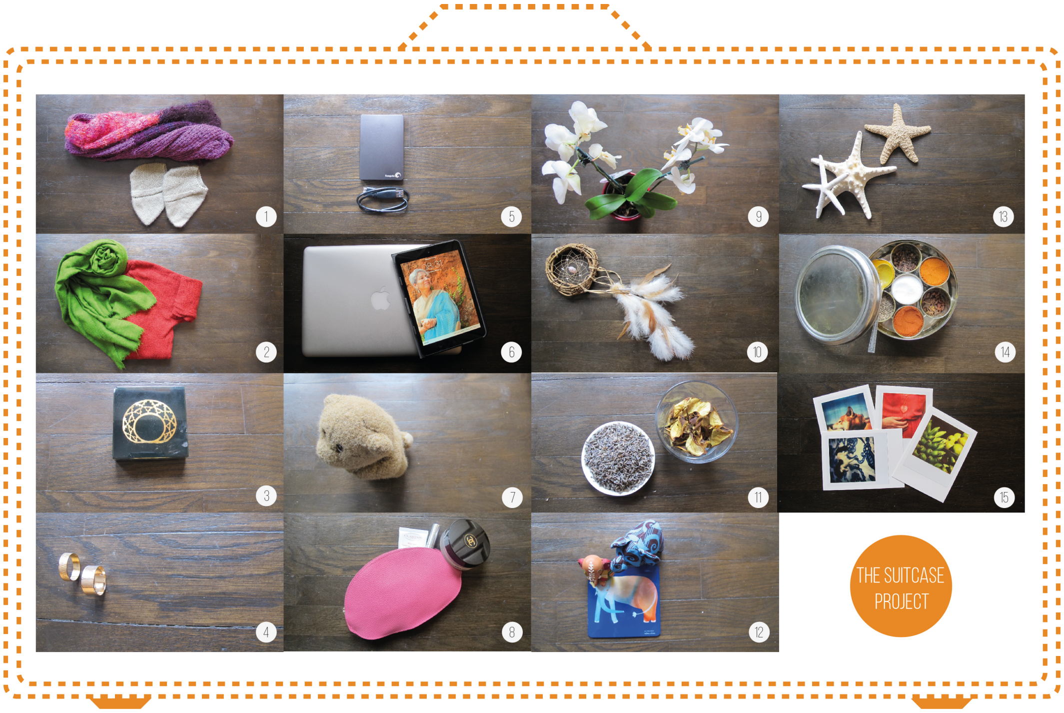


Fig. 9: An Autoethnographic Approach to The Suitcase Project (Photographed by Author)

Item 1: Hand Knitted socks and scarf- made by my grandmother and mother.

Item 2: Comfort Clothing- gifts from my grandmother and mother.

Item 3: Lucky Charm- originally my father's. A gift from him that is always on my bedside.

Item 4: Rings- My mother's engagement rings that are with me at all times.

Items 5 & 6: Computer and ipad- representational of connections to ongoing projects and a virtual social world.

Item 7: Soft toy- Named 'Bub' and has been with me since I was 7. A gift from my father.

Item 8: Makeup- an attempt to conceal illness.

Item 9: Flowers and Plants- a reminder of my Mother's bonsai garden in India.

Item 10: A Dream Catcher- for sending and receiving good thoughts.

Item 11: Lavender- a familiar and favourite fragrance.

Item 12. Assorted Elephants- for faith and a sense of beauty.

Item 13: The Starfish- symbolic of my connection to sand and water.

Item 14: The Spice Box- representational of home cooked food, the square dining table, family meals and lively memories.
Item 15: Postcards- it is for the last and final notes with enough space for a poem or a few lines.

As I began to photograph and assemble the virtual suitcase, there were a few questions that came to mind:

- Could my dogs visit me?
- Would live music be allowed in my room?
- Could I visit the beach?

Insights

The creation of the suitcase was initially challenging, however, it was almost meditative when one had to consider what was important and sacred to the self. Of course, the experience will differ for people who are closer towards end of life as opposed to my attempted exploration of creating a suitcase in a state of wellness as a communication and an engagement tool. It appears to be that my suitcase highlights the importance of love, family, home, nature and accomplishments.

Due to the stories and meaning behind every item selected for the suitcase, it was difficult to categorize them, as there were so many overlaps. For example, the scarf and socks are physical and tactile however their emotional value is high due to the people who made them. Other items like the elephants and lavender help create familiar environments that can be quite literal.

This version of the suitcase is perhaps the first of many. It would be interesting to document them and see which items stay and which ones evolve over time.

Persona

A persona was then created to further ground the recommended solution. The purpose of the persona was to portray a realistic representation of the intended user of the proposed solution. The persona is inspired by Tolstoy's character, Ivan Ilyich. Following this, the suitcase was created for the persona.

Name: Ivan Ilyich
Age: 81
Illness: Cancer and Multiple illnesses that have led to loss in dexterity, severe pain and a weak immune system.

Ivan was a director of a mid size investment banking business in Toronto. After retiring at the age of 62, Ivan dedicated his time volunteering with not-for-profits and charities.

By the age of 69, Ivan was diagnosed with a disease that was reducing his bone density and stage 1 of prostate cancer. After having a fall a year after, he was not as mobile as he would have liked to be. By the age of 73, his driving license was taken away from him after the shooting pain in his legs caused a minor accident.

Although he is dependent on his wife, Ann (who was 10 years younger than him), he continued consulting but the hours were shorter. He took care of his diet and went for walks everyday.

His daughter, Ira lives close by and brings her twin 4-year-old daughters to visit Ivan often. He looks forward to seeing them. While he entertains them, Ira helps Ann prepare batches of Ivan's food and other housework. Ann has a weak back and is prone to severe pain. However, with her father's needs paramount, Ira often overlooks her own well-being.

At the age of 80, Ivan had a terrible fall and broke both his legs. This, along with his multiple issues had him bedridden. Three weeks later, Ivan had a high fever. Thinking that it was due to the fall, he was rushed to the hospital. The cancer had spread quite rapidly and the doctor's said Ivan would only survive a few months. Ann could not take care of him alone, so the family decided to shift him to a nearby hospice.

While the pain is supervised and the illness is incurable, Ivan's mind is fairly alert. He just celebrated his 81st birthday two days ago. The room was filled with laughter and affection and he likes to remember it that way. The healthcare team is wonderful and they say Ivan is a very positive patient. However, Ivan feels bored and lost without a purpose. The doctors think it's best to put him on a mild anti- depressant but Ivan's wife is convinced he wants his life to be meaningful for the next six months. The hospice has art classes, band nights, etc. but these activities do not excite Ivan.

Ann and Ivan never spoke of the quality of life but have taken care of their will etc. They thought they'd know what to do when the time came.

He misses many things in his life- from little things like the smell of basil from his garden, the textured footstool in the family room, and the glass of wine he shared with his wife during dinner. But the focus is his 'illness.'

Fig. 10: Persona, Ivan Ilyich's Suitcase (Photographed by Author)

Item 1: Textured footstool from the family room

Item 2: Ivan's late father's sweater

Item 3: Books

Item 4: A soft blanket that is gentle on the skin

Item 5: Drawings from Ivan's grandchildren

Item 6: Fresh herbs from the garden

Item 7: Everyday clothes- mainly for when visitors visit and to maintain his appearance

Item 8: Electric shaver- a gift from his grandchildren for 80th birthday. It is also to maintain a routine
Item 9: An old letter from Ivan's wife accepting his marriage proposal
Item 10: A lightweight shawl
Item 11: A bottle of wine to continue the dinner ritual with his wife
Item 12: A bathrobe to personalize the bathroom

Additionally, Ivan wants his wife to be wife and not a caregiver. He feels like the hospice takes great care of his daily routines and this gives him quality time to read to his grandchildren, have a few sips of wine in the evening with his wife and stay connected to his loved ones. He wants to continue volunteering as a mentor for select not-for-profits and charities. Ivan is aware that his time is limited but feels like the contribution gives his a sense of purpose.

Observations

Ivan's suitcase has tangible and intangible items that are focused on family and memories. It is also clear that he would like maintain his appearance, continue his daily routine (shaving, reading books) and have a sense of home in his room. It seems apparent that Ivan wants to be remembered as a husband, a father, grandfather, friend and mentor.

NEXT STEPS AND THE LONG VIEW

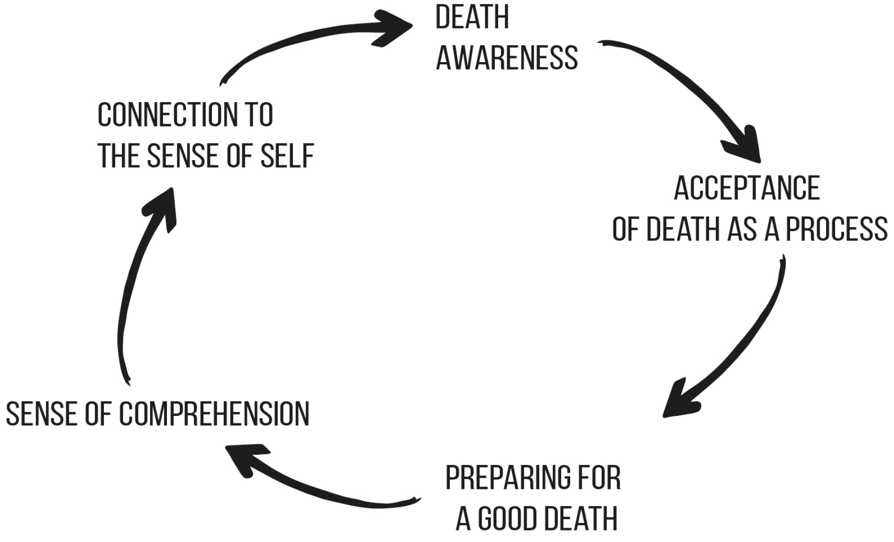


Fig. 11: Death Awareness- A Reinforcing Loop

The Suitcase Project hopes to support non- pharmalogical care by the meaningful gathering of sensory values in order to encourage personhood. The next step would be to create focus groups of stakeholders involved and facilitate the use of the probe. While health seekers will be invited with the hope of generating suitcases to better inform their sense of self for themselves (and their loved ones), the healthcare teams will be approached to create their suitcases with the perspective of building empathy for soft skill training purposes. Both the facilitations will encourage feedback sessions on how the information gathered may be integrated into the healthcare systems to better facilitate dignity, how the data may be stored and how it might better inform stakeholders about one another.

In the hospices, the experts interviewed subscribed to the desire to design for death better. While eliminating stigmas can be challenging, certain facilities of end of life based care like the hospices have made admirable strides towards managing the stigma. As the topic of death might make people vulnerable, collecting the contents of the suitcase as data to generate themes for the purpose of creating better products and services may not be the most appropriate fit. The Suitcase Project proposes that the user can help the project by leaving their data behind as a contribution to respect their personal information.

By gathering the items before the involvement of end of life care, it could prove to be a powerful tool to communicate the needs of the patient effectively to the healthcare teams involved. In the long term, The Suitcase Project could also expand to a virtual platform where items could be uploaded to a virtual suitcase and shared with the healthcare teams. This could assist in being better prepared for the patient prior to their arrival, perhaps go a step further and even create a more personalized atmosphere.

The idea that one's own competence provides a secure sense of identity is extremely crucial for the patients. Encouraging a clear and empathic line of communication can determine a patient’s state of mind- whether they feel empowered to experience a sense of wellness or unspoken concern, shame or guilt which may lead to a feeling of illness. By having ongoing conversations devoid of stigmatized words, The Suitcase Project is a sensory based cultural probe designed to assist in the enquiry, reflection and preparation for a good death. In the long run, it intends to reach out to health seekers of all age groups, encouraging meaningful conversations and serve as a preparation tool for the inevitable forthcoming event.

"I cannot say there is no vanity in making this funeral oration of myself, but I hope it is not a misplaced one; and this is a matter of fact which is easily cleared and ascertained."- (Hume, 1776)

BIBLIOGRAPHY

Addington-Hall, J. (2002). Research sensitivities to palliative care patients. *European Journal of Cancer Care,* 220-224. Retrieved October 10, 2014.

AGNES (Age Gain Now Empathy System). (n.d.). Retrieved December 23, 2015, from http://agelab.mit.edu/agnes-age-gain-now-empathy-system

Aker, A. (n.d.). On November 1, She Chose To Die With Dignity. She Voiced Her Final Wishes Here. Retrieved December 18, 2014, from

http://www.upworthy.com/on-november-1-she-chose-to-die-with-dignity-she-voiced-her-final-wishes-here?c=reccon2

Angus, J., Kontos, P., Dyck, I., McKeever, P., & Poland, B. (2005). The personal significance of home: habitus and the experience of receiving long-term home care. *Sociology of Health & Illness*, *27*(2), 161-187.

Assisted Suicide & Death with Dignity: Past, Present & Future – Part III. (n.d.). Retrieved January 25, 2015, from http://www.patientsrightscouncil.org/site/rpt2005-part3/#2

Ayuvastra. (n.d.). Retrieved July 17, 2014, from http://ayuvastra.ie/

Ayurveda, Ayurvedic treatment, Ayurvedic therapy, hospital, medicine - Arya Vaidya Pharmacy, India. (n.d.). Retrieved August 15, 2014, from http://www.avpayurveda.com/http://www.bibme.org/apa/book-citation/edit?item_id=446083320&parenthetical=true

Ayurveda. (n.d.). Retrieved July 8, 2014, from http://en.wikipedia.org/wiki/Ayurveda

Baillie, L. (2007). Patient Dignity In An Acute Hospital Setting: A Case Study. *International Journal of Nursing Studies,* 1-321. Retrieved October 18, 2014.

Baillie, L. (2008). Patient Dignity In An Acute Hospital Setting: A Case Study. *International Journal of Nursing Studies,* 23-37. Retrieved October 17, 2014.

Barry, A., & Yuill, C. (2011). Death and Dying. In *Understanding the sociology of health: An introduction* (2nd ed.). Los Angeles: SAGE Publications.

Bennett, A. (2013, April 1). We need a heroic narrative for death. Retrieved October 22, 2014, from http://www.ted.com/talks/amanda_bennett_a_heroic_narrative_for_letting_go

Berglin, L. (2013, November 6). Smart Textiles and Wearable Technology. Retrieved August 16, 2014, from http://www.hb.se/Global/THS/BalticFashion_rapport_Smarttextiles.pdf

Blackwell, T. (2014, October 1). The dreaded hospital gown, described as health care's prison jumpsuit, often imposed on patients needlessly: Study. Retrieved October 7, 2014, from http://news.nationalpost.com/2014/10/01/the-dreaded-hospital-gown-described-as-health-cares-prison-jumpsuit-often-imposed-on-patients-needlessly-study/

Boston, P. (2001). Embracing Vulnerability: Risk and Empathy in Palliative Care. *Journal of Palliative Care,* 248-253. Retrieved November 26, 2014.

Boudreau, J., & Somerville, M. (2013). Euthanasia is not medical treatment. *British Medical Bulletin,* 45-66. Retrieved January 4, 2015.

Cave, S. (n.d.). The 4 stories we tell ourselves about death. Retrieved February 24, 2015, from https://www.ted.com/talks/stephen_cave_the_4_stories_we_tell_ourselves_about_death?language=en

Care Companion. (n.d.). Retrieved August 20, 2014, from http://narayanahealth.org/care-companionhttp://www.bibme.org/apa/book-citation/edit?item_id=446083288&parenthetical=true

Carel, H. (2008). *Illness: The cry of the flesh*. Stocksfield: Acumen.

Christensen, C. M., Bohmer, R., & Kenagy, J. (2000). Will disruptive innovations cure health care?. *Harvard business review*, *78*(5), 102-112.

Choe, J. (2006, September 6). NHS hospitals' Interfaith Gowns. Retrieved September 26, 2014, from http://www.core77.com/blog/object_culture/nhs_hospitals_interfaith_gowns_4449

Comfort Care Clothing. (n.d.). Retrieved September 23, 2014, from http://www.comfortcareco.com/

"Common Menu Bar Links." Palliative and End-of-Life Care. Health Canada, 4 June 2009. Web. 16 Feb. 2015. <http://www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php>.

COONEY, W. (n.d.). Heidegger, Martin. Retrieved November 18, 2014, from http://www.deathreference.com/Gi-Ho/Heidegger-Martin.html

Dahlberg, K., Todres, L., & Galvin, K. (2009). Lifeworld-led healthcare is more than patient-led care: An existential view of well-being. *Medicine, Health Care and Philosophy*, *12*(3), 265-271.

Death Cafe. (n.d.). Retrieved January 13, 2015, from http://deathcafe.com/

"Designing for Dignity." *Designing for Dignity*. Web. 11 Mar. 2014. <http://www.designingfordignity.com/>

Diamond, J. (2013, March 1). How societies can grow old better. Retrieved October 27, 2014, from http://www.ted.com/talks/jared_diamond_how_societies_can_grow_old_better

Didion, J. (2005). *The year of magical thinking*. New York: A.A.Knopf.http://www.bibme.org/apa/book-citation/edit?item_id=446083258&parenthetical=true

Dignity Giving Suits. (n.d.). Retrieved September 20, 2014, from http://www.dignitygivingsuits.com/

Digni-fit Medical Gowns – by Size. (n.d.). Retrieved September 17, 2014, from http://rozharpercollection.com/product/digni-fit-medical-gowns-by-size/

Dying with Dignity. (n.d.). Retrieved January 25, 2015, from http://www.dyingwithdignity.ca/

End-of-Life Care. (n.d.). Retrieved April 10, 2015, from http://www.cancer.gov/cancertopics/advanced-cancer/care-choices/care-fact-sheet

Estate Planning - Ministry of the Attorney General. (n.d.). Retrieved January 10, 2015, from http://www.attorneygeneral.jus.gov.on.ca/english/justice-ont/estate_planning.asp

Fact Sheet: Hospice Palliative Care in Canada. (2012, May 1). Retrieved October 17, 2014, from http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf

Ford, S. (2012, February 15). 'Dignity gown' introduced in Nottingham. Retrieved September 19, 2014, from http://www.nursingtimes.net/nursing-practice/specialisms/management/dignity-gown-introduced-in-nottingham/5041140.article

Fowler, Robert, and Michael Hammer. "End-of-Life Care in Canada." SPECIAL SERIES – END OF LIFE CARE. Clin Invest Med, 1 June 2013. Web. 11 Apr. 2015. <http://www.cahs-acss.ca/wp-content/uploads/2013/08/End-of-Life-Care-in-Canada.pdf>.

Fryer, J. (2014, November 10). Inseparable: The dying woman, her devoted horse and their amazing bond of love forged over 25 years . Retrieved November 18, 2014, from http://www.dailymail.co.uk/news/article-2827489/Pictured-prime-horse-loving-grandmother-dying-wish-favourite-animal-one-time.html

Fuelfor | Innovation in health care. (n.d.). Retrieved January 26, 2015, from http://www.fuelfor.net/

Gawande, A. (2014). *Being mortal: Medicine and what matters in the end*.http://www.bibme.org/apa/book-citation/edit?item_id=446083248&parenthetical=true

Gholipour, B. (2014, September 23). The Case For Wearing Pants Under Hospital Gowns. Retrieved December 4, 2014, from http://www.huffingtonpost.com/2014/09/23/pants-hospital-gowns_n_5870410.html

G Kuppuswamy Naidu Memorial Hospital. (n.d.). Retrieved July 17, 2014, from http://www.gknmhospital.org/index.php

Gourdji, I., McVey, L., & Purden, M. (2009). A Quality End of Life from a Palliative Care Patient's Perspective. *Journal of Palliative Care,* 40-50. Retrieved November 26, 2014.

Grave goods. (n.d.). Retrieved March 21, 2015, from http://en.wikipedia.org/wiki/Grave_goods

Halifax, J. (2010, December 1). Compassion and the true meaning of empathy. Retrieved October 23, 2014, from http://www.ted.com/talks/joan_halifax

Hanson, M. A., Powell Jr, H. C., Barth, A. T., Ringgenberg, K., Calhoun, B. H., Aylor, J. H., & Lach, J. (2009). Body area sensor networks: Challenges and opportunities. *Computer*, *42*(1), 58.

Health Care in Canada, 2011: A Focus on Seniors and Aging. (2011, January 1). Retrieved September 24, 2014, from https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf

Hospice. (n.d.). Retrieved August 16, 2014, from http://en.wikipedia.org/wiki/Hospice

Hospital fabrics assist in protecting and promoting health. (2008, January 1). Retrieved August 16, 2014, from http://fabricarchitecturemag.com/articles/0108_ma_hospital.html

Hospital Gown : Development | Henry Ford Innovation Institute. (2012, September 17). Retrieved September 15, 2014, from http://henryfordinnovation.com/highlights/hospital-gown/

Hume, D. (n.d.). My Own Life. Retrieved February 17, 2015, from http://isites.harvard.edu/fs/docs/icb.topic880131

Improving access to palliative care in Ontario. (2013, November 16). Retrieved October 18, 2014, from http://www.mcmasterhealthforum.org/docs/default-source/Product-Documents/citizen-briefs/access-to-palliative-care-in-ontario-cb.pdf?sfvrsn=2

Jones, P. (2013). *Design for care innovating healthcare experience*. Brooklyn, N.Y.: Rosenfeld Media.

Jones, S. E., & Yarbrough, A. E. (1985). A naturalistic study of the meanings of touch. *Communications Monographs*, *52*(1), 19-56.

J. Smith, W. (2007, April 16). The Future of Assisted Suicide and Euthanasia. Retrieved January 15, 2015, from http://www.discovery.org/a/4000

Kagan, S. (2014, July 7). Shelly Kagan on the Future of Death When We Can Live Decades Longer. Retrieved January 10, 2015, from http://www.wsj.com/articles/shelly-kagan-on-the-future-of-death-when-we-can-live-decades-longer-1404764480

Kensington Health - Kensington Health. (n.d.). Retrieved November 30, 2014, from http://www.kensingtonhealth.org/

Kunja Lal Bhishagratna, K. (2008). *An English Translation of the Sushruta Samhita*. Kaviraj Kunja Lal Bhishagratna.

Lymberis, A., & Olsson, S. (2003). Intelligent biomedical clothing for personal health and disease management: state of the art and future vision.*Telemedicine Journal and e-health*, *9*(4), 379-386.

MacDonald Johnston, J. (2013, February 1). Prepare for a good end of life. Retrieved October 22, 2014, from http://www.ted.com/talks/judy_macdonald_johnston_prepare_for_a_good_end_of_life

Maslow's Hierarchy of Needs. (2007, September 17). Retrieved August 21, 2014, from http://www.simplypsychology.org/maslow.html

Mayo Clinic - Mayo Clinic. (n.d.). Retrieved January 20, 2015, from http://www.mayoclinic.org/

Meadows, D., & Wright, D. (2008). *Thinking in systems: A primer*. White River Junction, Vt.: Chelsea Green Pub.

MethodKit - Define, develop, structure. (n.d.). Retrieved January 25, 2015, from http://www.methodkit.com/

M. McKinlay, E. (2001). Within the Circle of Care - Patient Experience Receiving Palliative Care. *Journal of Palliative Care,* 22-29. Retrieved November 26, 2014.

My Gift of Grace. (n.d.). Retrieved November 10, 2014, from http://mygiftofgrace.com/

NHS England » How can we transform how care looks and feels like for patients? (n.d.). Retrieved October 22, 2014, from http://www.england.nhs.uk/about/imp-our-mission/patients/

O'neill, B., & Fallon, M. (1997). ABC of palliative care: Principles of palliative care and pain control. *BMJ,* 801-804. Retrieved November 9, 2014.

O'Neil, L. (2014, October 9). Brittany Maynard, 29-year-old cancer patient, explains her choice to die with dignity - Your Community. Retrieved January 3, 2015, from http://www.cbc.ca/newsblogs/yourcommunity/2014/10/brittany-maynard-29-year-old-cancer-patient-explains-her-choice-to-die-with-dignity.html

Ontario's Community Care Access Centres (CCACs) -Public Information - MOHLTC. (n.d.). Retrieved October 11, 2014, from http://www.health.gov.on.ca/en/public/contact/ccac/

O'rourke, M. (2014, October 14). Doctors Tell All—and It's Bad. Retrieved October 17, 2014, from http://www.theatlantic.com/magazine/archive/2014/11/doctors-tell-all-and-its-bad/380785/

Palliative Care | Hospice Care | Palliative Care Canada | Elder Care. (n.d.). Retrieved October 27, 2014, from http://www.chpca.net/

Palliative Care. (n.d.). Retrieved November 10, 2014, from http://www.chpca.net/

Patient's Journey. (2012, January 1). Retrieved November 2, 2014, from https://www.mm.dk/patients-journey

Payton, L. (2015, February 6). Supreme Court says yes to doctor-assisted suicide in specific cases. Retrieved February 15, 2015, from http://www.cbc.ca/news/politics/supreme-court-says-yes-to-doctor-assisted-suicide-in-specific-cases-1.2947487

Personhood in dementia. (n.d.). Retrieved December 10, 2014, from http://www.digitaljewellery.com/jaynewallace/personhood_in_dementia.html

Philip Beesley Architect Inc. (n.d.). Retrieved September 14, 2014, from http://www.philipbeesleyarchitect.com/

Psychology of self. (n.d.). Retrieved December 5, 2014, from http://en.wikipedia.org/wiki/Psychology_of_self

Raksha - The Hospice. (n.d.). Retrieved July 17, 2014, from http://www.gknmhospital.org/cms51.html

"Residential Care." Residential Care. Canadian Institute for Health Information. Web. 31 Mar. 2015. <http://www.cihi.ca/cihi-ext-portal/internet/en/tabbedcontent/types of care/community care/residential care/cihi010266>.

Robson, D. (2014, July 7). The ultimate comeback: Bringing the dead back to life. Retrieved January 20, 2015, from http://www.bbc.com/future/story/20140704-i-bring-the-dead-back-to-life

Saint Elizabeth: Home Health Care, Rehab Therapies, and Staffing Relief. (2015, January 14). Retrieved February 1, 2015, from http://www.saintelizabeth.com/About-Saint-Elizabeth/Media/News/January-2015/Samsung-Canada-and-Saint-Elizabeth-Team-Up-to-Expa.aspx

Saul, P. (2011, November 1). Let's talk about dying. Retrieved October 27, 2014, from http://www.ted.com/talks/peter_saul_let_s_talk_about_dying

Seng Beng, T., Ee Chin, L., Chong Guan, N., Hway Ann, Y., Wu, C., Sook Kuan, W., ... Boey Chiong Meng, C. (2014). The Experiences of Well-Being of Palliative Care Patients in Malaysia: A Thematic Analysis. *American Journal of Hospice and Palliative Medicine,* 1-14. Retrieved October 17, 2014.

Sims- Gould, J., Wiersma, E., Arseneau, L., Lou Kelly, M., Kozak, J., Habjan, S., & MacLean, M. (2010). Care Provider Perspectives on End-of-life Care in Long-Term-Care Homes: Implications of whole- person and palliative care. *Journal of Palliative Care,* 122-129. Retrieved November 29, 2014.

Smart Fabrics to Reach $2.6 Billion in 5 Years. (n.d.). Retrieved May 15, 2014, from http://www.marketwired.com/press-release/smart-fabrics-to-reach-26-billion-in-5-years-1663061.htm

Suter, E., Oelke, N., Adair, C., & Armitage, G. (2009, October 13). Ten Key Principles for Successful Health Systems Integration. Retrieved July 29, 2014, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3004930/

Swazey, K. (2013, April 1). Life that doesn't end with death. Retrieved October 27, 2014, from http://www.ted.com/talks/kelli_swazey_life_that_doesn_t_end_with_death

Tactility. (n.d.). Retrieved August 16, 2014, from http://www.thesaurus.com/browse/tactility

Thakur, S. (2011, July 29). Interpreting and Using the Formula for Change. Retrieved February 12, 2015, from http://www.brighthubpm.com/change-management/122241-gleichers-formula-a-scientific-approach-to-change/

The Order of the Good Death. (n.d.). Retrieved January 29, 2015, from http://www.orderofthegooddeath.com/

Terror management theory. (n.d.). Retrieved February 24, 2015, from http://en.wikipedia.org/wiki/Terror_management_theory

Terror Management Theory. (n.d.). Retrieved February 27, 2015, from http://www.tmt.missouri.edu/

Tolstoy, L. (n.d.). The Death of Ivan Ilyich. Retrieved November 18, 2014, from https://ebooks.adelaide.edu.au/t/tolstoy/leo/t65d/chapter7.html

Ulrich, R. (1984). View through a window may influence recovery. *Science*,*224*(4647), 224-225.

Verderber, S. (1986, July 4). Dimensions Of person-Window Transactions in the Hospital Environment. Retrieved July 29, 2014, from http://eab.sagepub.com/content/18/4/450.short

Wallace, J., McCarthy, J., C. Wright, P., & Olivier, P. (2013). Making Design Probes Work. *Session: Design Strategies CHI,* 3441-3450. Retrieved December 10, 2014.

Wallace, J., C. Wright, P., McCarthy, J., Philip Green, D., Thomas, J., & Olivier, P. (2013). A Design-led Inquiry into Personhood in Dementia. *Session: Mental Health CHI,* 2617-2626. Retrieved December 10, 2014.

Wallace, J. (2011, January 1). Personhood Project. Retrieved December 10, 2014, from http://vimeo.com/19431560

What to pack in your hospital bag. (n.d.). Retrieved March 20, 2015, from http://www.babycentre.co.uk/what-to-pack-in-your-hospital-bag

WHO Definition of Palliative Care. (n.d.). Retrieved September 10, 2014, from http://www.who.int/cancer/palliative/definition/en/

William Thomas | Ashoka - USA. (n.d.). Retrieved November 23, 2014, from http://usa.ashoka.org/fellow/william-thomas

APPENDIX A: Recruitment Guide

Experts (Doctors and Nurses): Verbal/telephone script

Hello, my name is Krittika Sharma and I'm a graduate student completing my Master of Design degree at OCAD University in Toronto. I would like to invite you to participate in a study that involves research in the area of dignity in aging. More specifically, the purpose of this project is to develop an understanding and provide recommendations/ products/ design interventions with regard to the role of sensory experiences and how it might address the concept of dignity for long stay patients with cognitive function. The format is a semi-structured interview and the guiding questions are given below:

1. I am looking for stories about patients/ caregivers and what they do to maintain dignity, sense of self, familiarity or/and privacy. Would you be able to share anything related to this?

2. What feels like care, in relation to sensorial interventions for long stay patients? How is care perceived?

3. Are there particular ideas that stood out for you? In what way does it impact the patient?

4. How do these innovations/ ideas impact your role?

If you have any questions or concerns, please feel free to contact me on krittika.sharma@gmail.com or 647 455 1805. Otherwise, if you're happy to participate, please let me know when you will be available for a meeting in the upcoming weeks.

APPENDIX B: Related Works on Dignity

There have been a number of studies that have tried to understanding dignity in the health care settings. The studies ranged from small to larger studies and were conducted all over the globe and in different models of health care systems. Almost all of them approach the data from a qualitative lens. The studies show the complexity of defining and articulating dignity from an individual, community and systems perspective.

The study of care which threatened the dignity of patients undergoing palliative care[87]

Participants: Patients
Size of study: Medium

In a Swedish study, Ohlen (2004) explored care which threatened the dignity of patients undergoing palliative care, using a phenomenological approach to interview sixteen men and women in-depth about their care experiences. They were not specifically asked about violation or dissatisfaction with care but examples they gave were of receiving bad news (about diagnosis) in a 'brusque and brutal way' and fundamental care needs being denied. Ohlen (2004) concluded that people who are life-threateningly ill are highly vulnerable to care-related violations and that caregivers must prevent such occurrences. The study's findings could be applicable to acute hospital settings too, where patients are also vulnerable.

---

[87] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

Research sensitivities to palliative care patients[88]

This paper considers the methodological challenges of researching the health care experiences of palliative care patients and their families. Difficulties in defining a ‘palliative care patient’ are highlighted, and the question of whether there are specific ethical issues when researching palliative care explored. Methodological issues are discussed, including the negotiation of access via health professionals, the choice of appropriate data collection methods and tools, the consequences of high attrition rates and the use of retrospective surveys of bereaved relatives. Key areas for research are identified. These include patients’ and families’ experiences of research participation, the impact of being approached on those who decline, how the characteristics of those who participate differ from those who do not and the likely impact of this on findings. Research is also needed into patient and family motivations for participation, and whether and how these change as the disease progresses. To ensure that the voices of palliative care patients and their families are heard by both service providers and policy-makers, research in this area needs to address the methodological challenges raised in this paper, as well as continuing to explore users’ views. (Addington- Hall, J. 2002)

---

[88] Extract from http://www.ncbi.nlm.nih.gov/pubmed/12296842

A case study of patient dignity in an acute hospital setting[89]

Participants: Patients and Ward Staff

Size of Study: Large

A qualitative case study examined the meaning of patient dignity and how patient, staff and environmental factors affect patients' dignity. The study's setting was a surgical ward, specializing in urology, and ethical approval was obtained. Data were collected from post discharge interviews with patients; four-hour periods of participant observation with follow-up interviews with patients and staff; observation of staff handovers; interviews with senior nurses; and examination of Trust documents. Data were analyzed using Ritchie and Spencer's (1994) framework approach. (Baillie, 2007)

---

[89] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

Challenges that nurses faced on a rehabilitation ward in a nursing home and how these affected patients' feeling of dignity[90]

Participants: Nurses

Size of study: Medium

In Norway, Stabell and Nåden (2006) conducted four qualitative focus groups with nurses, regarding the challenges they faced on a rehabilitation ward in a nursing home and how these affected patients' feelings of dignity. A limitation, therefore, is that the results were based on nurses' perceptions of these effects, not patients. Stabell and Nåden (2006) developed a theoretical framework which drew on Seedhouse's (2000) philosophy and thus the results were interpreted in relation to capability and independence. Nurses discussed situations where patients' disabilities prevented them from doing what they wanted to do; there were strong links made between dignity and independence. Some staff discussed how heavy workload impinged on their ability to promote dignity. Nurses expressed that treating patients as individuals was important for dignity but found it challenging trying to meet patients' varying needs.

---

[90] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

Understanding the role of privacy in acute medical and surgical wards[91]

Participants: Patients and Staff

Size of study: Small

Woogara (2004) (selected results published in Woogara, 2005; 2005) conducted an ethnographic study in three acute medical and surgical wards. His main focus was privacy, which has already been identified as important for dignity in this thesis and Woogara's model of privacy proposed that dignity is a component of privacy.

Woogara (2004) found that nearly all staff and patients considered privacy to be important but not as important as other aspects of care such as medicine administration, indicating a hierarchy of care. The majority of patients and staff expressed acceptance that patients had little privacy in NHS wards and Woogara (2004) observed that privacy was continually breached. He identified that patients had little control or choice in hospital, for example they were moved round the ward without their consent, disrupting the relationships they had formed with other patients. Overall, Woogara's (2004) findings portray a bleak picture of privacy in an NHS hospital, and if privacy is disregarded, dignity will be threatened.

---

[91] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

How male patients conceived integrity in medical or surgical wards[92]

Participants: Male Patients

Size of study: Small

In a Swedish study, Widang and Fridlund (2003) interviewed seventeen male patients from medical or surgical wards, the aim being to describe how male patients conceived integrity. The interview questions concerned integrity and three categories emerged from the data: self-respect, dignity and confidence. The category, 'dignity', related to how caregivers treat patients and was about being seen as a whole person, being respected (included providing privacy and listening) and being seen as trustworthy.

---

[92] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

The study of dignity in terminal care[93]

Participants: Patients

Size of study: Large

Enes' (2003) study of dignity in terminal care which explored the meaning of dignity also identified the negative impact of illness and treatment, and care which promoted dignity. Some participants expressed that treatment impacted on body image (e.g. weight gain due to steroids) but patients' ability to adapt and alter their perceptions of dignity was evident. All participants identified that lack of resources and poor organization had a negative impact on dignity. Staff attitudes, including empathy and conveying respect, could promote dignity. Gamlin's (1998) internet-based study of dignity in palliative care identified that offering choices and enabling control and conveying respect were staff actions promoting dignity.

---

[93] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

Understanding what components generate dignity for a person[94]

Participants: Patients

Size of study: Small

Matiti (2002) identified eleven categories (privacy, confidentiality, need for information, choice, involvement in care, independence, form of address, decency, control, respect and nurse-patient communication), the sum of which led to dignity being maintained.

---

[94] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

How dignity had been maintained or compromised in acute care settings[95]

Participants: Patients and Nurses

Size of study: Small

In a much smaller, Australian study, Walsh and Kowanko (2002) used a phenomenological design, conducting taped unstructured interviews with a volunteer sample of five patients and four nurses. Ideally, participants for such a small study should have been selected purposively to ensure quality rich data were gained. There is no detail about the participants, although the data infers an acute care setting. The participants were asked to describe experiences of how dignity had been maintained or compromised. There was close similarity between the themes which emerged from the patients' interviews (being exposed, having time, being rushed, time to decide, being seen as a person, the body as object, being acknowledged, consideration, discretion - including use of humour to reduce embarrassment), and those from the nurses' interviews (privacy of the body, private space, consideration of emotions, giving time, the patient as a person, the body as object, showing respect, giving control, advocacy). Most themes related to staff behaviour, and some related to how staff promoted dignity (e.g. giving control) while others related to how dignity was threatened (e.g. patients being exposed). Findings relating to privacy included issues such as prevention of exposure and personal space.

---

[95] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

The study of how terminally ill patients' dignity can be maintained[96]

Participants: Patients
Size of study: Large

A Canadian team of researchers have studied how terminally ill patients' dignity can be conserved (Chochinov, 2002; Chochinov, 2002; Chochinov, 2002; Chochinov, 2004; Hack, 2004; McClement 2004). Their dignity-conserving model incorporates both concepts of dignity and factors affecting dignity. Thus physical 57 or psychological distress (e.g. fear of dying) and reduced independence are factors that can threaten dignity while patients engaged in various dignity-conserving perspectives and practices to conserve dignity. McClement et al. (2004) identified how HCPs can assist with illness-related concerns and suggested ways to support patients with their dignity- conserving perspectives and practices. Hack (2004) continued the work of Chochinov (2002, 2002) with 213 cancer patients completing rating scales concerning their overall sense of dignity, symptom distress, pain, functional dependency, quality of life, social support, desire for death, anxiety, hopelessness, will to live and burden to others. All the instruments used had been previously validated. Nearly half of the patients reported some dignity concerns, if only occasional ones. Factor analysis indicated that patients who felt depressed, and whose physical health had deteriorated to the extent that they needed help with personal care, were more vulnerable to a loss of dignity. The findings and recommendations may have limited application to an acute hospital setting.

---

[96] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

The maintenance of ICU patient's dignity[97]

Participants: Patients

Size of study: Small

In the UK, Turnock and Kelleher (2001) studied the maintenance of ICU patients' dignity using an action research approach. Bodily exposure has been identified as a threat to patients' dignity (Matiti, 2002; Walsh and Kowanko, 2002) but Turnock and Kelleher (2001) assumed that maintenance of dignity is synonymous with prevention of bodily exposure without recognizing that other factors (e.g. staff interactions) might affect patients' dignity too.

---

[97] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

Within the Circle of Care: Patient Experiences of Receiving Palliative Care[98]

Participants: Patients

Size of Study: Small

It presents an overview of qualitative study of six recently discharged hospice parents, who had experienced at least two episodes of inpatient palliative care and who were interviewed about their experience of care. The resulting date formed a representation- the Circle of Care- with a central theme being the recognition of patient identity. Other emerging themes were: humour, being watched, caring manner, being safe, chosen isolation, relinquishment and relaxation, keeping control, awareness of mortality, recognition of the palliative care philosophy, and the effect of the aesthetic and spiritual environment. (McKinlay, 2001)

---

[98] Extract from http://www.ncbi.nlm.nih.gov/pubmed/11324180

The study of older people’s dignity[99]

Participants: Patients

Size of study: Small

Gallagher and Seedhouse's (2000) study of older people's dignity identified both threats to dignity and ways in which dignity could be promoted. Staff approach to patients was a dominant theme and ensuring comfort and cleanliness promoted dignity. Patients' conditions increased their vulnerability to a loss of dignity, for example, incontinence or confusion. As in the other studies reviewed in this section, participants highlighted the importance of privacy, not being exposed and caring interactions. A clean, pleasant environment promoted dignity but an inadequate environment with poor resources undermined dignity. In the light of this, Seedhouse and Gallagher (2002) emphasized that the better the resources, the more likely that patients will be dignified.

---

[99] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

Studies of Care Based on Bodily Exposure[100]

The use of curtains to screen patients is the key method of preventing bodily exposure in hospital wards and Burden (1998) found that curtains are also used to signify privacy needs. However, several studies have highlighted the inadequacy of curtains in protecting privacy as they are often poor fitting and not fully closed (Barron, 1990; Gallagher and Seedhouse, 2000; Jacelon, 2003; Matiti, 2002; Turnock and Kelleher, 2001; Woogara, 2004) and they do not provide a barrier against sound. Inadequate auditory privacy in hospitals has been identified in several studies (Barlos, 2001; Bauer, 1994; Hooper, 1995; Jacelon, 2003; Matiti, 2002; Matiti and Sharman, 1999; Maxwell, 2000; Pattison and Robertson, 1996; Rylance, 1999; Walsh and Kowanko, 2002; Widang and Fridlund, 2003; Woogara, 2004).

However studies, particularly with older people, have continued to identify mixed sex wards as a threat to dignity because of lack of privacy (Gallagher and Seedhouse, 2000; The HAS 2000, 1998) and the risk of bodily exposure (Woolhead, 2005).

Shotton and Seedhouse (1998) suggested that when resources are scarce, and there are obvious technical problems to deal with, it is easy to neglect patient dignity. Several studies identified that inadequate resources (e.g. linen) threatened dignity (Enes, 2003; 61 HAS 2000, 1998; Matiti, 2002; Seedhouse and Gallagher, 2002) and that they led to depersonalization (Calnan et al., 2005; Woolhead, 2005) and routinisation of care (Calnan 2005). A poor physical environment which threatens dignity includes inadequate bathrooms and toilet facilities (Gallagher and Seedhouse, 2000; HAS 2000,

---

[100] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

1998; Matiti, 2002). Several studies identified that staff shortages adversely affected dignity (Calnan, 2005; HAS 2000, 1998; Matiti, 2002; Reed, 2003; Seedhouse and Gallagher, 2002; Tadd, 2004; Woogara, 2004).

UK professionals identified organizational and resource issues that threatened the dignity of older people as being a lack of staff training and organizational issues, such as task-orientated culture, high pressure work, NHS priorities, managerial targets and lack of guidelines (Calnan, 2005).

Older people in focus groups stated that the care environment diminished individuality leading to loss of dignity (Tadd, 2004).

Staff exposing people's bodies and being inattentive to their privacy has been found to threaten patients' dignity in the care of older people (Applegate and Morse, 1994; Gallagher and Seedhouse, 2000; Jacelon, 2002; Woolhead, 2005) Matiti (2002) found that while staff expressed that privacy was important, they did not see themselves as 'intruders'. Overall, previous research from various settings indicates that 66 staff do not always uphold patients' privacy, despite patients' vulnerability and dependence in the healthcare setting. However, Bauer (1994) found patients were often accepting towards nurses intruding behind doors or curtains when they were undressed. Apart from lack of attention to privacy of the body, there are other forms of behaviour towards people's bodies that can threaten dignity. These include treating people's bodies like objects (Tadd, 2004, 2004, 2004; Walsh and Kowanko, 2002) and not treating a person's body after death with respect (Soderberg, 1997).

Additional Research[101]

The Observer campaign ‘Dignity on the Ward’. The Observer had highlighted the need for 'basic dignified nursing care: personalized care, promoting autonomy, personal hygiene and access to food and drink' (HAS 2000, 1998)

The HAS 2000's (1998) extensive results indicated that preserving dignity and individuality, when meeting essential needs, was not always achieved and although this sometimes related to a poor physical environment it was more often to do with staff attitudes. There was inadequate provision of essential personal care, and staff interactions which threatened dignity were evident, while reassurance and information-giving promoted dignity. The HAS 2000 (1998) found that some wards had a culture of respect for patients. This study provided the basis for health policies such as Essence of Care (DH, 2001) and the NSF for Older People (DH, 2001) which aimed to address the issues identified.

The 'Dignity and Older Europeans' project focused mainly on views about older people and dignity in society as a whole but some of the focus group findings related to how dignity was promoted or threatened in hospital, drawn from participants' experiences. Older people and professionals in the UK identified that dignity was threatened in healthcare when there was a lack of attention to patients' appearance, there was a lack of privacy and inappropriate forms of address were used (Calnan, 2005; Woolhead, 2005).

---

[101] Extract from https://www.rcn.org.uk/__data/assets/pdf_file/0006/414645/Baillie_L.pdf

APPENDIX C: Innovations in Gown Design

Henry Ford Innovation Institute Patient Hospital Gown[102]

The new patient gown – resembling a wrap-around robe that completely closes in the back and front– is being rolled out on several inpatient floors at Henry Ford Hospital in Detroit. It is among the first inventions to be made public by the Henry Ford Innovation Institute in collaboration with the College for Creative Studies. The newly designed gown is:

- Completely closed in the back, creating more privacy for patient.

- Made of a thicker, cotton/polyester blend material, which keeps patients warmer than the previous patient gowns.

- Double-breasted in the front, using three snaps, instead of ties, to close the gown.

- Intuitive in design, with different colored snaps and stitching along the left and right sides of the gown, making it easy for patients to put on.

- Accessible for IVs and other medical lines. The health care teams say it offers them uncompromised clinical access to the patient without needing to remove the gown.

The new gown is tailored to fit two patient populations. Using the snaps on either side of the gown, it can adjust from a size large to an extra large, allowing for it to fit more patients with a single design.

---

[102] http://henryfordinnovation.com/highlights/hospital-gown/

Digni-fit[103]

A free size, and fits most. The gown covers the patients back completely without having to worry about any embarrassing moments. The gown comes with snaps – open and close from side to side, top to bottom. One will feel relaxed at all times, because only the part of the body that needs to be examined will be exposed. Easy access for healthcare professionals – yet protect the dignity of the patient. Great for patients that can't be moved and needs to be sponged bathed. That's what makes our gowns different to all other hospital gowns.

All the gowns are made in the United States – fabric is 100% cotton. It's machine wash & dry with minimal to none shrinkage.

---

[103] http://rozharpercollection.com/product/digni-fit-medical-gowns-by-size/

The New Dignity Gown[104]

Nottingham University Hospitals NHS Trust's new gown can be worn like a dressing gown and also like a traditional hospital gown by being put on front-first and tied at the back.

A spokesman said: "This second use is essential for our nurses because it allows bed-bound patients to easily have the dignity gowns put on while lying down – as well as mobile patients."

"Essentially, we've combined the features of a standard patient gown and a dressing gown, to make one which is reversible. This increases the access and versatility."

He added: "We've also reduced the number of ties enabling the patient to fasten the gown more easily. Repositioning the remaining ties has enabled the gown to be secured by the patient without assistance."

Mark Stone, linen services manager at Nottingham University Hospitals, led the development of the reversible gown.

He said: "Everyone's familiar with the old type of hospital gown that can leave your bottom exposed. We had a lot of feedback from patients who were unhappy with this – and very rightly. This is a basic dignity issue for our patients. We decided to join up with a company called Interweave to see how we could improve them."

---

[104] http://www.nursingtimes.net/nursing-practice/specialisms/management/dignity-gown-introduced-in-nottingham/5041140.article

“The ‘dressing gown’ design is great as it wraps around at the front and gives complete coverage. However, we wanted to take this a step further so that the gowns can still be worn in the traditional way – front to back – so that nurses can still put the gowns on patients who are lying in bed,” he added.

“They fasten at the back of the neck and can then be tied and secured lower down as and when the patient is moved in bed. This is a crucial element for our nursing staff.”

Comfort Care Clothing[105]

The motto is to provide fashionable, easy-access clothing at a very reasonable price, made with fabrics that are cheerful, need no ironing and are strong enough to endure the rigors of institutional laundries.

Their collection of apparel has been adapted to best solve the particular dressing problems of wheelchair users, the elderly, geriatric patients and those suffering from such disabilities as stroke, arthritis, paralysis, diabetes, Alzheimer's disease, edema and incontinence. This in turn makes the role of the caretaker less stressful and demanding.

---

[105] http://www.comfortcareco.com/

Dignity Giving Suits[106]

Acting on feedback from young people and families, we enlisted the expertise of uniform design company Fashion at Work (UK) to develop an innovative solution which upholds a patient's dignity at every stage of care, while allowing quick, easy and dignified access for their procedure and follow-up care.

Our patients said they wanted a two-piece outfit which led to the development of a Karate-suit style design with a short-sleeved top and cut-off trousers. The fabric is comfortable, warm and hard wearing, lasting much longer than the current lightweight NHS gowns and ensuring value for money.

It comes in eight sizes to fit babies up to teenagers and adults, is joined with fasteners at 28 points and the top is reversible so the outfit can be used in every possible scenario in theatre and postoperative care settings, for example complex heart surgery, the insertion of a neckline or hernia repair, or accessing a plaster cast on a broken arm.

The design is fully registered with patent pending and is currently being adapted for the adult market which will be showcased to hospitals across the country later this year.

---

[106] http://www.dignitygivingsuits.com/

Interfaith Gowns[107]

NHS hospitals may soon offer a burka-style gown to female Muslim patients. The proposal for Interfaith Gowns was triggered by rising concerns that these women avoid medical treatment because standard issue gowns are not modest enough. The idea was the brainchild of Karen Jacob, linen services manager at Lancashire Teaching Hospitals NHS Foundation Trust, which runs Royal Preston and Chorley and South Ribble hospitals.

The "Inter-faith" gown provides extra comfort and cover for patients undergoing medical procedures and is particularly useful for patients whose culture and religion requires them to be modestly clothed.

But Karen says the gown is aimed at anyone who wants to use to preserve their privacy and dignity.

The gown is made up of five pieces - three head garments, a gown and trousers. They can be mixed-and-matched to allow the patient their required degree of coverage. The sleeves of the gown have elasticated cuffs to cover the patients' arms.

The gown was initially trialled at the Royal Preston Hospital, but proved to be so successful it has been rolled out across the country and is now available at many hospitals alongside traditional hospital gowns.

---

[107] http://www.core77.com/blog/object_culture/nhs_hospitals_interfaith_gowns_4449.asp

Karen said: "I came up with the idea when we were talking about promoting privacy and dignity within the trust. A lot of people are reluctant to go into hospital, as they do not want to be exposed. The gown is not aimed at any set religion or gender, but is there for everyone if they choose to use them."

"The gowns are well used at Preston and Chorley and I am surprised and delighted that so many other hospitals have taken the idea up."

The Inter-faith gown idea was developed by Interweave Textiles after being taken forward by TrusTECH – the NHS organization that manages innovation for the North West NHS.

APPENDIX D: Care Companion[108]

The Care Companion Program was born out of a collaborative partnership between Narayana Hrudayalaya (NH) and the Stanford University School of Design's course, "Entrepreneurial Design for Extreme Affordability."

The Care Companion Program (CC Program) was set up in direct response to the needs and to recognize patient family members as an untapped existing resource. The program harnesses patient attendant capabilities by creating a position for them within the current hospital personnel framework and, through a training and certification process, patient attendants become additional in-hospital care-providers, or Care Companions (CC).

The training program is designed to rapidly teach the diverse patient population, using interactive video training sessions, practical skills testing, and visual testing. By basing the course around practical and visual learning methods, NH provides family members with the skills they need, regardless of their literacy. After graduation from the program, they are allowed to perform the trained medical skills in the hospital, under the supervision of the nursing staff to build confidence. The benefits of this program are far reaching for the patient family.

By training, certifying and monitoring the success of family caregivers while in the hospital, the Care Companion Program helps Narayana Hrudayalaya send families back to their home with the highest continuity of care.

---

[108] http://narayanahealth.org/care-companion

This program exists in Mysore and NH Health City, Bangalore and is slated to be rolled out at all the NH hospitals in the next couple years.

APPENDIX E: Terms and Definitions

Ayurveda[109]

It is a system of Hindu traditional medicine native to the Indian subcontinent. Practices derived from Ayurvedic traditions are a type of alternative medicine. Ayurveda is a discipline of the upaveda or "auxiliary knowledge" in Vedic tradition. The origins of Ayurveda are also found in the Atharvaveda, which contains 114 hymns and incantations described as magical cures for disease. There are also various legendary accounts of the origin of Ayurveda, e.g., that it was received by Dhanvantari (or Divodasa) from Brahma. Ayurvedic practices include the use of herbal medicines, mineral or metal supplementation (rasa shastra), surgical techniques, opium, and application of oil by massages.

CCAC (Community Care Access Centres)[110]

CCACs also provide information about local community support service agencies and can link people to these agencies to arrange services.

The CCACs were established by the Ministry of Health and Long-Term Care in 1996 to help the public access government-funded home and community services, and long-term care homes. CCACs work together, and with physicians, hospital teams and other healthcare providers to enhance access and coordination for people who need care in

---

[109] http://en.wikipedia.org/wiki/Ayurveda

[110] http://www.health.gov.on.ca/en/public/contact/ccac/

their own homes in the community, in supportive housing, or in a Long-Term Care Home.

Community Care Access Centres coordinate services for seniors, people with disabilities and people who need health care services to help them live independently in the community. CCACs determine eligibility and make arrangements for admission to some day programs, supportive housing/assisted living programs, and to certain chronic care and rehabilitation beds, and to all long-term care facilities.

The Canadian Hospice Palliative Care Association (CHPCA)[111]

The Canadian Hospice Palliative Care Association (CHPCA) is the national voice for hospice palliative care in Canada. It is a bilingual, national charitable non-profit association whose mission is the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened.

CHPCA strives to achieve its mission through:

- Collaboration and representation;
- Increased awareness, knowledge and skills related to hospice palliative care of the public, health care providers and volunteers;
- Development of national norms of practice for hospice palliative care in Canada;

---

[111] http://www.chpca.net/

- Support of research on hospice palliative care;

- Advocacy for improved hospice palliative care policy, resource allocation and supports for caregivers.

CHPCA works in close partnership with other national organizations and will continue to move forward with the goal of ensuring that all Canadians, regardless of where they may live, have equal access to quality hospice palliative care services for themselves and their family.

Geriatrics[112]

1. The branch of medicine dealing with the diseases, debilities, and care of aged persons.

2. The study of the physical processes and problems of aging; gerontology.

Hospice[113]

Hospice care is a type of care and philosophy of care that focuses on the palliation of a chronically ill, terminally ill or seriously ill patient's pain and symptoms, and attending to their emotional and spiritual needs. Linguistically, the word "hospice" derives from the Latin hospes, a word which served double duty in referring both to guests and hosts.

---

[112] http://dictionary.reference.com/browse/geriatrics?s=t

[113] http://en.wikipedia.org/wiki/Hospice

Palliative Care[114]

According to WHO, palliative care is 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. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;

---

[114] http://www.who.int/cancer/palliative/definition/en/

- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Senior Citizen[115]

In Canada, age 65 is generally understood to be the defining age for seniors. It is at this age when many Canadians begin to receive social services, such as government pensions. At one time, 65 was considered the mandatory age for retirement in Canada; however, this is no longer the case in most provinces and territories, with many people working well into their 60s and beyond.

Smart Fabrics[116]

Smart textiles are defined as textiles that can sense and react to environmental conditions or stimuli from mechanical, thermal, chemical, electrical or magnetic sources. According to functional activity smart textiles can be broadly classified into three categories:

---

[115] https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf
[116] http://www.hb.se/Global/THS/BalticFashion_rapport_Smarttextiles.pdf

First: the introduction of new type of textile fibers and structures for example conductive materials.

Second: the miniaturization of electronics, which makes it possible to integrate electronics into textile structures and products.

Third: different kind of wireless technologies enabling the technology to be wearable and at the same time communicating with other devices such as computers or mobile phones.

Terminal Illness[117] [118] [119]

A patient who has such an illness may be referred to as a terminal patient, terminally ill or simply terminal. Often, a patient is considered terminally ill when their estimated life expectancy is six months or less, under the assumption that the disease will run its normal course.

By 2026, approximately 20% of the population will be over 65. Among Canadians aged 65 and older, about 80 percent have one chronic disease, and of those, about 70 percent suffer from two or more chronic diseases.

---

[117] http://en.wikipedia.org/wiki/Terminal_illness

[118] Hospice Palliative Care in Canada: A Brief to the Special Senate Committee on Aging, 2007

[119] http://irpp.org/wp-content/uploads/assets/research/faces-of-aging/residential-long-term-care-for-canadas-seniors/IRPP-Study-no1.pdf

As the Canadian population ages, all provinces will need to expand their residential long-term care capacity to accommodate frail seniors — those who are no longer able to function independently. Conservative projections based on current trends suggest that by 2041 Canada will need 320,000 beds across the country, up from the current 200,000.