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TU Delft

WHAT MATTERS

LIFE STORIES FOR END OF LIFE

Exploring life narratives as medium for meaning surfacing in terminally ill populations.

Gráinne Marie Buckley

MSC DESIGN FOR INTERACTION MASTERS THESIS

GRÁINNE MARIE BUCKLEY | MSC THESIS | FEBRUARY 2026

“telling the story of our lives is so basic to our nature that we are largely unaware of its importance”

(Atkinson, 1998)

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MASTERS THESIS
MSC DESIGN FOR INTERACTION

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“Storytelling is a fundamental form of human connection”

(Atkinson, 1998)

ABSTRACT

Facing terminality is a traumatic experience, one which entails a reorientation of one’s entire meaning system. Hospice care is an approach which aims to provide comfort in the face of this turmoil, through the pursuit and provision of quality of life and a good death, facilitated through the alignment of care decisions and resources with patient’s personal values.

For incurable head and neck cancer patients, the pursuit of ‘a good death’ is challenged as a result of their particularly short life expectancy – five months. This leaves patients with limited time to reorient, reassess, and reflect on what their values and priorities are in the unexpected face of death. Further complicating these efforts is the population’s elderly male demographic, wherein the influence of gender stigmas, taboos and cultural norms presents a cohort who are adverse to emotional vulnerability and expression.

Through an extensive literature review, in concert with secondary findings across forums, blogs, testimonies and conferences, the context of HNC hospice was mapped across three dimensions – the environment, the person, and the cognitive processes. Through delineation of findings, a solution space was identified and mapped, and an exploratory cycle undertaken in order to answer the core tension – discovering the fundamental meanings of the emotionally avoidant.

This project presents a theoretically grounded framework, which utilises the lens of legacy and life stories to act as a mediating interface between patients and clinicians, surfacing fundamental meanings and facilitating the alignment of care resources towards QoL through a shared understanding. In tandem, it answers patients desire to prevent suffering in loved ones after their death through the creation of a legacy document, which they can bequeath and which will provide comfort and a preserved sense of relatedness even after death.

This framework is presented in concert with a set of protocol considerations which dictate application and embodiment considerations for the frameworks successful deployment, including both within, and external to, the HNC domain, representing opportunities for its deployment in hospice care across the terminally ill, as well as its applicability in trajectories pre-hospice.

KEYWORDS:

HOSPICE, PALLIATIVE, HEAD AND NECK CANCER, LIFE NARRATIVES, LEGACY

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Lastly to Yan. Thank you for everything.

PREFACE

From a young age, I have always loved puzzles and mysteries - spending hours on Professor Layton, riddles, detective games, mystery stories - that person who would always predict the plot twists of movies before they happened. Analyzing the psychology and context of conundrums, and untangling the web of parts towards a eureka moment where it all came together was something I loved - a precursor to my eventual design career, wherein I could 'solve' and decipher the larger puzzles of the world.

As I grew older, I became more invested in activism - global affairs, inequality, politics, empathy for others. In response, I returned to academia out of a desire to further explore the field of design psychology, and social and humanitarian design - working in domains whose complexity and intricacy often result in perceived impossibility and commercial aversion, yet are the areas which need it the most, and signify huge potential for lasting, human impact. The areas which, ultimately, matter most.

It is the spaces where the most discomfort - political, emotional, or otherwise - is felt, wherein design can have the most consequential, transformative effects, and metamorphosise the contexts they exist within. It is this endeavor which has become what I aspire to do as a designer - what design means to me.

It was for this reason I gravitated towards this project - its sensitivity, vunerability, ambiguity, emotionality, complexity. When my thesis topic was repeatedly met with shock and apprehension regarding its intensity, it only further confirmed to me that I was where I was supposed to be; working in confrontational, uncomfortable spaces, and being able to design within, and around the discomfort, to create a world, for people, for the better.



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FOREWORD

BY PROF.DR.IR. PIETER DESMET, TU DELFT

This thesis was made possible by Erasmus MC. It was their palliative care team who first identified the challenge this research addresses, and their decision to invest in exploring it that set this project in motion. That decision reflects an institution that actively looks for new ways to enrich the care they provide, and that had the vision to explore what design thinking could contribute to that effort. It is not something every clinical partner is willing to do.

The nurses, clinicians and staff at Erasmus MC who engaged with this project, supporting Gráinne, did so with openness, generosity and a depth of care for their patients that left a lasting impression on everyone involved. Their contribution is woven into this report, and this work would be considerably poorer without them.

A note on the critical perspectives presented in the pages that follow. The report draws on a variety of sources—including peer-reviewed academic literature and interviews with nurses and next of kin who are not associated with Erasmus—to map the current landscape of palliative care for head and neck cancer patients. Where that literature or interview outcomes identify shortcomings in monitoring tools, psychosocial support systems, or end-of-life care practices, these findings reflect sector-wide challenges documented across the international research community. They do not reflect, and should not be read as reflecting, the practices or quality of care at Erasmus MC. On the contrary, Erasmus MC's engagement with this project is itself evidence of an institution already actively engaging with psychosocial support for their patients. It should further be noted that certain terms and concepts used in this report—including the definitions of palliative care and hospice care—reflect the author’s own interpretation based on the international literature consulted, and do not necessarily align with the clinical definitions and terminology used within the Dutch healthcare system or at Erasmus MC specifically.

It is in the spirit of Erasmus MC's own forward-thinking approach to patient wellbeing that this framework is offered, as a contribution to a collaboration we hope to continue, and a reflection of what becomes possible when clinical expertise and design thinking work together.

01

LIFE

*“We often think in story form, speak in stor
form, and bring meaning to our lives through
story”*

(Atkinson, 1998)



1 ORIGINS

INTRODUCING

This chapter introduces the origins and basis of the project, the basic context, and key preliminary decisions.

Left: Cisely Saunders, the mother of the hospice and palliative care approach, with a patient.

PURPOSE

This project focuses on terminally ill populations - specifically that of head and neck cancer patients - exploring ways to improve the understanding of what matters to these patients when facing death, facilitating the alignment of care resources towards these sources of meaning in order to increase patient fulfillment and quality of life in their final months.

INTRODUCTION

Palliative care is described as when treatment broadens from solely curing a disease to disease management - prioritising quality of life over longevity. Patients enter palliative care under varied circumstances - patient election, terminal diagnosis, or in addition to curative treatment. Palliative care also encompasses hospice care - comfort care provided to patients in the final six months of live. For those with Head and Neck Cancer (HNC), the disease's aggressive, unpredictable nature results in patients unexpected arrival at terminality, and an even shorter hospice expectancy - only five months (Hoesseini et al., 2024).

Considering this brevity, patient comfort is crucial in order to maximise perceived fulfilment during their remaining time - reorientating themselves, reidentifying what is important, and pursuing it. While palliative care aims to provide comfort and achieve quality of life, the myriad of aliments HNC patients face during this phase poses significant barriers. Traditional somatic symptoms such as fatigue and nausea are accompanied by speech impairments, nutrition deficiencies and anorexia (Henson et al., 2020), facial disfigurements, and more. These exacerbate patients` psychological and emotional distress experienced as they confront their end of life and are forced to reevaluate what truly matters in their new reality.

While both psychological and physical symptom sets require attention to facilitate true comfort and quality of life, psychological complaints are often neglected (Ferri et al., 2024). The palliative experience of HNC patients is unimaginable and complex, resulting in misaligned, insufficient care. With inadequate opportunity for needs to naturally emerge considering the terminal timeframe, this failure renders the primary goal of palliative care - fulfilment and quality of life - to ultimately be left unmet. Some institutions have begun attempting to rectify this problem - for example, through questionnaires and healthcare monitors. However, it pales in the face of the complex, contextual-dependent emotions and needs of patients facing death, precluding any meaningful insights and improvements.

Annually, there are 890,000 new diagnoses of HNC, with 450,000 succumbing to the illness (Barsouk et al., 2023); half a million vulnerable patients deprived of a comfortable end of life. This is a major opportunity to improve the support which defines the final and most sacred months of life of a global population, and deliver true, complete palliative care.

ORIGINS

This project was initiated as part of a multi-study exploration to enhance the palliative care experience of head and neck cancer patients, investigating the application potential of the 13 fundamental needs in improving the understanding of patients psychological, spiritual and psycho-social spaces, and improving care alignment.

OBJECTIVE

How can we help Head and Neck cancer patients recognise their priorities, values and desires in the face of terminality, and support the articulation and monitoring of these surfaced preferences to facilitate care alignment towards sources of fulfilment, delivering quality of life?

PERSPECTIVE

In this project, a design for emotion perspective was adopted. This perspective advocates for the preservation of the basic facet of experience – emotion – as the leading principle in processes of design. This thread runs and underlines the basic foundations of this project, as intensive research and analysis into the subjective experiences of the populus defined emotion tensions, which were used to frame the design solution space and guide the projects ultimate outcome. Final communications equally focused on emotion, with the medium – a video – specifically directed and developed to trigger reflection and understanding on an emotional level, rather than a practical, theoretical level. The final outcome of the project represents this perspective, as stories and legacy – a primary means for the human-human expression and relation of emotion – are positioned as the central essence.

APPROACH

This project was initially framed in a human-centered design approach, with a later acknowledgement and incorporation of a service design approach as the project began to crystallise. HCD, similarly to the design for emotion perspective, advocates for the preservation of users at the center of the project, and whose desires, needs and perspectives informs the designs outcome on a holistic level. In this case, this approach was facilitated through the extensive familiarisation with the population through secondary sources, in response to the population's vulnerability and inaccessibility. In adopting HCD, it is important to advocate for users, avoid personal bias and assumptions, and ensure that design decisions are ultimately made with the populus, and their desires in mind.

In early research, the contextual understanding elucidated the necessity for an intervention which supports users, throughout their life. This warranted the adoption of a service design approach to act as a guiding reference for the creation of an intervention, wherein the users' experiences and interactions are considered across (a visualisation of) the users contextual timeline. It warrants an analytical approach and consideration of systems and interfacing networks and channels; while design is often focused on the tangible, service design is intangiably focused, where embodiment and material qualities evolves as a secondary response rather than a driver. This scenario and experiential thinking contributed towards the ultimate decision towards a framework based outcome, which considered the users holistic experience.

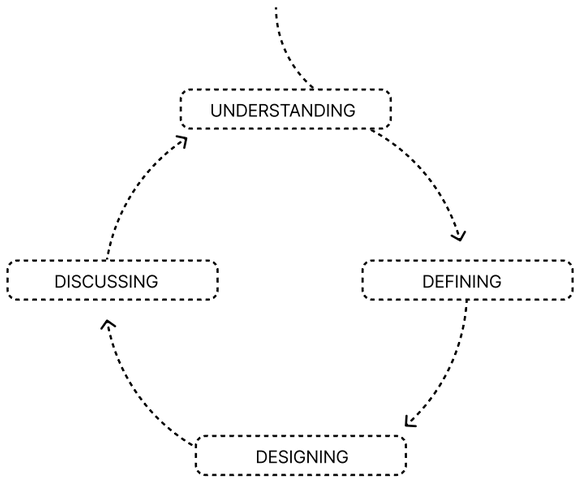
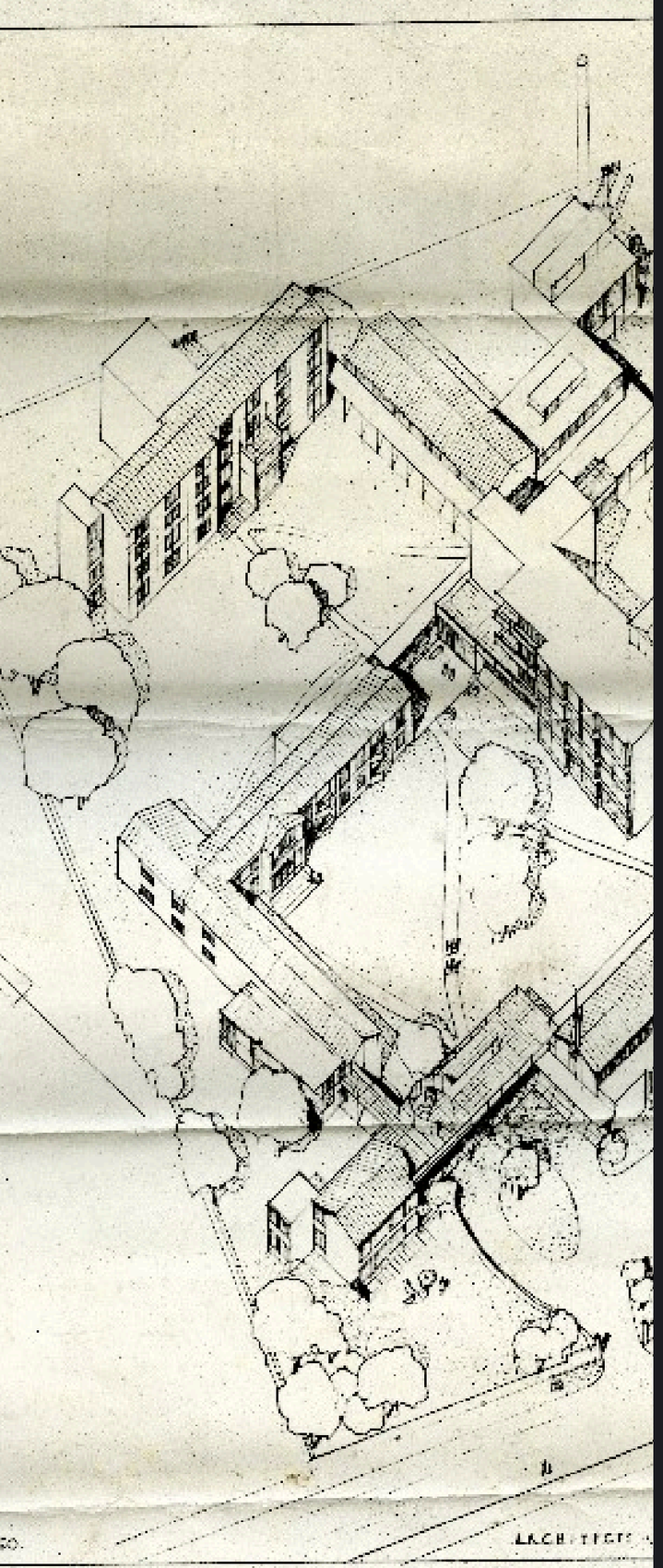


Figure 1: model of the project design process

NOTE TO THE READER

This project was initiated by and executed in close collaboration with Erasmus MC, whose palliative care team brought both the clinical expertise and the forward-thinking ambition that made this research possible. Their decision to explore the potential of design thinking in the context of palliative care reflects an institution that continuously seeks to enrich and deepen the quality of care they provide to their patients.

The patient and caregiver voices, citations, and testimonials appearing throughout this report are drawn from published academic literature, patient forums, conference proceedings, and publicly available testimonials, as well as from interviews conducted with nurses and next of kin not associated with Erasmus MC. None of them should therefore be read as reflecting the experiences or practices at Erasmus MC. Where critical perspectives on current care are expressed through these voices, they represent the broader international landscape of palliative care as documented in the research literature, and sector-wide systems, not the reality of any specific institution



II

DISCOVERING THE MILIEU

‘Milieu’ [noun] the physical or social setting in which people live or in which something occurs or develops

(Merriam-Webster, 2009)

- Left: Architectural Plans for St. Christopher’s Hospice, the first modern hospice, in South London(Oliver, 2016)

INTRODUCTION TO CONTEXT

PALLIATIVE CARE

RQ: What Is Palliative Care?

Palliative care is a holistic approach (or mindset) to patient care. Instead of a monomaniacal, myopic chase of a cure, palliative care advocates for balanced disease management – pursuing a cure without compromising patient's quality of life (QoL). It is not an alternative to curative treatment, and can be delivered at any age and stage in serious illness (Smith, 2021) (Mayland et al., 2020) – rather than an alternate treatment track, it is simply a lens through which patients treatment plans are viewed. Experts recommend that palliative care is incorporated and discussed in patient treatment plans right from initial diagnosis and planning, and followed concurrently with curative care or other treatment plans (Mayland et al., 2020) in order to provide optimal QoL and reduce symptom intensity (Mali, 2024).

When dealing with long term, serious illnesses, there are major, life-altering impacts on patients' lives. Patients are faced with both physical and psychological suffering; aggressive symptoms and side effects, psychosocial difficulties, mental illnesses, and more. Although the intent of most traditional medical treatments is to improve patients' health, through the curing or minimising of disease, the side effects and repercussions of treatment can be significantly damaging to patients' quality of life (QoL) involving expensive long term hospitalisations that can drastically impair quality of life (Mali, 2024). In response, palliative care incorporates a multi-disciplinary approach, involving not only oncologists, radiologists, and curative staff, but also professionals which work towards the restoration of patient's psychosocial needs. For HNC, examples include speech therapists (in response to voice impairments caused by treatment), dieticians (to help with nutrition in response to treatment affects on taste and swallowing), clerics (for spiritual guidance), physiotherapists, dentists, and social workers (Goldstein et al., 2008).

Palliative care acts as a mediator of sorts between two facets – longevity and quality of life. It recognises that while patients are often preoccupied with longevity treatments (Mayland et al., 2020), longevity achieved through chronic discomfort, immobility and psychological distress ultimately is futile and unfulfilling. It promotes a balanced consideration of care planning, and follows a selective treatment plan, sometimes turning down aggressive or invasive treatments which are predicted to impact patient's quality of life beyond a reasonable level (Mali, 2024).

> *Palliative care sees the person beyond the disease*
>
> *– (Smith, 2021)*

SPECIALISED PALLIATIVE CARE

The delivery of palliative care is the result of a unified mindset towards a patients needs, and is supported by the intentions and actions of everyone involved in the patient's life – their GP's, nurses, carers, family, and themselves. These stakeholders, unified by a shared understanding, make sure that choices and actions align with the upholding of the patients QoL.

In complex cases, where extreme or involved choices and actions need to be made in order to ensure patients QoL is not compromised, specialist palliative care may be needed. Think of instances such as intricate health plans, restricted medications or specific expertise such as physiotherapy. In cases such as these, patients general care team may need to be expanded to become multi-disciplinary (Mayland et al., 2020), including speech pathologists, dieticians, radiation specialists, physiotherapists, and more. These experts support the general team in ensuring QoL is delivered. In HNC, most patients require specialised palliative care because of the unique complexities involved.

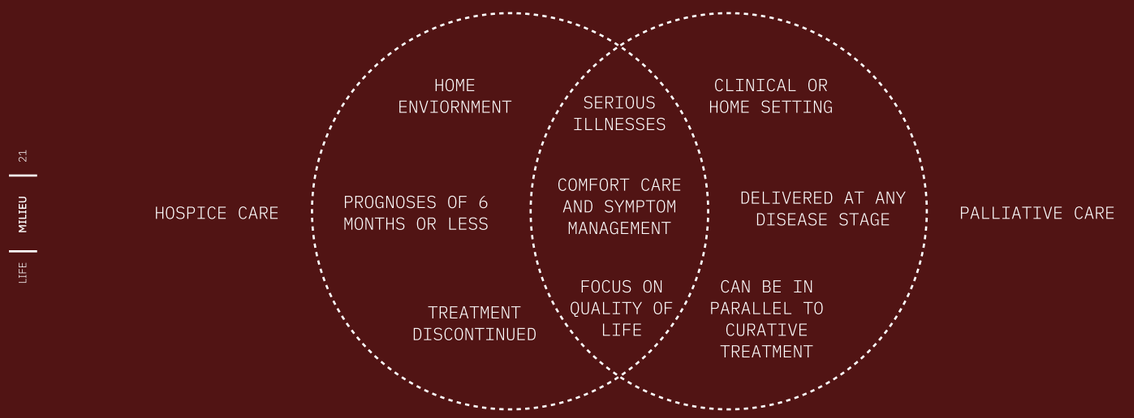


Figure 4: Venn diagram of hospice care and palliative care

CLARIFYING TERMINOLOGY

This project was initially framed in the context of palliative care, referring to incurable HNC patients. However, during initial research across literature, it became clear that this term was erroneous.

Contrary to general perception – within public and medical spaces – palliative care does not refer to incurable patients. The term, when coined by Cisely Saunders, did originate in terminal populations - however, in modern medicine, palliative care has instead evolved to simply refer to a comfort-focused approach to care which can, and should, be incorporated in patient care plans, from initial diagnosis to end of life. It advocates for a holistic perspective, where both quality, and quantity, of life is considered, and advocates for the reconsideration of life-prolonging treatments and interventions where an unjustifiable impact on life quality is anticipated (Mayland et al., 2020). However, the misconception and association with death results in the widespread aversion to palliative consideration.

The population intended to be represented in the original brief framing was head and neck cancer patients who have been incurably diagnosed. In this understanding, a more accurate term would be ‘hospice’. Hospice care refers to care in the final six months of a patient’s life (Wajid et al., 2021). Because HNC patients average life expectancy at incurable diagnosis is five months, this population is encompassed within the space of hospice care. For further understanding and information on this discernment, please see the following section.

During this project, a number of sources and literature referred to palliative care, but implied hospice care, and were therefore included in research and analysis. However, within the body of this report, they will be referred to as hospice care, rather than palliative, for reader clarity.

This definition was defined based on the international literature and sources consulted throughout the course of this thesis, and is not representative of any individual institutions perspective.

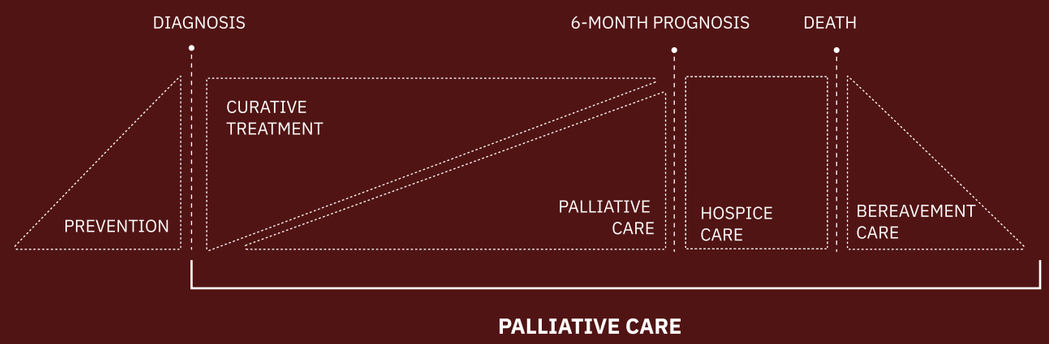


Figure 2: model representing blend of preventative, curative, palliative, hospice, and bereavement care, over the disease timeline

MISCONCEPTIONS

> *“patients are like ‘no, no, no, I don’t want that’”*
>
> *– Healthcare Professional, (Mayland et al., 2020)*

Like many (Flieger et al., 2020), you may have thought of palliative care as care for patients at end-of-life - and you would not be alone. Societal misconceptions about palliative care are rampant (Mayland et al., 2020), with many equating the term ‘palliative care’ as interchangeable with ‘hospice care’. This is however, not the case.

> *“We’ve told friends that (patient name) seen a palliative care consultant and you can see them going… as if palliative care is in the last 6 weeks of your life”*
>
> *– Carer, (Mayland et al., 2020)*

While palliative care poses such significant benefits for patient treatment courses, it is unfortunately also widely misunderstood within patient populations, and as a result, widely underutilised (Mali, 2024). These misconceptions unfortunately also prevail beyond the general public, and are present also within the health professional community (Mayland et al., 2020), an issue which was personally experienced during interactions and consultations with healthcare staff during the course of this project, wherein an expert stated that palliative and curative treatment can never be sought in parallel. In a published paper by Erasmus MC, palliative care is described as the ‘…phase, which begins when cure is no longer possible or when curative treatment is refused’(van den Besselaar et al., 2025). Similarly, another study, Mali, 2024, said palliative care is generally elected when cancer becomes inoperable or metastatic and untreatable.

> *“…quite an experienced district nurse, clearly though [sic, thought] the way that most people think about palliative care… that they’re the people that come in in the last 6 weeks of life”*
>
> *– Patient, (Mayland et al., 2020)*

As a result, patient misconceptions and fears surrounding the term ‘palliative care’ are often enforced rather than challenged, resulting in reluctance, apprehension and agitation when palliative care is proposed (Mayland et al., 2020). Healthcare professionals themselves can be reluctant to broach the topic, especially with patients receiving curative treatment, predicting patient distress as a result of misunderstanding, and further delaying adoption of palliative care into care plans (Mayland et al., 2020). One of the reasons for this is consultants’ uncertainty regarding when palliative care should be introduced to patient treatment plans; although advice exists for the inclusion of palliative care from initial diagnosis and throughout disease trajectory (Mayland et al., 2020), eliminating consultants need to decide ‘when’ at all.

> *“I have always been a bit conflicted about whether you should confront these people with palliative type discussions at this stage”*
>
> *– Healthcare Professional, (Mayland et al., 2020).*

While decisions to reject palliative care are often made with good intentions and a desire to increase longevity and quality of life, these often-ill-informed perspectives result in delayed referrals (Mayland et al., 2020) and consequently hindering patients achievable QoL. As mentioned, experts recommend palliative care be included as a consideration throughout the disease trajectory, right from diagnosis and initial treatment planning (Mayland et al., 2020). Early adoption empowers patients to use their limited time remaining to its maximum potential, allowing patients to find as much fulfilment and peace as they can before they reach their end of life (Mayland et al., 2020).

A further complicating factor impeding the more widespread adoption of palliative care is the dissonance between its perceived (incorrect) meaning, and modern society. While the medical and tech advancements over the last century have been life changing for the worldwide population, medical progress and the ‘curative push culture’ have led to avoidance of topics such as death and end of life care (Mali, 2024) which stand as a reminder of the limitations and ‘failures’ modern medicine still oppose. Clinicians and institutions operating in this era of modern medicine often have moral objections and reservations about forgoing life-prolonging treatments, further mitigating the adoption of palliative care treatments for patients in need (Mali, 2024).However, this aversion only has negative impacts on the dying – and wider society – wherein in wealthier countries, this general viewpoint has contributed to the majority of patients dying in intensive care units whose conditions are in violation of the facets considered critical to a ‘good death’ (Mali, 2024). This ‘curative’ mindset can be seen in the responses of patients towards palliative care, who uninamously viewed aggressive intervention positively, while equating palliative care with ‘giving up’ (O’Sullivan & Higginson, 2014).

HOSPICE CARE

RQ: What Is Hospice Care, And How Is It Different To Palliative Care?

While palliative care is recommended throughout patient trajectories, Hospice care is a component of palliative care - comfort care specifically delivered to terminal patients with a remaining life expectancy of six months or less (Wajid et al., 2021). It is a philosophical approach to care (Smith, 2021), which welcomes and recognises death's approach, and strives to deliver as comfortable an end-of-life as possible – a 'good death' (Mali, 2024). Like palliative care, it involves comprehensive, multi-disciplinary care teams, yet expands even further than that of palliative care, introducing additional services such as 24-hour-per-day helplines, home-based care, and grief counselling, which is available for up to a year even after the patient's death (Wagner & Marks, 2024).

The advanced care planning involved in palliative care also broadens towards the inclusion of end-of-life considerations, asking questions such as who patients nominate to act as a decision maker in the case of their incognition (Smith, 2021).

> *"[in hospice care] what makes your life worth living?"*
>
> *– (Smith, 2021)*

WHY IT'S IMPORTANT

The primary goal of palliative and hospice care is to provide quality of life (QoL) to the patient. This not only includes adequate pain relief and symptom management – both physiological and psychological – but also ensuring patient autonomy, control and dignity in place, context and those present regarding their death, enabling the patient to say goodbye, and more (Seifart et al., 2020). In the pursuit of these goals, the additional resources and support it provides - interdisciplinary care teams, services and resources – improves both patient care, but also carer care through supportive guidance and decreasing (family) carer burden (O'Sullivan & Higginson, 2014). These additional resources allow the patient and family carers to fulfil the desire to keep patients in the home setting, with those following a hospice [palliative] care plan significantly more likely to die in the home environment as opposed to a hospital (Mali, 2024). As one carer (wife of patient) said, while home hospice can initially be intense, care teams will meet your needs and help you adjust, and eventually both the patient and carer will become settled and see the positive impacts (Head and Neck Cancer Alliance, 2024).

While this may sound like palliative and hospice care simply ensures quality and comfort towards end of life and neglects longevity in its totality, this is not the case. Studies have shown that early adoption of palliative or hospice care actually prolongs patient survival as opposed to hastening death (Mali, 2024), as a result of increased positivity, satisfaction and joy – key components that quality of life delivers (van den Besselaar et al., 2025).

> *"..Symptom control isn't… as good as it could have been if there was help alongside the way"*
>
> *– Healthcare Professional Testimony, (Mayland et al., 2020)*

PLANNING FOR THE END OF LIFE

Hospice and palliative care also improves advance care planning (ACP), and dealing with topics that are important to raise with patients prior to deterioration. These include aspects such as 'Do Not Rescuitate' (DNR) orders, medical power of attorney, and establishing a living will. All of these are crucial for establishing patients wishes at end of life, and ensuring they have a dignified death in line with their values and desires (Mali, 2024). Prompt management of these topics alleviates stress from the family and patient, who may have to instead hold these difficult conversations in latter stages of the disease, where emotions are higher and time more valued. Worse still is the potential situation where the family has to make these decisions alone, without patient input, should there be a crisis and the patient rendered incapacitated, both straining the family and their fear they are not acting aligned to patients wishes, and stripping the patient of their autonomy and control of their own care. ACP also ensures the presence of a clear protocol should a crisis arise, preparing caregivers in advance and avoiding unessential ER visits (Mali, 2024).

However, our primal instinct is survival, and topics of death, dying, or specifically, intentionally deciding to prepare and accept death, is unnatural. Reservations towards these conversations remain, even in light of the abundance of benefits, both from patients, carers and even healthcare professionals alike. In a study, patients unanimously reported a preference towards maximum medical intervention instead of palliative care, even when the treatment was aggressive (O'Sullivan & Higginson, 2014). Patients, even though they acknowledge the importance of these discussions - for both them, and their loved ones - find it difficult to engage because of the confrontational nature. In one study, while 82% of patients agreed these conversations were critical, only 23% had actually documented their preferences for end of life (Smith, 2021).

> *"[the nurse]... has to be on hand very quickly… and [can] only deal with situations as they see them, rather than [hospice] palliative… constant care"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

HEAD AND NECK CANCER

RQ: What Is Head And Neck Cancer?

Head and Neck cancer (HNC), sometimes referred to as Ear Nose Throat (ENT) cancer, is a term used to describe a group of carcinomas . This group of malignancies include cancer affecting the mouth (oral cavity), nasal cavity, ear, eye, sinuses, skull base and larynx (Goldstein et al., 2008, Barsouk et al.). It is the seventh most common cancer worldwide (Gormley et al.), and accounts for over 890,000 new cases and almost half a million deaths annually (Barsouk et al.). Globally, its incidence is predicted to rise by 30% by the year 2030 (Gormley et al.).

RISK FACTORS & THE TYPICAL PATIENT

HNC disproportionately affects males, with a ratio of 2:1 diagnosis compared to females (Lokker et al.). It primarily effects older adults, with the majority of cases being diagnosed in those aged over 50 (Gormley et al.) Historically, HNC incidence has been associated with tobacco and alcohol consumption, as well as areca nut consumption being a prevalent risk factor in Asia (Barsouk et al.). HNC has also be associated with lower socioeconomic classes, often indicating limited healthcare access, escalating the stage of diagnosis and aggravating and prolonging symptom burden (Mali, 2024).

In recent years, these demographics have shifted, as HPV-related cases have begun to emerge in younger generations (30-50 year olds). While these cases are still male-predominant, they equally show a rise in the prevalence of female cases (Thome et al., 2018). This development has been primarily attributed to the shifting social norms surrounding sex and an increasing number of intimate partners, as well as the decline in tobacco and alcohol consumption as a result of health campaigns. However, this growth is forecast to stall as a result of the HPV vaccine rollout for those under 30. As a result, it is likely that the former demographic will remain preeminent.

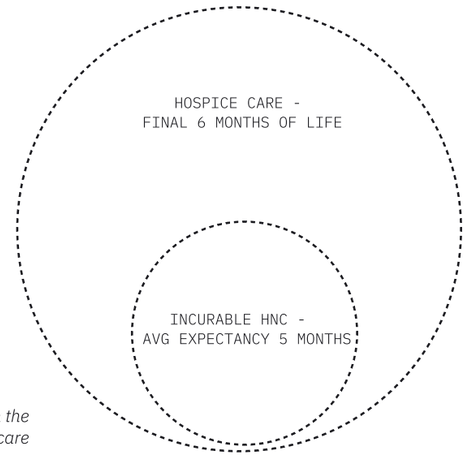


Figure 3: model representing incurable HNC, within the timeframe of hospice care

THE DISEASE TRAJECTORY

DIAGNOSIS

HNC is generally diagnosed at an advanced stage (Creaney et al.); roughly 10% of patients who are diagnosed with HNC will be dead within six months of diagnosis (Talani et al., 2019). An aggravating factor towards these statistics is the lower socioeconomic class and age, wherein patients may delay addressing health problems until they become unavoidable. This late-stage diagnosis exacerbates the intensity of symptoms and side effects patients experience, as well as its difficulty for home management (Mali, 2024). Its late diagnosis positions it as a particularly deadly disease, with five year survival rates averaging at around 50% (Gormley et al.), and recurrence rates of approximately 60% for those in advanced stages of the disease, with a median survival rate of less than one year (Mali, 2024).

PROGNOSIS

HNC has a unusually unpredictable disease trajectory with both treatment outcomes and life expectancy hard to prognosticate (Mayland et al., 2020). Predictions, when made, are often inaccurate and often overestimated, leading to further distress for patients and their loved ones when the reality of their prognosis is relayed, particularly in relation to life expectancy (van den Besselaar et al., 2025). As a result, many consultants avoid prognosticating for fear of inaccuracy and future angst. This avoidance is one of the many reasons palliative care is sub optimally utilised in HNC, as consultants delay conversations for fear of rebuttal and complaints (van den Besselaar et al., 2025).

> *"'How long do I have left' and he did say 'Well... I could give you months, I could give you one, two… I don't know'… Then you think… come on, you must know something"*
>
> *– (Mayland et al., 2020)*

While treatment options for HNC have evolved, cure rates over the last five decades have remained stagnant. The consequence of this is patients experiencing quiescent periods, followed by disease recurrence and bouts of serious illness (Goldstein et al., 2008). Ultimately, treatments only serve to prolong the course of the disease; not curing, but repressing. The particularly high recurrence rate associated with HNC gives rise to equally high anxiety cases (Goldstein et al., 2008), with up to 50% of HNC cases demonstrating symptoms of depression.

THE PHYSICAL IMPACTS

While all chronic illnesses bring significant challenges, head and neck cancer is uniquely complex due to the disease's locality and affect on primary senses and functions (Mayland et al., 2020). Tumors and sequelae affect core bodily functions such as breathing, speech and eating, significantly impacting patients' physical health and autonomy. Many patients are confronted with invasive medical supports such as nasal feeding tubes or peg tubes for nutrition delivery, or tracheostomies for compromised airways (Mali, 2024). Symptoms such as dysponea (van den Besselaar et al., 2025), dysphagia, malodorous wounds and extreme cachexia can cause severe distress for both patients and their carers due to their visibility and severity. There is also a high risk of carotid blowout, which is a severe major bleed, often fatal, and for carers and patients at home, incredibly difficult and distressing to deal with. However, in many cases, although home based end of life care increases the likeliness of a home death, the significance of HNC related symptoms and side effects results in as little as one third of deaths actually occurring in the home environment (Mali, 2024).

The diseases localisation and impact also has profound psychological implications. Speech impediments and distorted speech affects patients' ability to converse, socialise and self-advocate, while surgery and treatment on tumour sites frequently result in facial mutilation and disfigurement (Mali, 2024). This can exacerbate or instigate further psychological distress, anxiety and depression, as well as suicidal ideation. As a result, psychological support is recognised as critical esp for those with mutilating surgeries, but also recognised as an area of care that could be improved (Mayland et al., 2020).

MUCOSITIS	INFLAMMATION OF THE DIGESTIVE TRACT LINING
SIALORRHEA	INVOLUNTARY, UNCONTROLLABLE DROLLING
XEROSTOMIA	EXCESSIVE ORAL DRYNESS AS A RESULT OF SALVIA DISRUPTION
DYSPHAGIA	DIFFICULTY SWALLOWING
ODYNOPHAGIA	PAINFUL, UNCOMFORTABLE SWALLOWING

Figure 6 - An example of some of the HNC squelae (Goldstein et al., 2008)

BRINGING IT TOGETHER: HEAD AND NECK CANCER HOSPICE TREATMENT

As a result of the uniquely short prognosis, comprehensive hospice care is particularly crucial for patients with head and neck cancer (HNC). While patients with other serious diseases will likely have a period of non-curative treatment, prior to entering hospice care, this is not the case for HNC patients, as the aggressive nature of the disease results in an average of a five-month life expectancy once curative treatments end. As a result, once treatments cease, patients are immediately considered hospice, since their five month prognosis is less than the six-month window associated with hospice care.

Their extremely limited trajectory leaves them with little time to grapple with the emotional and logistical factors of death. Palliative and hospice care can help patients significantly with these challenges, identifying and treating sources of physical and psychological suffering early, and empowering patients in finding as much peace, fulfilment and quality of life prior to passing (Mali, 2024).

Considering this brevity, denying patients access to the resources of hospice care is devastating, and it is paramount that patients are informed at the earliest opportunity – as recommended by experts, at initial diagnosis. However, because of the misconceptions surrounding palliative care, the loaded topics of death and dying, and the difficulties with predicting life expectancy and prognosis, palliative care is sub-optimally used in HNC cases. The inaccuracies surrounding prognosis equally makes it difficult for patients themselves to plan what they want and need (van den Besselaar et al., 2025). Additionally, as a result of the short trajectory of the disease and hospice phase, HNC is associated with particularly high levels of aggressive treatment even during the end-of-life phase (Mayland et al., 2020).

Despite this crucial importance of palliative care for HNC patients, it is often overlooked. In one UK-based study, as little as 25% of HNC patients were attended to by palliative specialists (Mayland et al., 2020). Better knowledge of the population's needs is required (Mali, 2024) and there has been little to no specialised studies conducted (Mayland et al., 2020). The population poses unique study challenges, among them the limited life expectancy. In one study, in the short period between participant consent and interview dates, one third of the participants had passed away. Interviews also have to be designed with voice impairments and discomfort in mind, and often have to be supplemented with written resources, and time limited (Mayland et al., 2020). The limited life expectancy also brings an additional layer of sensitivity, where patient time is precious, and emotions particularly unsettled. All these factors can make uncovering true patient needs challenging (Mayland et al., 2020).

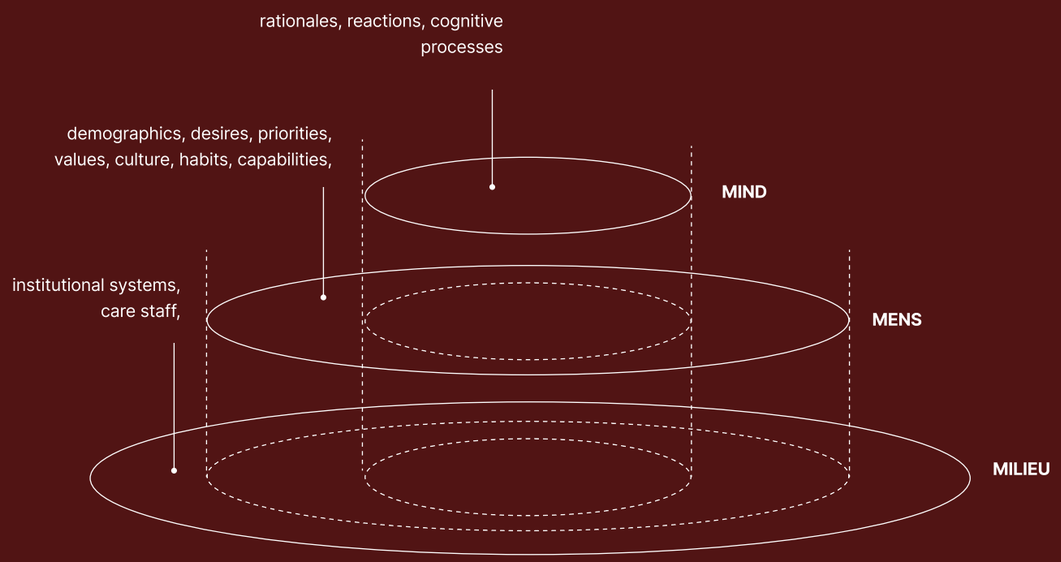


Figure 7 - Diagram showing the defined dimensions of context and their nested nature, and some examples of the facets contained within them

THE CONTEXT DIMENSIONS

The unique complexity of head and neck cancer (Mayland et al., 2020) hospice care infers an equally complex context, with knotted entanglements between the reality of head and neck cancer, the reality of facing death, and the relationships between these elements and the systems and structures they reside within. Context refers to the circumstances which an entity exists within; whether that entity be a person, idea or artefact (Shahare & Gurumoorthy, 2007). It establishes the factors which influence the entities state of being – what it is shaped and bound by.

In this project, the contextual factors are not only that of the 'person' and 'milieu', but also the mental context; the cognitive processes that the patient follows in their emotions, values, distresses and suffering. For the purposes of clarity in this report, I have outlined each of these facets below:

The Milieu

The 'enviornmental' context, meaning the institutions, systems and policies that the intervention must exist within, and is bounded by. In this case, this includes the palliative care system, Erasmus MC and the processes they have in place, as well as the governmental and political restrictions of healthcare, insurance policies etc.

The Mens

The 'people' context, meaning the demographics, culture, intentions, needs and desires that the intervention will interact with, and be shaped by.

The Mind

The 'cognitive' context, meaning the place within the patients mental landscape that the intervention exists. It determines what mindstate the interaction occurs within, 'who' (psychologically) and what it is interacting with, and the stages of reasoning or thinking that are encountered and which the design has to be situated within.

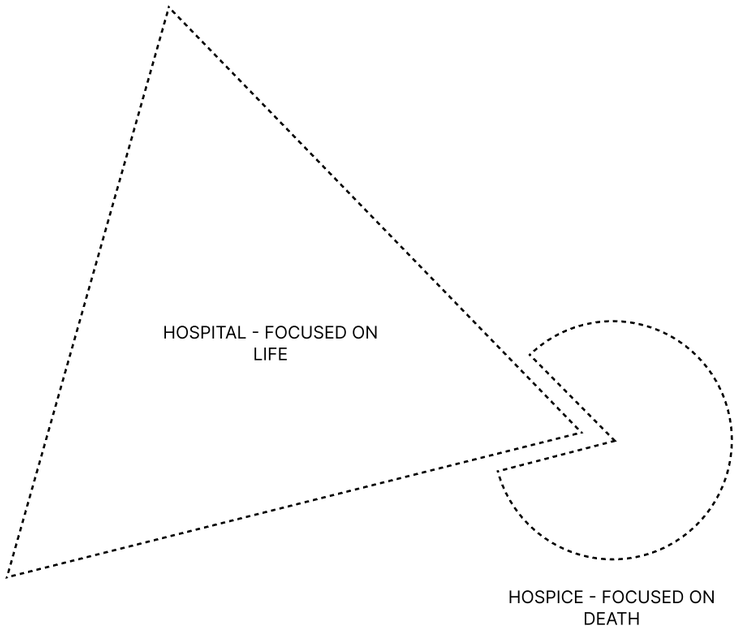


Figure 8: Diagram representing dissonance between hospice care and hospital care

THE PROVISION OF HOSPICE CARE

The core goal of hospice care is the provision of a ‘good death’ – a phrase that encompasses not only a physically pain-free passing, but also the circumstances around it; being able to say goodbye to loved ones, pass in a comfortable environment, a death in line with your values. Hospice care openly accepts the inevitability of death and welcomes it in a dignified manner.

Conversely, the modern medical system focuses primarily on curative treatments and intents – life-prolonging treatments and the pursuit of medical advancements. Over the last century, modern medecine has made huge leaps in this endeavour, as life expectancy worldwide continues to rise and technology progresses.

These two institutions lie in dissonance – one focuses on life, the other, death. However, for many, the provision of hospice care – death care – is provided through their medical system. While private, specialised hospices are common, these often come at a cost – a cost which is prohibitive for many of the lower socioeconomic class patients in the HNC population. Many patients therefore cannot elect specialised care as a result, choosing instead for hospital-provided hospice as it is usually covered by insurance or covered by governmental grants (wherein private hospices may not be). Further obscuring more comprehensive, hospice-centric care is the current scarcity of home care staff in the Netherlands. This provision of death-centric care, though an institution which is primarily focused on cure and prolonging life, can cause significant tensions – tensions which are felt in the patients experience of hospice care.

THE HOSPICE CARE EXPERIENCE

Patients hospice experience relies heavily on the provider – hospice care provided through their hospital will likely look different than that which would be provided by specialist institutions. For example, Erasmus MC’s palliative [hospice] care system consists of a remote care approach, where patients are monitored remotely - every 6-8 weeks (figure 9), patient compete the EORTC questionnaire (figure 11), which is submitted digitally, reviewed by a clinician, and then followed by a check in conversation. In contrast, specialised hospice providers may utilise tools such as the PCOC tool, however rather than remote care and imtermittent checkins, operates through frequent home calls and physical check-in’s to the pateints home, including services like night nurses, who stay in the patient’s home, providing assistance and allowing the family carers to rest. The specialist focus of the latter provides more comprehensive aid to both patients and families, improving perceived support, both physically and mentally. This approach also shifts some of the burden off family carers, allowing them to rest and recover, with this respite restoring physical and mental wellbeing and enabling them to care for their loved ones with increased competence and vitality.

In both cases (hospice and hospital), the nurse the patient is assigned is consistent throughout their hospice journey – ensuring a trusting, familiar relationship. In the case of Erasmus MC, this hospice nurse is preferentially, and usually, the same nurse that acted as the patients contact point during their curative journey, further bolstering comfort and trust, a dimension that cannot be achieved through hospice-specialist providers due to their disconnect from hospitals and curative staff. These nurses act as the primary contact point for patients – helping patients to find and arrange resources (including therapists), medication, and discussing care options (advanced care planning), connecting patients with support groups that the institutions are in contact with. In Erasmus MC, this nurse also provides support to the patient immediately following the diagnosis conversation, as well as a two-week follow-up consult to provide further information and support after the patient has had time to process the news and collect their thoughts and questions.

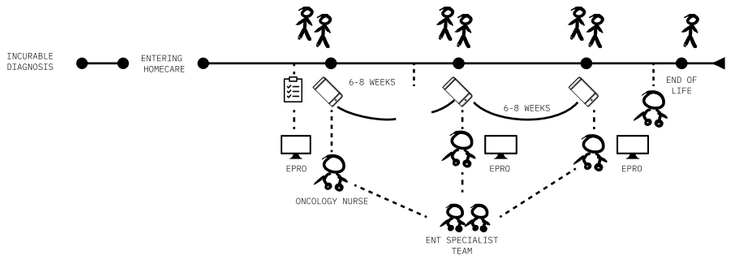


Figure 9 - Illustration showing the typical remote patient pathway in Erasmus MC (Kim, 2025)

PSYCHOLOGICAL CARE IN HOSPICE

The confrontational diagnosis, high symptom burden and short lifespan of HNC create a tempest of physical, spiritual, psychological and psychosocial distress for patients to navigate. This complexity entails a comprehensive support structure across all of these dimensions in order to support patients through the disease, and deliver on the core tenant of hospice (and palliative care) – the promise of quality of life.

Yet, despite this necessitated treatment and monitoring across these facets, a predominant focus is nonetheless given towards physical symptoms and pain, with psychological considerations being addressed insufficiently (Ferri et al., 2024). Studies have shown that patients and carers alike feel this incompleteness, with frequent expressions of desire for more psychological support (Mayland et al., 2020).

> *"Psychologically I find they need a lot of support… they could do with more"*
>
> *– Healthcare professional, (Mayland et al., 2020)*

Physical pain and symptoms are relatively intelligible; they can be measured through scientific means, monitored using advanced equipment, and treated through the huge advances of modern medicine. However, psychological, spiritual and psychological symptoms are intangible and abstract. This form makes them immeasurably harder to measure, monitor and treat, and requires a more involved discovery and addressal – and a different approach. Considering the aforementioned common provision of hospice care through hospitals this oversight and imbalanced focus on physical rather than psychological could be attributed towards the dissonance between hospitals focus on life and chase of cure and treatment through scientific monitoring and medication, rather than hospices focus and acceptance of death.

> *"…just, having somebody to explain or ask you what your fears are"*
>
> *– Patient, (Mayland et al., 2020)*

This inadequate addressal of psychological, spiritual and psychosocial wellbeing ultimately renders the core goal of hospice and palliative care – quality of life – unachieved.

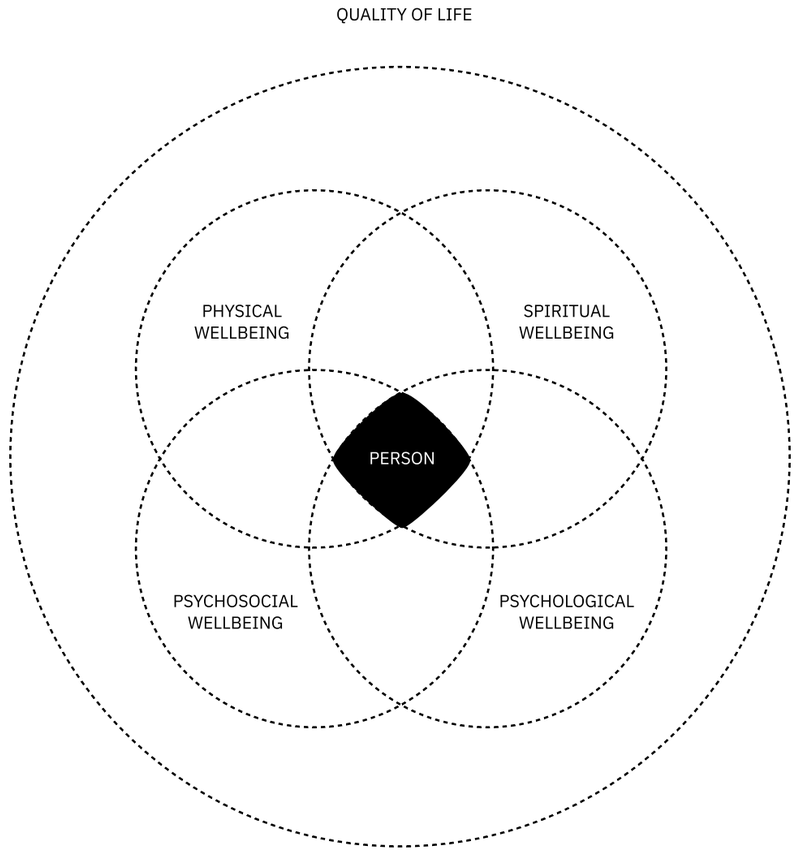


Figure 10, model outlining the facets needing attention in order to fulfill needs in hospice [palliative] care, (Nejadmasoom & Mirshahi, 2025)

MONITORING PSYCHOLOGICAL WELLBEING

Quantitative questionnaires are an academically-validated and broadly recognised tool used to monitor the wellbeing of patients during treatment and disease. These are particulary suitable considering their numerical basis, cooperation with standard digital systems, and ability to clearly indicate where care staff should intervene. A myriad of tools exist which have been developed in this realm, wherein tools used from institution to institution vary widely.

These include the EORTC QLQ (figure 11) and the PCOC tool. These tools attempt to gain a basic understanding of problem areas and highlight them as action points for nurses or other professionals on the patients care team. While this are suitable for application towards curative populations and the treatment of symptoms, the majority of these tools tend to be symptom-based. They do provide insight towards monitoring the quality of life of patients on a physical dimension, and identifying where QoL is impacted by somatic issues, however they fail to address the complex psychological factors around purpose and meaning that arise in the face of fatal illness, and pale in these contexts (Salmon et al., 1996). In the case of EORTC, while there are fourteen questions covering a blanket of physical symptoms, but only one question (Q15), which addresses quality of life – disconnected from a physical symptom. Considering QoL pertains to the whole life of a person - the spirtual, social, physical and psychological - these tools are insufficient. During interviews with patients and nurses who utilise these questionnaires, dissatisifaction was raised, with patients expressing frustration at the expectation to summarise their ‘Quality of Life’ across multiple weeks into one scale - something which healthy, able bodied people, free from the trauma and burden hospice patients face, would even likely find difficult considering the dips and peaks life brings. Nurses described the tools as ‘meaningless’, instead opting to simply talk to the patients themselves.

> *“Yeah… what is quality of life when you are dying?”*
>
> *– Patient, Interviewed*

Alternatively, the ‘Life Evaluation Questionnaire’ (LEQ) (figure 12) is a questionnaire which was specifically developed to monitor and measure the meaning of life for incurable cancer patients, detached from physical symptoms (Salmon et al., 1996). It was developed in collaboration with incurable patients, and addresses the aspects of psychology and existence that typical routine instruments neglect. While it is also a quantative instrument - something that was personally questioned for its applicability in the qualitative face of emotions and psychology - it employs more nuanced, experiential questions to assess overall meaning and quality of life. This acts as an example for how to bridge this gap between the monitoring and scientifc approaches of institutions, and the importance of quantative data for efficiency and specificity, and the abstract nature of psychogical wellbeing.

> *“A patient expressed their desire for the questionnaire to be more personalised”*
>
> *– Experts*

Figure 11 - Image of the EORTC QLQ-C15-PAL questionnaire, with limited psychological-centric questions highlighted (Groenvold et al., 2006)

LIMITED NUMBER OF PSYCHOLOGICAL QUESTIONS, SCALED AND QUANTATIVE

EORTC QLQ-C15-PAL (version 1)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: ☐☐☐☐
Your birthdate (Day, Month, Year): ☐☐☐☐☐☐☐☐
Today's date (Day, Month, Year): ☐☐☐☐☐☐☐☐

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
2. Do you need to stay in bed or a chair during the day?	1	2	3	4
3. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
4. Were you short of breath?	1	2	3	4
5. Have you had pain?	1	2	3	4
6. Have you had trouble sleeping?	1	2	3	4
7. Have you felt weak?	1	2	3	4
8. Have you lacked appetite?	1	2	3	4
9. Have you felt nauseated?	1	2	3	4
During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
10. Have you been constipated?	1	2	3	4
11. Were you tired?	1	2	3	4
12. Did pain interfere with your daily activities?	1	2	3	4
13. Did you feel tense?	1	2	3	4
14. Did you feel depressed?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

15. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7
Very poor Excellent

Table 2. Results of principal components analysis of LEQ responses. Items loading at ⩾0.40 are shown. The ratio shows numbers of patients agreeing/disagreeing with each item as stated (neglecting those scoring at the midpoint)

	Ratio	Freedom versus restriction	Appreciation of life	Contentment	Resentment	Social integration
I am able to do all the things I want to	59/114	0.66				
I sleep well	110/63	0.65				
I never feel tired	48/101	0.60				
Symptoms don't stop me doing or enjoying things	84/88	0.57				
I am keeping active	117/61	0.57				
I find it easy to relax	127/43	0.56				
I do not have symptoms that bother me	87/87	0.54				
I do not expect illness to cause pain in the future	64/97	0.51				
There is a lot I can do to make myself better	140/39	0.50				
There are many things I'm looking forward to	159/15	0.44				
I appreciate things more than I did	162/25		0.58			
My illness has helped free me from doing things	47/111		0.55			
I have a much clearer idea now what is important in life	124/45		0.54			
There are many people I feel closer to now	130/54		0.50			
Something good has come out of my illness	90/83		0.45			
I never feel lonely	154/26			0.61		
I have enjoyed life so far	170/18			0.60		
The doctors and nurses understand what I need from them	181/15			0.60		
Every day there is something I enjoy	173/12			0.60		
I can deal with the problems that face me	146/38			0.59		
I am happy with the way I was told about my illness	146/40			0.52		
My life is not disrupted by visits to the doctor	114/60			0.49		
My illness has not cut me off from people	146/43			0.44		
I worry a lot about how long or short my life will be	66/107				0.78	
I am frightened of what dying will be like	43/121				0.67	
I can't take my mind off my illness	51/123				0.63	
My illness has upset important plans	85/95				0.54	
When I get sad it stops me doing things	38/143				0.52	
Minor upsets bother me more now	37/143				0.50	
I always feel frustrated	71/99				0.47	
I am embarrassed about illness and treatment	54/132				0.47	
Symptoms bother me every day	87/87				0.47	
I always feel angry	31/138				0.46	
I am worried that I'll be a burden	100/77				0.46	
I am a great burden to people	32/149				0.44	
It feels unfair that I have this illness	91/77				0.40	
Friends know just how to deal with me	144/19					0.66
On the whole life has treated me well	172/11					0.64
There is always someone I can talk to about how I feel	181/12					0.64
My friends and family give me all the support I want	189/10					0.54
My home/family life has been rewarding	184/10					0.51
I have many close friends	161/18					0.50
I am very satisfied with the amount of information I have about my illness	175/15					0.50
I have enough people to talk to about my illness	168/20					0.43

Figure 12 - Image of the Life Evaluation questionnaire, with limited psychological-centric questions highlighted (Salmon et al., 1996)

SUPPORTING PSYCHOLOGICAL WELLBEING

Considering the trauma and challenge associated with facing impending death, many may assume that one of the most important disciplines patients would need to access would be a therapist. However, this was found to not be the case; instead there is a distinct lack of clarity regarding who in patient care teams is responsible for the patients psychological needs. Through primary research communications with multiple providers, institution's common opinion appears to be that psychological care is delivered by the nurses themselves – however, this is not officially recognised in care team structures. In personal, primary communications with institutions, there appeared to be an insinuation that the provision of hospice care, and psychological support provided through hospitals is not strictly required, and that what the hospitals do provide should be appreciated and seen as a 'bonus' of sorts. This could, again, be connected back to hospitals overarching focus on curative care, and the incongruous presence of a hospice approach.

Nurses express insecurity and doubt regarding their ability to deliver this psychological care they are supposedly responsible for, and wish that patients could instead access expert, qualified providers. Nurses also notoriously over-burdened and preoccupied with an already insurmountable amount of responsibility, and attributing this responsibility to them is both detrimental to the nurses own wellbeing, as well as the care patients – across the hospital - receive.

'I was working there for over 20 years… we repeatedly called on upper management to provide therapists or something, but they just never responded… I never heard anything back'

– Nurse (Interviewed)

During primary research consultations , nurses recounted how they had campaigned for the addition of a psychologist to hospice teams. In all cases discussed, (including a 20 year, tenured nurse), a response was never received. Considering the obvious harrowing nature of the hospice phase, it seems logical that a psychologist or therapist is indispensable.

'It's always too early, until its too late'

– (Smith, 2021) , Referencing the conversation project (2013)

PLANNING FOR THE END OF LIFE

A core tenant of hospice and palliative care is advanced care planning (ACP) – where care path decisions are discussed and reflected on, and decisions made, in advance, that align with patient values. These discussions are important not just to give patients QOL and comfort now by relieving current distresses and improving quality of life by focusing care towards areas of fulfilment, but also to discuss how to ensure comfort towards the end when there are even greater physical and psychological restrictions, and protect patient wishes and values even in death – particularly when patients may be incapacitated and unable to advocate for themselves.

While there may be discomfort involved in these conversations, they cannot be simply avoided; unfortunately, they often are. Healthcare professionals evade the topic, justifying their delays on the 'right timing' and afraid that the conversations would cause further distress and hopelessness (O'Sullivan & Higginson, 2014). As few as 30-40% of patients have been found to have discussed end of life care with their consultant prior to death (Seifart et al., 2020). Instead of early discussion, as palliative and hospice care advocates for, EOL discussions are instead delayed, often only being addressed when in dire crisis or death is imminent (Seifart et al., 2020).

In the rare cases that patients can access a professional to talk to, the effects of HNC on their speech can restrict the amount they can speak, limiting their ability to fully articulate their thoughts, and the ability to get to the crux of their issues. In some cases, patients may not be able to speak at all, making these conversations even more difficult when conducted through the medium of written text.

Patients struggle with emotional expression further derails these conversations, where their inability to open up may preclude revelations. Considering this guarded nature, getting to the crux of issues is difficult, and again, with speech impairments limiting conversation length, real progress can be impossible.

"Consultants should raise it with the patient… as a wife and carer, you are very close to the patient… it can be… too sensitive"

– Partner/Carer, (O'Sullivan & Higginson, 2014)

planning for the end of life, continued:

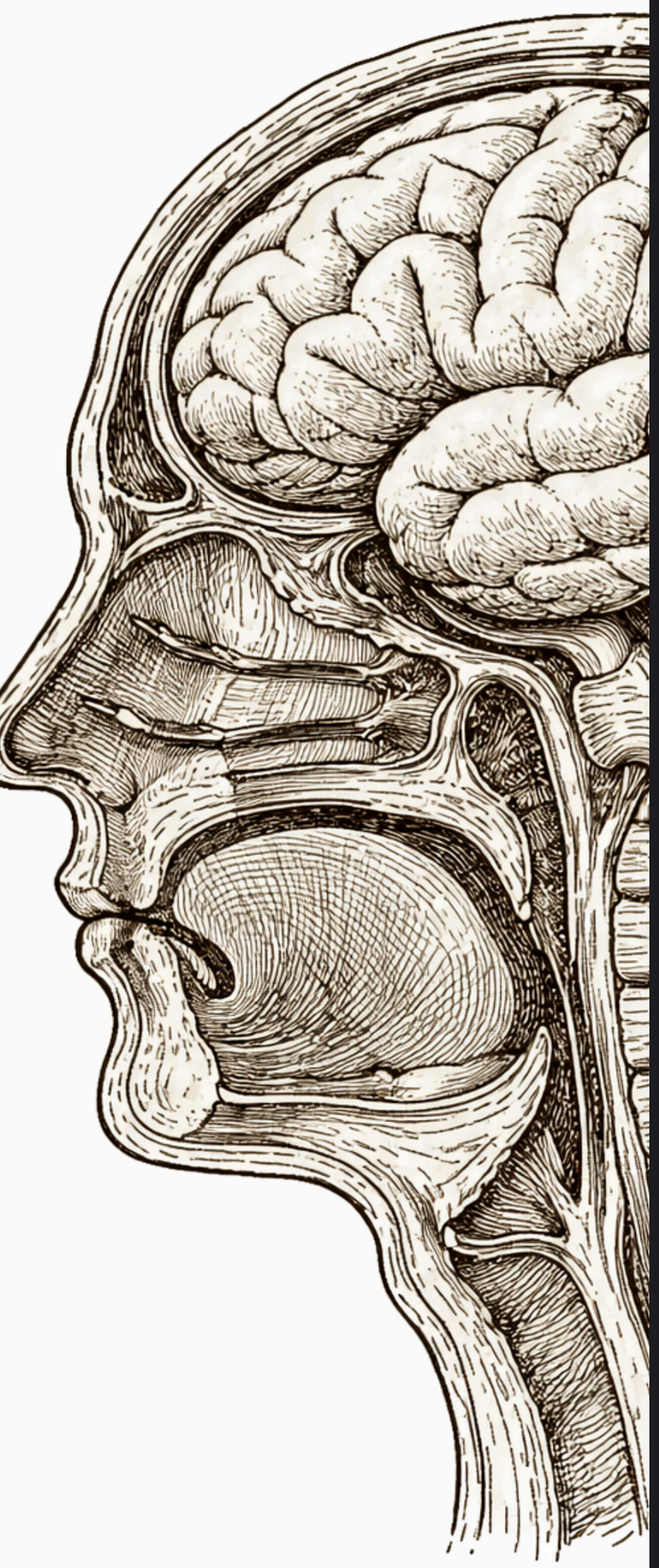
Patients and partners alike felt as if these topics were too sensitive and loaded to raise themselves. They felt that the shared relationship, grief and anguish would only serve to aggravate the desolation of the other, and preferred that the medical professionals should initiate these discussions as a neutral, emotionally detached party. Couples however dissented on whether or not these topics should be discussed at all, with carers wanting topics like DNR requests to be discussed openly and repeatedly, while patients wished to wait (O'Sullivan & Higginson, 2014). While 90% of patients acknowledged the importance of talking to their loved ones about decisions and care at end of life, only 27% of patients were found to have actually done so (Smith, 2021).

> *"'Yes, it should be discussed with him…. it's too sensitive between us because my emotions are involved as well…. Although he hasn't talked to me about that side of things..."*
>
> *- Carer, (O'Sullivan & Higginson, 2014)*

It is undeniable that discussing subjects like 'Do Not Rescusitate' orders, living wills, funerals, euthanasia and palliative sedation are distressing and challenging for all involved – particularly considering these patients demographic and particular characteristics. Unfortunately, natural HNC death is rarely peaceful and without struggles, and has been described as 'one of the most unpleasant and agonising ways a person may die' (O'Sullivan & Higginson, 2014). An important way to minimise the potentiality and pain is prior discussion of these topics. Broaching patient prognosis openly and early on helps patients become comfortable with the topic, eventually making these conversations easier, and ultimately facilitating a dignified death (Mali, 2024). It allows patients to choose where, and how they would like their death to be handled when the time arrives, as well as planning who they would like there, and give them sufficient time to handle their affairs and say their goodbyes in a peaceful a manner as possible. This care not only provides a good quality of life, but also quality of death (van den Besselaar et al., 2025).

CONCLUSIONS

This chapter defined the goals and systems of palliative and hospice approaches - quality of life delivered through care alignment with patient values and desires. It presented insights into the systems in place that aim to achieve an understanding of patient psychological wellbeing, and illustrated strengths and weaknesses.



DISCOVERING

III

THE MENS

‘Mens’ human [noun] a person

human being [noun] a person

man [noun] human beings taken as a whole; the human race

SECONDARY RESEARCH

PAPERS AND JOURNALS

~86 papers read
~45 referenced in final thesis report

BOOKS

4 Books Read and Referenced
(Dignity Therapy, Meaning-Centered Psychotherapy, Life Story Interview, Handbook of Psychotherapy in Cancer Care)

FORUMS, BLOGS

~40 Discussions read
1 blog reviewed comprehensively
(https://jakeseliger.com/)

CONFERENCES, VIDEOS

~5 videos viewed from cancer websites
1 hr long conference reviewed and referenced comprehensively
(https://www.youtube.com/watch?v=55INtd3bwMk)

Above - Example of patient insights

PREFACE - THE VOICE OF THE PATIENT

In order to design for a population, you have to understand the population. However, in this case, it is almost impossible to fully ‘understand’ the experience a HNC patient goes through. Being suddenly faced with your death in such a short window – five months – is something incredibly unnatural and incomprehensible, and something that is practically impossible to imagine how you would really feel.

Yet an understanding must be attained in order to design something that these people would truly appreciate. In most cases, the best way of doing this is by immersing yourself in the population – living their reality, visiting their environments, hearing their story – participatory design. Not taking the time to do so is actually a disservice to those you claim to design for.

However, with a population as vulnerable as these, the ethics of participatory design flip on their head. Inserting yourself into these people’s lives and searching for insights and perspective becomes immoral, as you are valuing the projects needs above the people’s needs – stripping patients of valuable moments of their short five months, and for an outcome which they will likely not live to see. This ethical dilemma can be seen through the existing literature, where much of it represents patients in an earlier phase of the disease trajectory, rather than those at end of life (Mayland et al., 2020).

In cases where engaging in research is something patients find joy and meaning, this becomes excusable – mutual benefit. However, finding patients who genuinely find fulfilment from helping others is a process in itself, where you still have to burden patients with emails or other contact forms in order to find these select few.

As a result, in this project, the majority of insights will come from secondary sources. Blogs, forums, academic papers, online conferences, support group testimonies. These will act as a voice for the patients – ensuring their inclusion without furthering their burden.

PAST, PRESENT, FUTURE

In order to understand a person's present, you must also consider their past and future. Our past is what shapes us – our culture, traditions, upbringing. Our future defines us – what we desire, what we work towards, our choices and goals as we chase it.

For a project like this with a larger population, it is of course impossible to generalise everyone's past and future. However, what this population does share is their cancer experience in the years leading up to hospice – their curative treatments, trials, diagnosis.

They also share the unnatural awareness of their approaching end of life, and an unusual, rare knowledge of what it will likely look like. While this project focuses on, and works with patients present and their navigation of the hospice phase, it is therefore also important to illustrate the pre-hospice trajectory, and end of life reality.

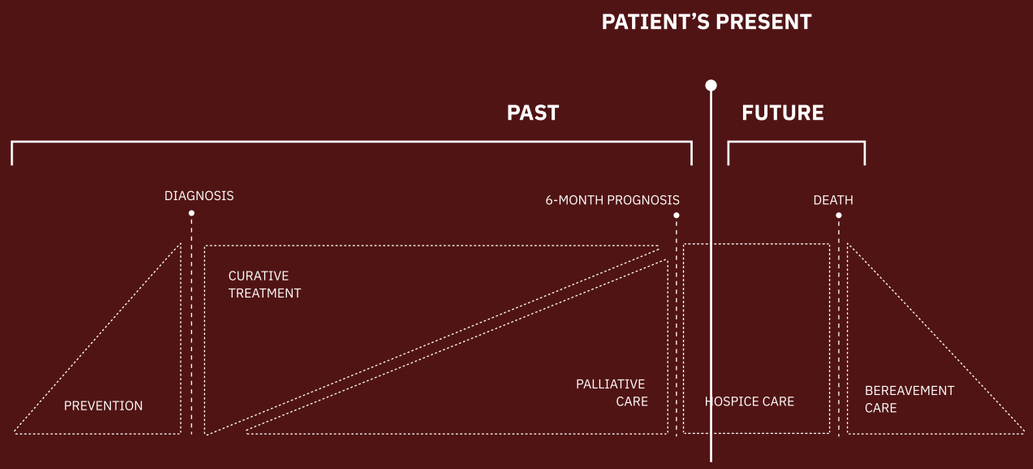


Figure 13: project point-in-time focus within care trajectory

THE CURATIVE PHASE

Prior to their incurable diagnosis, patients have already faced significant challenges. It is important to briefly illustrate these facets, contextualising and understanding the patient's present self and struggles as only a portion of their overall experience.

RQ: What Are Patients Experience Of The HNC Trajectory?

TREATMENTS

The aggressive, exigent nature of HNC entails commensurately aggressive treatments to combat its progression – considering the short trajectory, immediate aggressive action is imperative. Originally, HNC treatment consisted solely of surgical approaches, a treatment still preferred in non-metastasized cases for the complete removal of affected tissue. However other treatment modalities emerged as medical science developed, including radiation, chemotherapy, immunotherapy, as well as combination approaches such as chemoradiation (Contrera et al., 2025). The aggressive assault of these treatments towards the disease, though warranted, can cause incredible damage to patients psychologically and physically, both through their administration, side effects, but also the psychosocial and emotional tolls involved.

THE TRANSITION TO HOSPICE

Because of the difficulty in prognostication, the moment of incurable diagnosis is often shocking and unexpected. Patients and their loved ones arrive to the hospital, expecting another typical consultation, with updates on their treatment options, and are instead met with the news of their incurability. Being suddenly told your life expectancy is changing from ten or twenty years to five months is incomprehensible - yet patients are expected to absorb it, ask their questions, and then are sent home – often with no pamphlets, resources, support to turn to as the news gradually sinks in.

> *"you know, if Dr…. said 'go away and absorb the information, I'll set up for you to come back in a weeks' time… that would have been… a really good way of managing a very difficult situation"*
>
> *– Patient, (Mayland et al., 2020)*

> *"I had no idea they were going to say you know, well this is it and you only have a few weeks"*
>
> *– Patient, (Mayland et al., 2020)*



Figure 14 - Radiation mask that is clipped over patient's head and face when recieving radiation treatment (Head & Neck Cancer Support Aotearoa, 2024)

THE PATIENTS PRESENT - TERMINALITY

Entering hospice, patients are faced not only with the trauma of a terminal diagnosis, but the deteriorating nature of HNC squelae. Separately, these bring a myriad of psychological, psychosocial, spiritual and physical impacts, which when presented in concert, illustrate the loaded, complex, harrowing reality HNC patients suddenly, unexpectely, find themselves in. Research was extensively conducted, and insights triangulated to obtain a holistic image of these patients realities. For audience comprehension these insights are presented bipartite.

PART 1 - THE IMPACTS OF HNC

First, the impacts of HNC are presented. As these were found to be generally emergent from physical squelae, they are presented categorised by the relevant symptom.

PART 2 - THE IMPACTS OF TERMINALITY

After this, the impacts and influence of terminality is presented. These are presented thematically, with insights triangulated into four primary themes.

THEME 1 - IMPORTANCE OF LOVED ONES

THEME 2 - NORMALCY

THEME 3 - EMOTIONAL EXPRESSION

THEME 4 - CHOICE, CONTROL AND DIRECTION

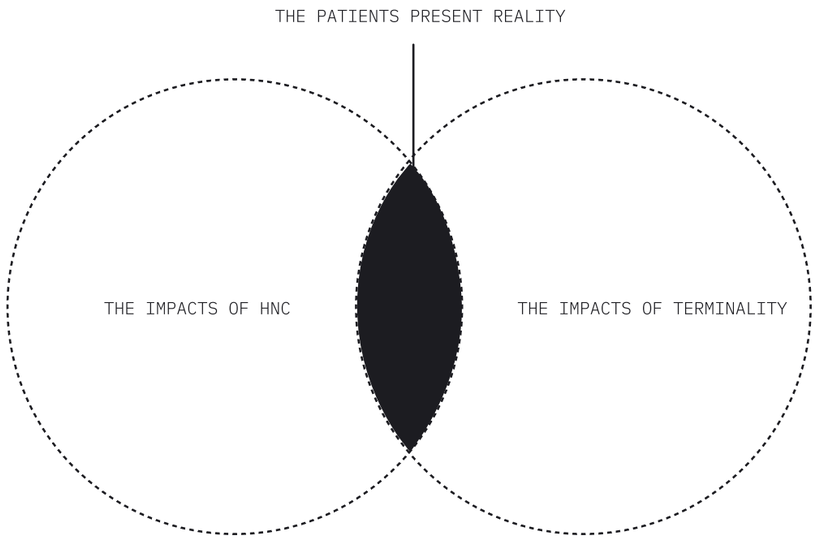


Figure 15: Venn diagram collating patient impacts

THE IMPACTS OF HNC

RQ: How Does The Presence Of HNC Affect Patient QoL- Physically, Psychologically, Spiritually And Psychosocially - In The Hospice Phase?

HNC involves a myriad of complex side effects stemming not only from the disease's progression, but from treatments themselves. These squelae not only have a physical impact, but also profound psychological, physical, psychosocial and spiritual repercussions. This physical-psychological impacts are presented in concert in the following pages.

BODY IMAGE

The severe effects of nutritional issues can result in body image issues, beyond solely the face. Cachexia, drooling, and the army of medical equipment can create a huge rift between patients and general society, and have major implications on patients day to day life. Patients may be unable, or not want, to leave the house at all, not only changing the patients own social dynamics, but also those of their loved one (Goldstein et al., 2008).

> *"A lot of people, friends… have said, 'You're still the same person. It doesn't matter what you look like."*
>
> *– Patient, (Gibson et al., 2021)*

SPEECH IMPAIRMENTS

The mucositis, xerostomia, and other Pharyngolaryngeal impacts of HNC has significant impacts on patients ability to converse and speak. These impacts can be transient, but often they can also be permanent (Goldstein et al., 2008). These impacts range from impact to the sound of patients voice, limitations in conversation capacity length, or in some cases, the loss of speech entirely. Patients may need to use an assistive device (Goldstein et al., 2008) and rethink their method of communication.

Predictably, this has major consequences on patients psychosocially. Conversation is an important facet of sustaining meaningful relationships, and a core part of many social rituals. Patients may no longer be able to converse with their loved ones in person or on the phone, further isolating them socially, with emailing and text inadequate for conveying the level of emotion that the hospice period entails.

PATIENT'S PRESENT - THE IMPACTS OF HEAD AND NECK CANCER

MUCOSITIS, SIALORRHEA AND XEROSTOMIA

EATING AND SWALLOWING

FOOD AVERSION AND ANOREXIA

As a result of the myriad of squelae affecting the throat and mouth region, HNC has a huge impact on patients ability to eat and swallow. In cases where patients can still take oral nutririon, many foods may be forbidden due to patients limitations in swallowing competency. For these patients, impacts can still be felt through the loss of taste or smell, or disinterest in permissible food options, impacting patients ability to enjoy food regardless. Dentists and speech pathologists are often avaible to patients to assist with meal preparation, however in many cases, patients will evetually have to move to alternate means of nutrition (Goldstein et al., 2008).

These issues can cause broader challenges, such as the development of anorexia due to lack of food-related interest as a result of these alterations to patients taste and smell. This in turn can result in cachexia, which can be distressing for both patients and loved ones alike (Goldstein et al., 2008).

> *"I'm only a small build so I looked like something out of a concentration camp"*
>
> *– Patient, (Gibson et al., 2021)*

> *"Most of my nutrition is taken through a tube. It affects me because I can't travel a very far distance [from home] without having to deal with the tube feeding. It is cumbersome and somewhat messy. So, I don't want to go very far"*
>
> *– Patient, (Goldstein et al., 2008)*

CULTURAL IMPACTS

This impact has significant psychosocial impacts. In society, eating and food are hugely important social rituals (birthdays, Christmas) as well as in religious and cultural circles (Ramadan, communion) (Thamm et al., 2023). Exclusion from these celebrations compounds patients existing distress.

MOBILITY

Sometimes, this inability to eat can result in patients needing to use a feeding tube which can have further devastating impacts on patient's mobility. Patients constantly need to adapt their plans and schedule to accommodate the care needed for the tube – flushing the tube, preparing formula, privacy. Unfortunately, this is a common affair. This further compounds patients isolation and loss of normalcy.

While bolus feeding may help liberate patients from the reliance and restrictions of frequent pump feeding (Goldstein et al., 2008) it is often ill-suited as a result of the side effects, such as bloating and nausea, and its unsuitable nature for those with gastroesophageal diseases such as GERD or gastroparesis.

Surgical intervention remains a popular approach in the treatment of HNC due to its absolute nature. While its effectivness is indisputable, its impacts on ones person are significant.

> *"It's not something that you can have an operation and nobody else would know or the side effects."*
>
> *– Spouse, (Thamm et al., 2023)*

FACIAL DISFIGURMENT

HNC is a distinctly visual disease (Thamm et al., 2023), one which cannot be 'hidden'. Feeding tubes and equipment, surgery impacts, weight loss, all create an evident presence of HNC. Surgery is the most disfiguring of these, where the removal of tumours can result in removal of parts of the throat or neck,and reconstruction work of soft tissue required in the aftermath of tumour-removal surgeries. This can result in dramatic changes to patients visage and appearance. Physical and occupational therapists can help patients work through and adjust to these changes, but ultimately can not change the surgeries visual outcome (Goldstein et al., 2008).

> *"I didn't even recognise myself. I didn't even know who I was. I looked in the mirror and I didn't even see myself. That's how different I was"*
>
> *– Patient, (Gibson et al., 2021)*

Our faces are a fundamental aspect of our self-concept, and the cornerstone of our identiy. Every morning, one of the first things we do is see ourselves in the mirror; for patients, this first experience only serves as a reminder of the cancer, and often, their discomfort and hatred towards their new appearance. This fracturing of identity can have huge psychological and psychosocial consequences (Mali, 2024).

> *"People say they don't notice it, but I do and I hate it more than anything"*
>
> *– Patient, (Gibson et al., 2021)*

PATIENT'S PRESENT - THE IMPACTS OF HEAD AND NECK CANCER

SURGICAL AND INVASIVE INTERVENTIONS

FACIAL DISFIGURMENT, CONTINUED

As our primary mode of communication and medium for expressing ourselves to the world (Gibson et al., 2021), our visage largely defines how society perceives you and how we express ourselves to the world (Thamm et al., 2023). Departing from this expectation of beauty by society can lead to social exclusion, ostracization and aversion (Thamm et al., 2023), leading to social isolation. This can also occur as a result of patients own self-consciousness and subsequent retreat from public (Mali, 2024).

> *"I'd have people walk up talking to like me and [partner], family friends walk up and start talking, they were talking to her, and they were sort of looking at me and looking away. They didn't even know who I was. And then [partner] would go 'Aren't you going to say hello to [redacted]?' and they were like, 'Oh.' Nobody knew what to say to me"*
>
> *– Patient, (Gibson et al., 2021)*

Intimacy and partner relationships are also endangered, as the impacts of facial reconstruction and disfigurement can lead to spousal disgust and rejection. Participants in a study by Gibson et al., 2021, said they anticipated repudiation from their intimate partners as a result of their surgeries, and said they would understand if their spouses were repulsed and wanted to leave them (Gibson et al., 2021).

> *"…she said, 'That's your dad there.' 'No, that's not Dad'… she took one look and went outside and burst out crying."*
>
> *– Patient, (Gibson et al., 2021)*

When dealing with chronic, serious illnesses, some of the pain and discomfort that patients experience cannot be attributed to any distinguishable source - such as muscle pains or aches, which cause further distress and discomfort. As a result of the older demographic associated with HNC, this cohort of patients face a substantial amount of this generalised pain - fatigue, restlessness, malaise. However, these symptoms are often magnified by the simultaneous presence of HNC.

> *"I think it's what turns off a lot of people is the constant coughing, hacking, sick-looking patient…"*
>
> *– Doctor, (Thamm et al., 2023)*

DEPRESSION AND ANXIETY

While HNC patients suffer a myriad of designated side effects, patients also suffer from general, indistinguishable pain (cramping, discomfort, etc). In the case of HNC, this undefined 'pain' brings with it additional stress and concern, as patients worry that this pain is being caused by tumour growth, which, it often is.

> *"…worry that every pain or discomfort means that the cancer is back?"*
>
> *– Patient, (Goldstein et al., 2008)*

Patients also may face changes or limitations in the medication and formulas they can take in order to deal with this pain, as mucositis and other squelae cause difficulties in swallowing (Goldstein et al., 2008), potentially requiring medication changes and adaptations.

As is clear, HNC patients suffer a huge symptom burden, both psychologically, psychosocially, spiritually and physically. This frequently gives rise to depression, with the HNC population twice as likely to die by suicide than other forms of carcinoma (Gurren et al., 2022).

> *"…I did have some intermittent bouts of depression… I would like a quick return to a normal lifestyle. I would very much like to eat real food again and converse as normally as possible."*
>
> *– Patient, (Goldstein et al., 2008)*

SELF-BLAME, GUILT AND STIGMA

Due to the high attribution of HNC cases with alcohol or tobacco use, feelings of shame, guilt and self-loathing are widely reported by HNC patients (Goldstein et al.), as patients blame themselves for their own illness. While these feelings of self-disgust and regret exist intrinsically, they are often exacerbated extrinsically. Lifestyle related medical challenges – such as those caused by substance abuse and addiction – are heavily stigmatised by society, with the general population placing blame on the suffers' themselves (Thamm et al., 2023), with patients experiencing scorn instead of sympathy.

However, substance use of tobacco and alcohol has had a less consistent societal image. Over the last decades, it has consistently oscillated between rejection and acceptance (Thamm et al., 2023), from the initial health claims of big tobacco to widespread scrutiny, to the introduction of vapes and other cigarette-alternatives. Nevertheless, the condescension of society, family and even nurses remain.

> *"They can frigging wait for their pain relief, if they're well enough to go out for a cigarette."*
>
> *– Nurse, (Thamm et al., 2023)*

In addition to dealing with their own guilt, and blame from society, patients also feel shame for how their self-inflicted disease is now inconveniencing and impacting the lives of their loved ones (Goldstein et al., 2008).

> *"….[they] say 'are you a smoker?' first, and then you say 'yeah', and they go, 'well there you go'."*
>
> *– Patient, speaking about Nurse attitudes, (Thamm et al., 2023)*

THE IMPACT OF TERMINALITY

RQ: When Faced With Death, How Do Patients Values Change, And What Are Their Priorities And Concerns At End Of Life?

While the exploration of patients physical symptoms provided significant insight into resultant psychological and psychosocial challenges, it would be remiss to expect that this corporeal-based investigation would encompass a holistic understanding of patients psychology.

When confronted by the death, the manner in which we evaluate our lives, our meaning (Salmon et al., 1996), our purpose and priorities, changes. Aspects which were important before - prestige, novelty, achievment and success become irrelevant, replaced by preoccupation and priortisation of relationships and harmony become central (Fegg et al., 2005). This shift is shown in Fig x, which illustrates these patients migration towards action for the greater good, and regression from self-driven goals and values.

To determine patients priorities, desires and perspectives during this phase, insights were triangulated across blogs, forums, literature, conferences and other sources to distinguish overarching themes.

Be ready for changes in the patient's world and what matters to them – it narrows

– Spouse, (Head and Neck Cancer Alliance, 2024)

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

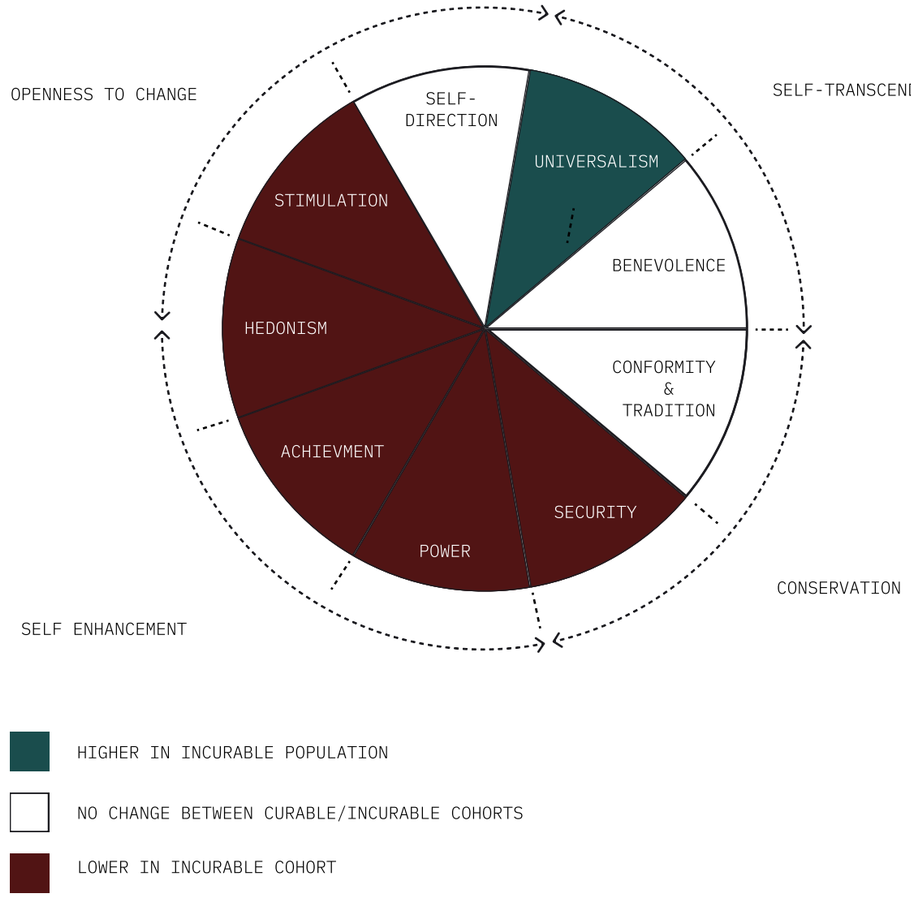


Figure 16: Image showing value construct changes in terminally ill population (Fegg et al., 2005)

THEME 1 - IMPORTANCE OF LOVED ONES

In hospice care, previous sources of importance such as ambition and success, respect and prestige, wealth and respect become pale. Instead, patient's priorities shift towards their loved ones – preserving and enhancing their welfare, both before, but also after, their death (Fegg et al., 2005). This was the predominant theme which emerged from this research cycle - the importance of connection and relatedness to patients with their loved ones. It was a central theme throughout forums, value-centered literature as well as papers and studies, as patients said their new reality changed their perspective and priorities, neglecting materiality and consciously cherishing their relationships with those around them (O'Callaghan et al., 2020).

> *"[Before my diagnosis] Travel was very important, and you know... like dining out… I would go shopping. And now things more important have become family time, friends"*
>
> *– Patient, (O'Callaghan et al., 2020)*

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

THEME 1 - IMPORTANCE OF LOVED ONES

TIME WITH LOVED ONES

Spending time with family, friends and loved ones clearly presented as a high order priority for patients in the hospice stage. The inevitable realities of HNC can hinder the fulfilment of these desires, as even something as simple as going out for dinner can be rendered impossible as a result of feeding tubes, mobility, and more. Patients' limited energy also can make forward planning events impossible, as what is socially or physically okay one day may entirely pivot the next (Head and Neck Cancer Alliance, 2024 and Goldstein et al., 2008). Equally, patients expressed intentions for their 'lasts' – last anniversary, birthday, etc – may heavily misalign with the reality. While they often hope to participate in order to give their loved ones happy final memories, and find closure themselves, the arrival of the day can be confronting. Patients and partners alike speak of 'grief hangovers' on the day following, grieving the finality of it all (Head and Neck Cancer Alliance, 2024).

Much of patient's desires resolved around family matters and loved ones – manifesting in a myriad of ways. For some patients, it consisted of simple, quality time with their partner, such as a shared coffee in the morning – for others, it concerned specific matters, such as surviving to see the birth of a grandchild. For another patient, attending his daughter's wedding was his priority. Originally only able to open his mouth slightly, he engaged in intensive work with a cooperating speech therapist, in order to deliver a speech on the (rescheduled to his disease trajectory) wedding day (Head and Neck Cancer Alliance, 2024).

In some cases, this desire for time with their loved ones dictated the care patients selected. For example, one patient attributed their decision for home care/death to their wish to be able to maintain contact with their grandchildren.

> *"Their parents wouldn't be happy taking them to a hospital and a hospice doesn't cater for small children"*
>
> *– Patient; explaining their desire for home hospice in order to continue seeing their grandchildren, (O'Sullivan & Higginson, 2014)*

However family time, particularly with younger children, was a loaded topic, with some patients expressing sadness during their final months regarding how their relationship with their grandchildren became strained as a result of an incomprehension of the disease, and fear revolving around the visual symptoms of HNC.

"…they've got a pool, so I hopped in and had a swim, and she got out of the pool and said to her mother, 'Should Granddad be swimming in our pool because he's sick? He won't pass anything on that we could catch, will he?' Yet my daughter had sat down with her and tried to explain and yet that was one of her fears, that she was frightened that she would catch what sickness I had."

– Patient, (Thamm et al., 2023)

"…happiness is not: "I will be happy when I have partners, children, house… when I retire… when I loose 30 kgs… when I get my degree… when I get the better job." No, you need to find out happiness now. With… your family, your friends… wherever you are now."

– Patient, (O'Callaghan et al., 2020)

"Patients often mention that they have difficulties sleeping at night because of concerns, which often relate to worries about their financial situation or loved ones

– Experts, Interviewed

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

THEME 1 - IMPORTANCE OF LOVED ONES

CONCERN FOR LOVED ONES

Patients with head and neck cancer face an incredibly complex and challenging disease, with significant symptom burdens and a huge mental toll (Mayland et al., 2020). As such, it could be expected and forgiven for these patients to be self-absorbed and wallow in pity. Yet, research through forums and literature clearly shows that a large portion of patients concern and grief is directed towards their loved ones, as opposed themselves.

Patients expressed worry for their loved ones, expressing that the preserved welfare of friends and family was a priority (Fegg et al., 2005). However, these concerns also applied to their loved ones wellbeing after their (the patient's) death. These sentiments ranged from the emotional, where patients were anxious about the level of psychological support their loved ones would receive after their death, to the logistical, and concerns regarding financial impacts (O'Sullivan & Higginson, 2014). One recently bereaved partner relayed how she had lost over 50% of her late husband's pension as he had died three days before his retirement (Head and Neck Cancer Alliance, 2024). While it may seem superficial to have concerns about such practical affairs during such an emotional period, it matters to patients that they know their loved ones will have the space to grieve when they need it, without having to worry about arrangements such as these. (Thompson, 2019)

'I have organised and paid for my funeral and put some money aside for the people that come to have a drink on me afterwards'

– Patient, (Thompson, 2019)

'I get sad and frustrated about what is to come, about the financial situation my wife will face… I stopped working before I met her and she therefore won't get any of my pension'

– Patient, through expert consultations

'I worry about [my husband] after I am gone... wish there was more clear guidance for grief support for them, he's not good with that'

– Patient, interviewed

THEME 1 - IMPORTANCE OF LOVED ONES

THE GUILT OF BURDENING

> *"Myself and my wife, that's the family… so, it's all going to fall on her shoulders and that is colossally unfair"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

Although patients expressed their appreciation of how much care they received during their final months, and the love they felt from this care (O'Callaghan et al., 2020) they simultaneously felt guilt and shame for this burden (O'Sullivan & Higginson, 2014). In most cases, patients spend hospice in a home environment, with the burden of care typically falling on their spouse – considering the complexities and challenges of HNC, this responsibility is huge, and which trained HCP's themselves oft struggle with (O'Sullivan & Higginson, 2014). While continued home care is preferred by both patient and carer, it does not negate patient's feelings of inconvenience and guilt.

> *"Well, it would depend how bad it was… I wouldn't want to put anyone under such pressure… it's important to think of others first, I wouldn't want to put a strain on them any more than you have to"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

THEME 2 - NORMALCY

Abnormality is a reminder to patients of their unavoidably unnatural situation – medical devices and people fretting or tiptoeing around them only stands as a unwelcome cue towards their cancer and approaching passing. Patients crave a simple sense of normalcy - a life before the chaos - and find a great deal of comfort in its presence.

> *"So happiness is simple things to me… [the] sun coming up in the morning. East out here, comes right in the door."*
>
> *– Patient, (O'Callaghan et al., 2020)*

JOY IN THE SMALL THINGS

Terminal diagnosis requires a total life recalibration; repositioning and reframing your entire perspective. This confrontation causes patients to significantly change their perspective on life, loosing interest in larger, particularly material goals, and instead leaning into appreciation of the simple joys and beauty of everyday life (O'Callaghan et al., 2020). Things such as the laugh of a child, a pretty sunset or sunrise, or just their presence and appreciation for being able to live another day. Patients were also more cognizant of the fleeting nature of time and life, and intentionally focused on living in the present (O'Callaghan et al., 2020)

> *"[happiness is] a fairly fleeting sensation that we should cherish when it happens. And it can be caused by the smallest thing… Feeding the birds; there is one out there waiting for me now and the hedgehogs at night."*
>
> *– Patient, (O'Callaghan et al., 2020)*

FOCUS ON THE PRESENT

> *"I live every day for today. I don't look to what is coming at me tomorrow. Because that won't help me."*
>
> *– Patient, (O'Callaghan et al., 2020)*

Similarly, patients tended to speak about the present, and not dwell on the future. This was partially attributed to the uncertainty and darkness the future signified, but also the desire to fully relish in life, the present, and the now. Surprisingly, very little evidence was found for a 'fear of death'; however this could be explained by the stoic nature of the population.

> *"happiness is now"*
>
> *– Patient, (O'Callaghan et al., 2020)*

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

THEME 2 - NORMALCY

FAMILIARITY AND THE HOME ENVIORNMENT

One of the primary wishes expressed as part of maintaining a sense of 'normalcy' was patients – and their loved ones – desire to keep the patient in the home environment for as long as possible; if feasible, up to and including death (O'Sullivan & Higginson, 2014).

> *"I want to stay in my own home for as long as possible… in the home environment you still have personal things around you, you're still able to move around your personal space whereas in a hospice or acute ward it's more regimented"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

Patients described the home environment as a 'place that would help them to focus on living'(O'Sullivan & Higginson, 2014), while being on a trolley in a hospital would just act as a reminder that death is near. Some patients did express a preference to spend their final days in a hospice or care ward as opposed to at home; this was attributed primarily to a feeling of security, and knowing there were trained professionals at hand should a crisis arise (O'Sullivan & Higginson, 2014).

> *'I think it depends on the individual as well, and how much they're willing to help themselves... when I had open wounds I dressed them all myself…Other people might be too scared; they might feel better in a hospital environment or acute ward, where they feel safer'*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

> *"…it's the mental issue of feeling that I'm here (hospice) because I'm going to die"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

THEME 3 - EMOTIONAL EXPRESSION

Because of the demographics involved in HNC – elderly, male – I hypothesised early on that emotional expression would be of thematic importance. Death, grief and loss are hard topics to discuss for people in general – paired with this demographic, who are already adverse to emotional expression, it is a recipe for stoicism. This was validated in this research stage, with frequent references arising regarding patients' unwillingness or inability to express their feelings, and consequent impacts on the delivery of psychological care.

> *"It's about the whole stigma attached like "oh my God I'm going to see a psychologist!""*
>
> *– Healthcare Professional, (Gurren et al., 2022)*

> *""My cohort are 60-year-old farming gentlemen who've lived all their life on a tractor. They've never had a problem. They don't speak about things. So it's a typical Irish male.""*
>
> *– Healthcare Professional, (Gurren et al., 2022)*

TABOO AND CULTURE SURROUNDING DEATH

Taboos are rampant in the relam of HNC – towards death, dying, mental health and emotions. It is critical that these patients discuss these topics – both to ensure quality of life, but also quality of death. Timely discussion of eolc is critical for quality of death, but a unwillingness to talk about these topics prevents this. Many societal influences uphold the intensity of these misgivings – particularly religious and conservative populus. Although Fegg et al., (2005) found that traditional ideas and religion can help protect patients QoL, particularly their spiritual wellbeing, it can also be incredibly damaging to their overall care path and advance care planning *(O'Sullivan & Higginson, 2014)*.

> *"[patients] Equate a DNR request with "that euthanasia type of thing" or "giving up""*
>
> *– (O'Sullivan & Higginson, 2014)*

A large cohort of patents favoured maximum medical intervention, and became incensed when topics such as euthanasia or palliative sedation were raised. For many countries suicide and euthanasia are still heavily debated topics – for instance, in Ireland, a historically religious and conservative country, suicide was only decriminalised twenty years ago, with assisted suicide and euthanasia still penalised (O'Sullivan & Higginson, 2014). These historically conservative countries often still view death as 'God's choice' and intervening blasphemous.

DISORIENTATION AND DISCOMBOBULATION

Patients across sources expressed a sense of 'being lost' during the hospice phase. Ill-prepared for the reality they were about to face, and ill-equipped for dealing with the day-to-day mechanics home hospice required. Patients felt abandoned and left alone to try muddle through and figure it out themselves, not knowing where to turn to or what to fret about.

> *"I wish that when I was diagnosed I could have been put in the direction of a head and neck support team, with people that have been through this"*
>
> *– Patient, (Mayland et al., 2020)*

One carer shared that one of the most impactful adjustments made in their family home was the use of a recliner chair with a power lift, recounting how it allowed her husband to be included at the family dinner table, to sit up during visits, etc (Head and Neck Cancer Alliance, 2024). Having a formalised, singular place to share or find these kinds of information would be of huge import to these patients and loved ones.

BELLICOSE NARRATIVES AND LANGUAGE AROUND CANCER

An unexpected, silent contributor towards the theme of resistance of death, emotion and vulnerability, is the ubiquitous metaphors and descriptors present throughout the cancer domain. While these are often employed with well-meaning, their receipt by cancer patients can cause significant harm.

Cancer descriptors are often aggressive – associated with war or battle, and enforcing the sentiment that cancer is an entity which should, and has, to be fought. Patients have been found to resent these analogies, saying that it implies the patient as a party in this 'battle', and therefore also positions them as a 'loser' or failure should the cancer win, framing the patient as guilty, shameful: that the patient is responsible for a loss (Hauser & Schwarz, 2019). It implies implicit criticism should treatments not work out.

Cancer is not a sentient being, it is not conscious and wilful – it is simply a disease, not something which can be fought (Buechler, 2023). Another patient pointed out that the cancer is within them, part of their self, their cells – therefore framing cancer as something that should be fought implies that the patient should, and is, battling themselves (Buechler, 2023).When considering hospice care, this metaphor becomes even more destructive, as the patients terminality means there really isn't anything to fight.

This approach and narrative surrounding cancer as something that should be fought only enforces patients pressure to participate in this fight, further deterring conversations around palliative or hospice care as a shameful act of 'giving up the fight'.

> *'The patient failed their front line therapy…. The patient lost their battle anyway'*
>
> *– (Buechler, 2023)*

> *"I did not fail... it simply didn't work for me"*
>
> *– (Buechler, 2023)*

'Journey' metaphors were another identified cliché that caused aggravation in patient populations. Some patients describe journey as a thing associated with enjoyment, choice, discovery – something which cancer is not (Buechler, 2023).

Yet another ill-percieved phrasing tendency in society was describing cancer patients as a 'cancer survivor' or other similar terms. Instead, patients would rather they be referred to as a 'person with cancer' – this positions the person as central, and the cancer as a secondary presence, rather than a person who exists in secondary reference to their disease (Buechler, 2023).

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

THEME 3 - EMOTIONAL EXPRESSION

STOICISM AND THE MALE GENDER

> *'Men have been raised to be self-reliant: stand on your own two feet, fix it yourself, don't make a fuss'*
>
> *– (BACP, 2025)*

Men and mental health is a widely recognised problem, with huge campaigns – such as movember - established in recent decades trying to revert the centuries old stigmas and gender norms that contribute to the male suicide and mental health epidemic. Taboos around therapists and psychological interventions also run rampant, particularly among older generations. The older attitude of 'I'll be grand' and not wanting to bother or worry others prevails, and the trope of 'keeping up appearances for society' and avoiding showing any sign of weakness or problems further deters these older patients from taking the steps towards the care they desperately need. Struggles with vulnerability, and admitting that one needs help delays patients from seeking therapy, instead waiting until things become critical. In studies, men have been found to describe therapy and emotional support as 'self-indulgent' or 'pointless', perceiving therapy as 'not for them' – particularly in cases where there is no obvious, or visible, mental illness (BACP, 2025).

> *"Being able to get up in the morning and having the pain so I know I am not dead"*
>
> *– Patient, (O'Callaghan et al., 2020)*

Quotes such as this were commonplace for male patients when asked in-depth questions about their feelings – circumventing emotional depth, and not wanting to discuss more vulnerable topics. Attitudes towards therapy remain negative, with fewer than 30% of men having sought professional help. While these statistics have been improving in recent years, this shift is largely related to younger generations. However, of those who have eventually sought therapeutic help, over 75% said they would recommend it to others (BACP, 2025).

> *"You know, definitely the younger generation are way more open and see [psychology/mental health services] more as part of healthcare, whereas I think an older […] [generation] think "Oh my god I don't need them, do I?" You know?"*
>
> *– Healthcare Professional, (Gurren et al., 2022)*

STUBBORNNESS

[paraphrased from dutch] 'I've been smoking for 65 years, I am not about to stop now'

– Patient, Observed

An unexpected finding was the stubbornness of the HNC patient population. Even though feelings of guilt and shame regarding the self-inflicted nature of the disease, a resistance to disengaging from these behaviours pervaded in its dissonance. In one study of patients, 64% of patients still self-reported as actively smoking, and 71% as actively drinking (van den Besselaar et al., 2024). Observations echoed this, as one patient, whose scent betrayed his persistent habits, clearly bristled at the suggestion to give up smoking, even when informed that continuing would almost certainly result in fatality. When pressed, the consultant revealed this was customary.

On the other hand, it also arose as a theme related to patients perspective on terminality – the willingness to engage and do whatever possible to persevere, even in the face of death.

"I'd be all for it… I'd continue as long as I could and die when I can't help it"

– Patient, (O'Sullivan & Higginson, 2014)

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

THEME 3 - EMOTIONAL EXPRESSION

GRIEF AND DENIAL

"I'm only… what… 74… there;s guys that live to 80 or 90 so…"

– Patient, (O'Sullivan & Higginson, 2014)

It is an inherently unnatural experience to grieve ones own passing. Studies show that there is considerable deviation and variation in patients' attitude towards direct discussion of death and dying, and the reality of the end-of-life phase based heavily on personal preferences and coping styles. While some wanted full disclosure as they thought they would cope better with a realistic understanding (O'Sullivan & Higginson, 2014), others were more passive and focused on the present, and others still, entirely closed to the subject.

> *"I wouldn't like to be told exactly. I live very much in the present… You don't really look ahead"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

Patients also recounted their experience of mourning their life while still alive – their jobs, social lives, hobbies, goals. One patient interviewed mentioned how she was due to start a new job, one which she had been building her career towards, however was diagnosed only a couple of weeks before the start date, and the contract was voided – this was something she found incredibly hard to accept.

THEME 4 - CHOICE, CONTROL AND DIRECTION

This final theme deals with facets of autonomy, control of care, and direction in care, but also life. It distinguishes patients priorities in retaining control of their life, while equally struggling to distinguish where and how to go about organising and controlling the uncontrollable nature of terminality .

> *"'Yes, it should be discussed with him…. it's too sensitive between us because my emotions are involved as well…. Although he hasn't talked to me about that side of things [I feel certain that my husband] doesn't want any more treatment. He's had enough'*
>
> *However, her husband expressed contradictory views, revealing a marked lack of... congruence."*
>
> *– (O'Sullivan & Higginson, 2014)*

LACK OF PURPOSE

The certainty of death and the absence of a future can leave patients wondering where their purpose is. Most of their goals, hopes, desires were situated in a future that no longer exists, and little remains to live in the pursuit of. Patients expressed a sense of aimlessness and spiritual disrest.

> *"Should I figure out some way to make a grand donation to charity as my legacy? What's the difference? I won't be here to watch it work."*
>
> *– Patient, (Miller, 2016)*

A popular answer to this distress was legacy building activities. The content and form of these is subjective – it is simply a means of preserving 'you' beyond the earthly form. It also brings closure, as well as a sense of caring for your loved ones past a time when you physically can. One patients prepared advance gifts for her children for special occasions, another left phone calls, another wrote letters to their friends and family. While the worth of this was questioned by carers as a result of the extreme heartbreak it can cause – 'He sobbed the whole way through' (Head and Neck Cancer Alliance, 2024) - patients found it a huge source of comfort and peace.

> *'I received so much good care and support. I also want to give something back'*
>
> *– Patient*

Other patients found purpose in giving back to community - to their loved ones, to their nurses and care teams, or in working towards creating a better environment and support system for future sufferes.

SELF ADVOCACY

Retaining control of medical decisions was of considerable importance. While patients expressed a high degree of concern for their loved ones in grappling with their [the patient's] disease, often putting their loved ones concerns above their own, this concern hierarchy became more complex concerning decision making. (Fegg et al., 2005)

Patients' altruism subsisted, with patients acutely recognising that their decisions and desires would not only have to be actualised by their carer, but that they would also have to live with the consequences beyond the patients own death. Patients felt that decisions about DNR requests and such need to be made with the family, but also expressed a fear and worry as to whether their wishes would be respected or over ridden (O'Sullivan & Higginson, 2014). This created a degree of tension and turmoil within the patient, who felt their ability to exercise autonomy was restricted through their preoccupation for their loved ones wellbeing.

> *"You can't make that decision without consulting your partner. It's my decision but I think you have to pay consideration to people who are around you or behind you"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

Some patients were concerned that as their disease progressed, the influence and voice of their loved ones may also increace exponentially. They feared a time where their wishes may be overruled and the wishes of loved ones instead adhered to, particularly in cases where the family prioritised life prolonging treatments above else.

> *"I did have a lot of trouble like, with my family trying to make all the decisions for me"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

> *"I would not be happy personally, if a decision was reached between the consultant and my wife about the rest of my life. I wouldn't be happy if people were talking ABOUT me rather than TO me."*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

While patients expressed this fear of decisions being made for them rather than by them by their carers, carers dismissed this. While they desired a degree of involvement during care discussions and decisions, carers were equally resolute in their belief that decisions should ultimately be made by the patient themselves (O'Sullivan & Higginson, 2014).

> *"It is the patient's decision because, it's their life... he's the one who's going to die!"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

While patient-controlled decisions are universally seen as ideal, the reality of hospice care is that it is likely that at some stage, the patient will be rendered incapable of making decisions. Advance care planning, a key component of palliative care, aims to mitigate the effects of this by having protocols planned in advance with the patient for potential scenarios, however, should the situation arise where the patients wishes cannot be expressed, both patients and carers agreed that the carer should take responsibility (O'Sullivan & Higginson, 2014) as the voice of the patient – as they likely know the patient best.

> *"I'm not stupid, he's twice the size of me… I'd have to have a discussion about what stage do we… not admit defeat but say… we can't cope any more"*
>
> *– Carer, (O'Sullivan & Higginson, 2014)*

VALUE OF TIME

One of the most critical factors that arose very early in the research phase is the importance of patient's time. Head and neck cancer patients in this disease phase, on average, only have a five-month life expectancy – therefore their time is indescribably valuable and should be reserved only for activities and topics which signifies importance or fulfilment to them. This factor is so critical that it in fact arose before the project even had officially begun, during discussions on project planning and patient contact, and limiting it only to questions which could not be addressed through other means.

However, although it should be of obvious importance, research showed that the boundary is still breached. After entering the hospice phase, there are a myriad of logistical, financial, and other life affairs patients are suddenly faced with, on top of medical care, advance care planning and organising equipment like wheelchairs, hoists, and more. Similarly to discussed in previous themes, a lack of resources and information provided by isntitutions leave patients with few instructions on how to access or organise these affairs. During an interview, a patient said she was forced to spend hours on the phone and internet just to try ascertain how, and where, to pre-emptively source a wheelchair for her future use. It is incredibly important that patients know where, how and when to navigate healthcare systems and access the resources they require so that they are not spending their precious time on menial tasks (O'Sullivan & Higginson, 2014) that could be significantly simplified, or responsibility given elsewhere; something which patients regret is not yet implemented on a wider basis.

> *"They got no support because she didn't have a medical card… but we were calling for them for weeks"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

> *"spent weeks just trying to find a wheelchair... things you'd much rather be spending your precious little time on"*
>
> *– Patient, Interviewed*

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

THEME 4 - CHOICE, CONTROL AND DIRECTION

POWERLESSNESS

> *"I would want to go where all the medical expertise is at hand and can be called upon at a fraction's notice.. because its split second decisions that save the day … they want to do their best for you.. but at the end of the day… it probably isn't enough"*
>
> *– Patient, (O'Sullivan & Higginson, 2014)*

As the hospice phase progresses, patients become more and more powerless, left to the discretion and care of others. While patients are incredibly complimentary of their loved ones and the care they receive, they also exhibit restlessness and discomfort with their lack of freedom.

Patients are acutely aware that should the time come that their carer is no longer able to support them in the home environment, they will have no choice but to move to hospice care. They see their partners struggles in caring for them, and their emotive questioning of their ability to deliver care; both physically (O'Sullivan & Higginson, 2014), but also mentally. The end of life phase is full of unpleasantries, and carers have the tense job of monitoring their own emotions and expression and premeditaed grief and trauma in order to maintain patients' comfort and dignity. They expressed fear about harming their loved one, and felt a sense of guilt for their predicted failure and inadequacy (O'Sullivan & Higginson, 2014). According to Offerman et al., 2010, increased distress in partners (carers) and feelings of hopelessness and isolation and impacts on their mental wellbeing result in impaired cognition, subsequently resulting in reduced levels of care and support to their partners/patient (Offerman et al., 2010), as well as the distress it causes the patient in observing their carers distress and pain.

> *"I'm not stupid, he's twice the size of me… I'd have to have a discussion about what stage do we… not admit defeat but say… we can't cope any more"*
>
> *– Carer, (O'Sullivan & Higginson, 2014)*

PATIENT'S PRESENT - PRIORITIES AND DESIRES, THEMATIC TRIANGULATION

THE END OF LIFE

Knowing when you will die is an unnatural situation to find oneself in; knowing when, and also how, you will die, is unspeakably unusual. For HNC patients, their understanding of the latter can bring a significant amount of unease and trauma due to manner in which HNC often ends.

> *"[HNC is] one of the most unpleasant and agonising ways a person may die"*
>
> *– (O'Sullivan & Higginson, 2014)*

HNC and its localisation can result in incredibly upsetting complications in latter months. Palliative sedation – providing comfort for patients by putting them into a medicated sleep - and euthanasia are not uncommon in this cohort; in one study, approximately 20% received palliative sedation, and almost 6% euthanasia (van den Besselaar et al., 2024). These topics can be a major source of discomfort and distress for patients and loved ones alike, and can cause conflict in clashing options and perspectives. Palliative sedation should also be considered in the context of the patients already short expectancy, as their final weeks may be spent in an unconscious state.

Symptoms, such as cartoid blowout (a sudden major rupturing of an artery) and haemorrhages can be disturbing not only for the patient themselves but also their loved ones – dark coloured blankets are advised to be kept bedside as a precaution, with the colour disgusing the amount of blood lost, and minimising distress. While the information and awareness of these potentialities are critical for mitigation of unease at end of life, the awareness also serves as a further source of stress and upset in the months prior to death.

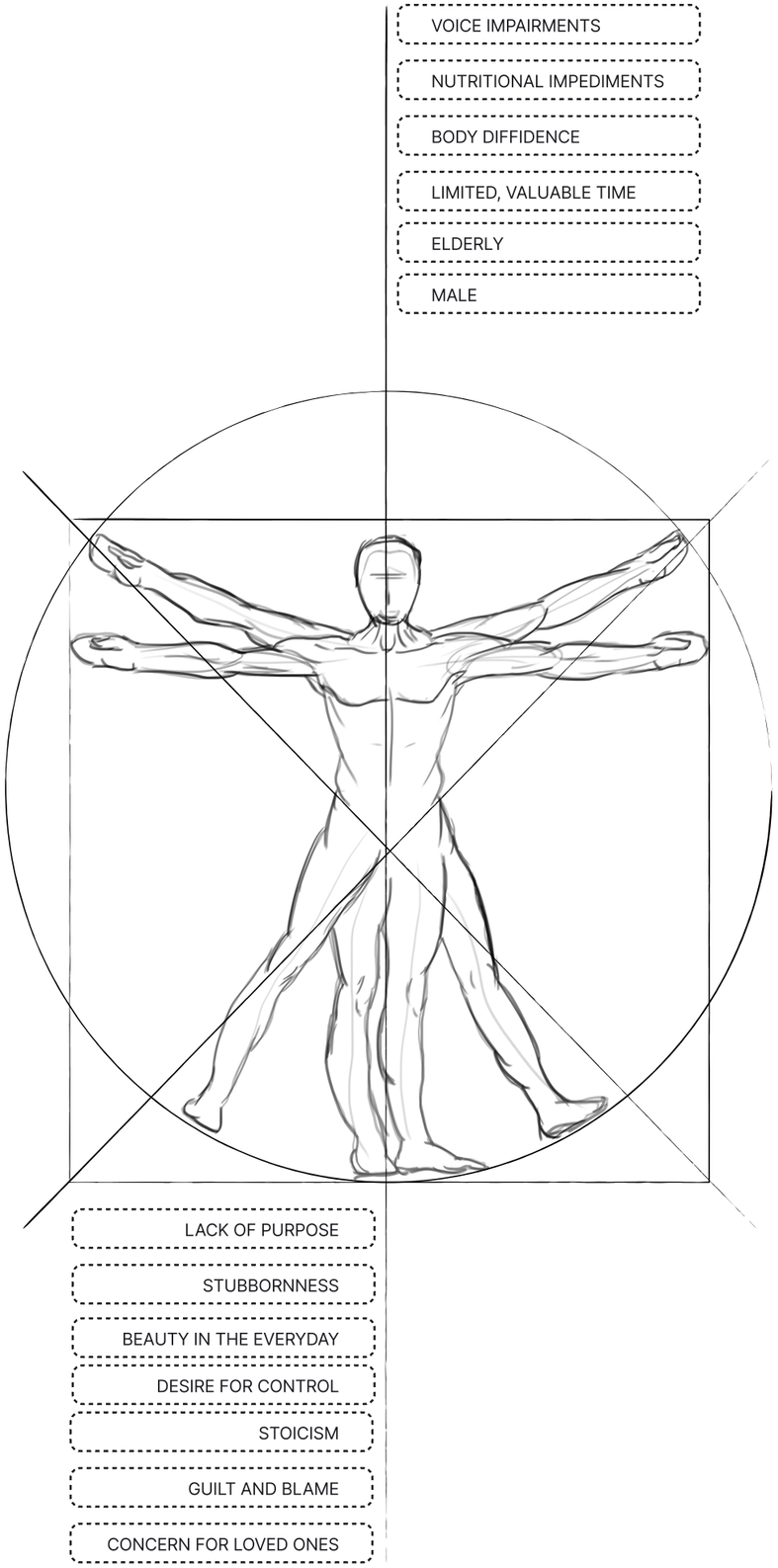


Figure 17: Image showing summary of HNC persona

CONCLUSIONS

This chapter explored the emotions, desires, priorities and needs of the population as mandated by the human centered design approach, presenting a holistic understanding of the contextual user.



IV

DISCOVERING THE MIND

‘Mind’ [noun] the element or complex of elements in an individual that feels, perceives, thinks, wills, and especially reasons

(Merriam-Webster, 2019)

THE COGNITIVE REACTION TO TERMINALITY AND DEATH

RQ: What Is The Cognitive Reaction To Incurability, And What Rationalising Processes Are Employed In The Repositioning Of Ones-Self And Reidentifing Priorities, Desires, Values And Needs?

Being diagnosed with an incurable illness is a traumatic event, one which likely requires a reassessment of ones ambitions, and a major reorientation and recalibration of their life as a whole. It can be assumed that this is a complex, confusing process, entailing a huge cognitive load on top of the physical and psychological burden that the patient is already dealing with.

Thus far, the project's design goal has been framed as helping patients 'recognise, priortise and articulate' what truly matters to them in the end-of-life phase; helping them reason and reconcile their feelings in as sensitive yet fast manner as possible to maximise the time they have left to find fulfilment. The quicker they do the finding out, the more time they have to make use of it, considering the brevity of hospice.

However, a major unknown in this statement is the process wherein patients reach this clarity – recognition, prioritisation and articulation. Is this process linear, and are these the order of steps it follows? If so, what are the criteria that takes a patient from one step to another? What processes of reasoning, grief, acceptance are employed, and how do they work?

In order to design an intervention that will empower and help patients in navigating their mental wellbeing, an understanding first had to be established of what terrain we are navigating across. This 'terrain' or landscape is what I am referring to by the 'mental context'.

By understanding what cycles of mentation and cerebration patients go through during this period, and the interplaying factors, we can understand, who, in terms of mental state of mind, is interacting with the intervention, and what they are traversing. This allows the intervention to be designed to help the patient in this navigation, and find where, or what, their end destination is or should be.

There was no specific model found which defines the cognitive process that head and neck cancer patients undergo post incurable-diagnosis, nor for hospice in general. Instead, research was conducted into theories, models and frameworks which outlined humans mental responses to traumatic events or life transitions, particularly those related to health and illness. These were studied and used to create an amalgamated model. Each of these theories will be introduced separately, and then the integrated map presented.

THE FIVE STAGES OF GRIEF

Perhaps one of the most well known models, the Five Stages of Grief was a model introduced by Elizabeth Kubler Ross in her 1969 book ‘On death and Dying’ (Kubler-Ross, 1969), where she conducted interviews with terminally ill patients to explore their experience of dying and death.

In this book, she proposed that people go through five stages during end of life – denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1969). These eventually came to be ubiquitously known as the ‘Five stages of Grief’, and have since been tried and applied in domains far beyond solely the terminally ill and dying.

However, although the model has been widely adopted and accepted, it has equally been met with growing criticism.

One of the most controversial aspects of Kubler-Ross’ original model is the presentation of grief and its process as being in ‘stages’. Kubler-Ross originally presented the model linearly, where one progresses from one stage, or phase, to the next (Avis et al., 2021). Not only does this portray grief as a rational and sequential process – which it is not (Avis et al., 2021) – but has also led to the models use as a prescriptive guideline rather than used as a descriptive representation (Avis et al., 2021).

Instead, grief has been found to be an oscillating model, where people and their emotions and mind move back and forth between stages in a fluid, dynamic manner (Bisconti et al., 2004). Recent visualisations and applications of the model have reflected these criticisms, and begun to veer towards more circular and flexible configurations of the original model. Equally, the belief that all individuals will reach the final stage of grief- acceptance – has been countered. This is not to say that these individuals will not reach any sense of serenity or mental relief, as any movement within the model – whatever direction – will regardless bring with it mindset shifts and progress (Silver & Wortman, 2007). Perhaps most importantly, researchers have suggested that misuse of the model may lead people to believe that they are grieving ‘incorrectly’, leading to increased distress and burden (Avis et al., 2021).

Cognitive Reaction to Incurability - Theory 1, Five Stages of Grief

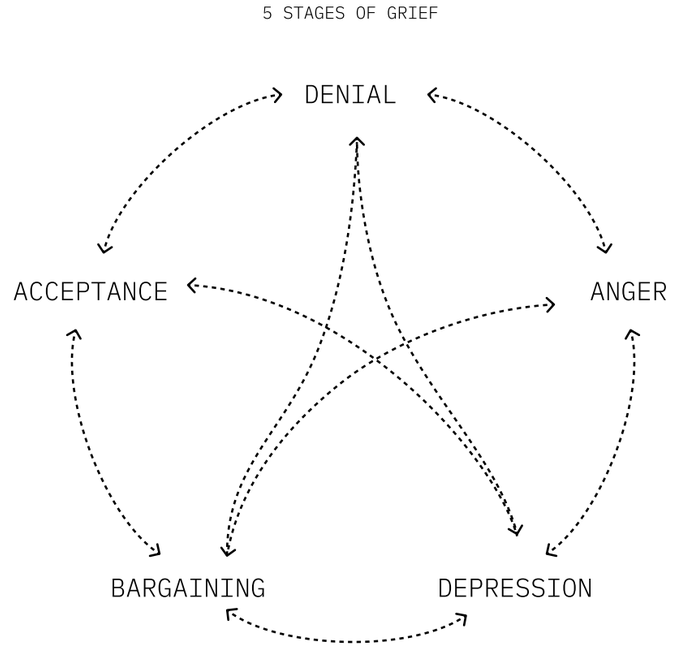


Figure 18 - Reimagining of the original linear model of the five stages of grief, illustrating its unpredictable oscillating nature

CONSIDERATIONS AND INTERPRETATION

When designing interventions in the realm of grief, trauma and challenge, it is important to be sensitive to its ‘irrationality’; the dynamic, murcurial, volatile variability of progress and regression. Designing an intervention which aims only to ‘solve’ – or drive users to a final ‘solution’ or outcome – fails to recognise that these emotional processes never arrive to a final ‘stage’; there is no linerality, and no conclusion or ‘end’. Even those whose difficulties are decades ago will still feel anger or another ‘early’ stage from time to time.

THE MEANING MAKING MODEL

The meaning making model is a framework which outlines the mental process which occurs when people are confronted with new, particularly challenging, situations. It comprises of two core concepts; ‘Global Meaning’ and ‘Situational Meaning’ (Park, 2022).

Global meaning refers to ones fundamental and foundational orienting beliefs; ones attitudes, value hierarcharies, opionions and goals – such as health, fairness, wealth. It also includes ones perspective on life (Park, 2022).

Situational meaning refers to how one interprets and appraises their circumstances – this is a constant, living process. It refers to the way ones interprets meaning within a specific context, and often requires and involves constant, evolving rounds of reappraisal (Park, 2022).

The meaning making model applies these two levels of meaning, and poses a process whereby distress is experienced when a situation or circumstance compromises and is inconsistent with ones global meaning. When this occurs, one engages in ‘meaning making’, a process whereby one tries to reconcile the discrepancy between the situations appraised meaning and their global meaning system (Park, 2022).

This process of meaning making can occur under many conditions – positive appraisal, whereby one reminds oneself of the benefits or searches for the ‘silver lining’, comparing ones situation to others in real or hypothetical ‘poorer’ relative situations, seeking positive reinterpretations, or exploring benign explanations for the circumstances (Park, 2022). This new perspective is coined ‘Meaning made’. It aligns with the criticisms of the five stages of grief model, outlining a consistently looping process rather than a final, ultimate end.

People who have been found to have successfully followed this meaning making model have shown long lasting positive impacts on mood and mental health, as well as reductions in self blame and PTSD. Successful meaning making also reduces persistent rumination regarding ones traumatic experiences, significantly decreasing patients likelihood of developing depression and experiencing long term distress (Park, 2022)

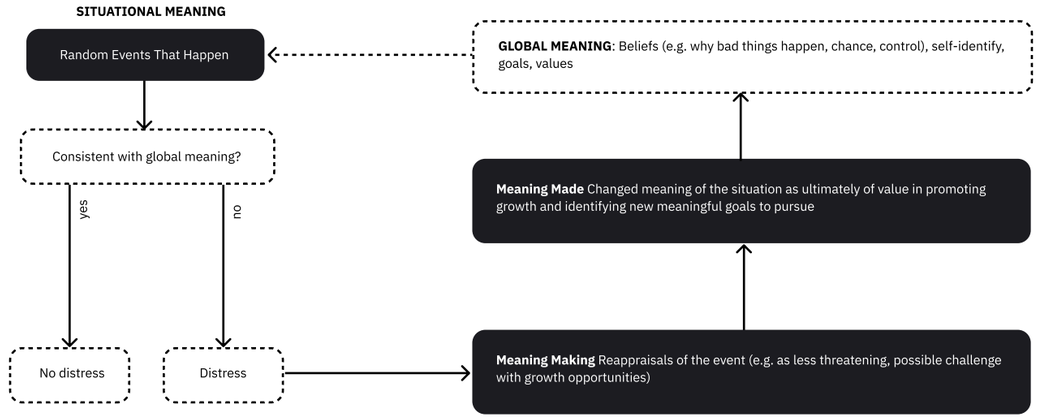


Figure 19 - The meaning-making model, illustrated based on (Park, 2022)

CONSIDERATIONS AND INTERPRETATION

For incurable patients, their traumatic circumstances results in a catastrophic fracturing and disharmony between their context and innate meaning framework. The mental loop engaged to resolve consequent distress involves repeated, consistent reinterpretations of reality in order to restore peace - constant divergences from what likely are venerable, long-standing beliefs.

Patients global meaning likely shifts considerably from their pre-diagnosis self to their new identity, with this overhaul potentialy causes rifts in self-perception and clarity in opinion and priority.

An interesting application of this theory could be the illumination of this ‘global meaning’ structure, enabling nurses to discern an understanding of patints based on the exposed values, beliefs and goals, and identifying components that are causing dissonance with their reality.

GOAL ADJUSTMENT THEORY

Goals provide a direction for our actions. They provide purpose to life through pursuit, and, through their presence, help define who a person is. In the course of life, people frequently encounter obstacles that make the pursuit of goals challenging. In some cases, this provides further richness to life and satisfaction when the goal is ultimately achieved; however, sometimes these obstacles can render goals impossible. When this happens, people's perspective and perceived purpose in life can fracture, threatening peoples quality of life and sense of reason (Mens et al., 2015).

As we get older and our time, resources and health deteriorate, these obstacles can occur more frequently. Life events, such as the diagnosis of disease or illness, is one example. In these cases, how can people avoid loosing sight of meaning in life? In 'Goal Adjustment Theory', Mens et al., 2015, proposes that adaptation of goals is the answer. This consists of two steps – first, disengaging from the original goal, which incorporates both withdrawing efforts, but also commitment, and reengaging in a new, achievable goal instead.

In this theory, the author emphasises the central difference between 'disengagement' and other maladaptive processes, such as 'giving up' or learned helplessness. In these latter states, effort is generally withdrawn across the board, where one adopts a general perspective of hopelessness towards life as a whole. Disengagement, instead, is the controlled and intentional withdrawal from a singular task. Successful disengagement ensures avoidance of sustained stress experienced from the pursuit and repeated failure towards an unfeasible goal, as well as rumination and the distress it can cause. It also opposes entrapment, where people preserve goal commitment as a result of the sunk cost fallacy. It also ensures, particularly in cases where resources are limited, that effort is reserved for realisable goals, and enabling further successes and joy.

Reengagement comprises of three stages – identification of an alternate goal, and committing and pursuing this new goal, redirecting focus from failure to potential (Mens et al., 2015).

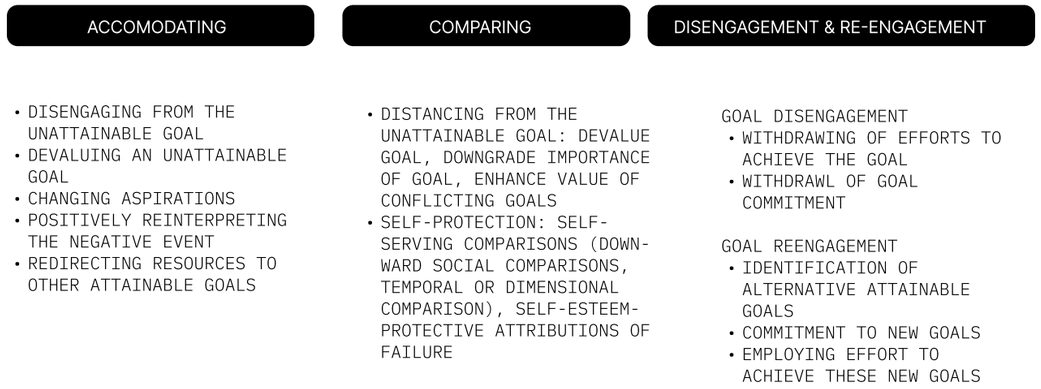


Figure 20 - The various methods of approaching unattainable goals in the Goal Adjustment Theory (Mens et al., 2015)

CONSIDERATIONS AND INTERPRETATION

One of the impacts of terminality is the impact on patients' long-standing hopes and dreams that exist in a future that they can no longer see. Goal adjustment theory outlines the process which successful goal adjustment follows, but also provides insight into the consequences of failed goal adjustment.

While the theory is insightful, it does not provide recommendations for how to help people to follow the adjustment route should they struggle with disengaging, signifying design opportunity in this regard.

PROPOSING A HYPOTHETICAL COGNITIVE PROCESS

In order to clearly map the cognitive process wherein patients mentally navigate their newfound realities, a hypothetical combined model was created that illustrates what the cognitive process of incurable patients may look like. Patients are undergoing constant evolution regarding their assessment of their situation and their consequent psychological reactions, and subsequent actions.

OSCILLATING MODEL

As depicted by the meaning-making model, as well as the critique and revision of the five stages of grief, patient cognitive processes engaged in response to trauma are of an oscillating nature, with no defined end. No ‘finality’ can be found in conclusions, as patients work through repeated reframings and reinterpretations in pursuit of harmony. An assumption here is the potential that a coherent sense of harmony may be unattainable for some, wherein the reality and gravity of the loss of a future may inhibit total acceptance and peace.

MEANING

The meaning-making model introduces the notion of global meaning - an internal framework of beliefs, goals, values which is used to assess and establish how we react to a given event. Interestingly, this aligns with the design for emotion theories, which also illustrate the relationship between goals, needs and values, and how they influence the apprasial of an event and the consequent emotional outcome.

MENTAL REFRAMING

The goal adjustment theory provides insight into some of the methods which may be employed in attempting to rectify the dissonance between the new reality and the person’s perception of meaning.

OPPORTUNITY IDENTIFICATION

The combined model provided an understanding as to the the relationship between the models and the design for emotion approach. The illustration also provided opportuinity identification. One previously noted opportuinity was in response to the goal adjustment theory, where it was noted that while clear theory was presented for the steps that patients go through in response to trauma, none of the theories propose means for how people can be progress through these steps, or how to overcome barriers or blockages.

This is the solution space of the project - an intervention which helps people navigate through this central cognitive space, recognising the infinite looping nature and inevitability of regression and evolution, and considering the processes wherein progress occurs - reframing, comparing, reappraising and re-engaging.

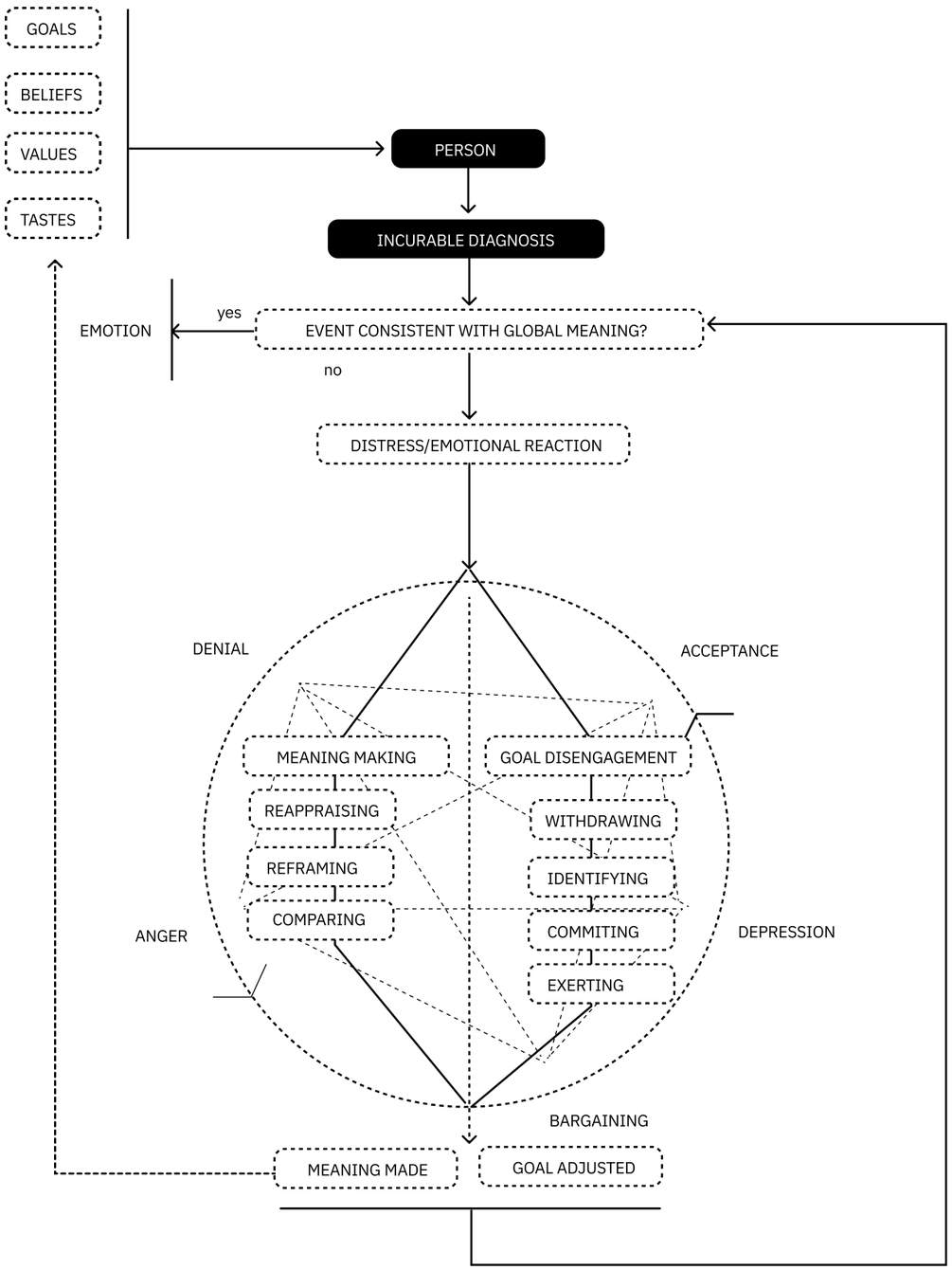


Figure 21 - hypothetical combined cognitive model

A CHANGE IN TERMINOLOGY

‘MEANING’

When analysing and researching the meaning-making model, one insight emerged disconnected from the actual theory and its design application - instead revolving around the language. Thus far, I struggled to coin the concept of what the brief was actually about ‘needs’ or ‘priorities’ are too superficial.

This concept of ‘meaning’ is essentially what this project is about; helping patients to find where meaning lies for them - what is important to them, what they want to priortise, where they find value - and encourage, and empower them to chase it during their final months. Thus far, this project has used terms such as ‘priorities’ ‘needs’ ‘desires’ ‘values’, but each still missed the core essence. Meaning truly encompasses the intent - the important, needed, wanted, and valued - what holds true meaning to patients.

This theory shows that these meanings can be discovered through discussion of life and stories - that the process of reflecting and remembering does inspire and reintroduce purpose is more than a speculative concept.

Therefore, from this point, I began using the term ‘Fundamental Meaning’ to refer to the abstract element the intervention was actually trying to surface - that which is central to their heart, a intimate mix of their prioities, values and needs which shape that which is most important to them during this final stage.

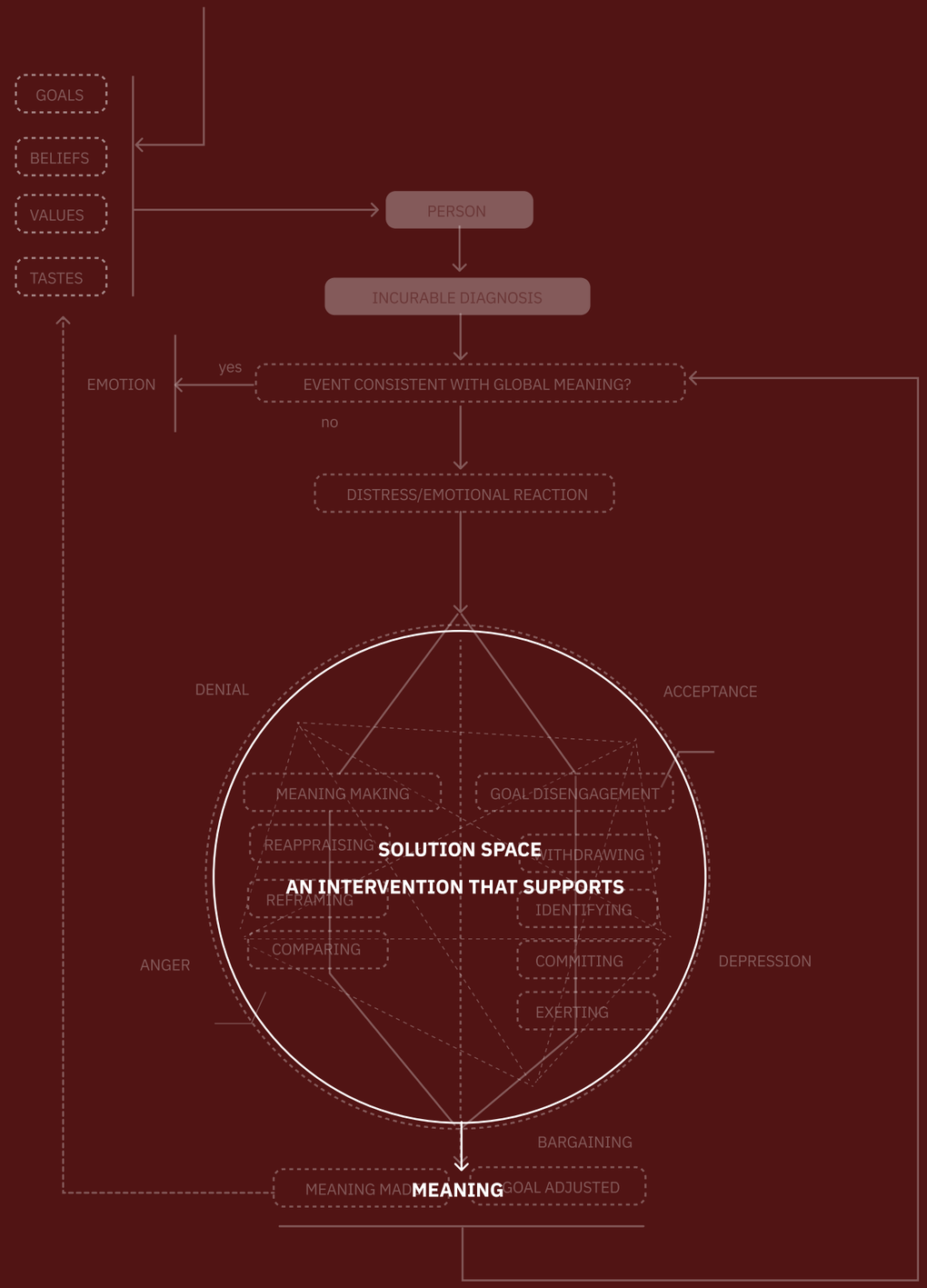


Figure 22 - hypothetical combined cognitive model indicating solution space

RQ: What Is The Cognitive Reaction To Incurability, And What Rationalising Processes Are Employed In The Repositioning Of Ones-Self And Reidentifing Priorities, Desires, Values And Needs?

Th creation of this combined model provided evidentary insight into the cognitive landscape of patients in the hopsice phase.

It illustrated the central need - an intervention which would support patients in navigating through reframings, reflections, reappraisals while reorienting themselves in their new reality.

It also introduced the relationship between emotions and fundamental needs with this process, and that the intervention outcome should introduce patients to a sense of meaning, with this surfaced meaning being able to be traced back to a fundamental need.

IDENTIFIED RESEARCH QUESTION

RQ: How Can Design Support A Patient In The Process Of Reappraising, Reframing, Compring, Reflecting And Recommiting When Faced With Death?

PROJECT IMPLICATION

Based on the oscillating nature of the cognitive process identified in this chapter, it became evident that the design would not be a singularly deployed intervention. Instead, it would need to be consistently present througout the patients hospice phase, responding to ever-changing meanings.

As a result, from this point forward, a service design approach was also incorporated to guide the design towards a holistically considered experience.

COLLATING

V

APPROACH

This chapter reviews the research findings and defines insights for the approach of the creative phase.

APPROACHING DESIGN

While reviewing research, and scoping and defining the project, insights and remaining research questions began naturally falling into two categories - approaches towards ensuring design adoption, and approaches towards ensuring the design could be feasibly integrated. I realised these two questions were hinting towards an established model - the DVF model, popular in human centered design for ensuring the preservation of the user central to the design.

In this model, viability generally refers to profitability. However viability also refers to the ethics of a design, and its social impact and rationale for it's existence. This social need has been clearly defined throughout the prior chapters and introduction, considering the aggressive nature of HNC and the burden patients face in their repositioning. It is in this manner viability will be interpreted here, presented through the creation of the final problem definition.

Under each category, this chapter will interpret research and create constraints to define barriers for the following creative phase.

DESIRABILITY

> *Considering The Value Of Time For This Cohort, How Can We Ensure That The Design Interaction Experience Is Desirable And Fulfilling, And Makes Users Naturally Inclined To Keep Using It?*

FEASABILITY

> *Considering The Complex Entangled Context, How Should The Design Be Situated In The Reality Of The Medical Sphere?*

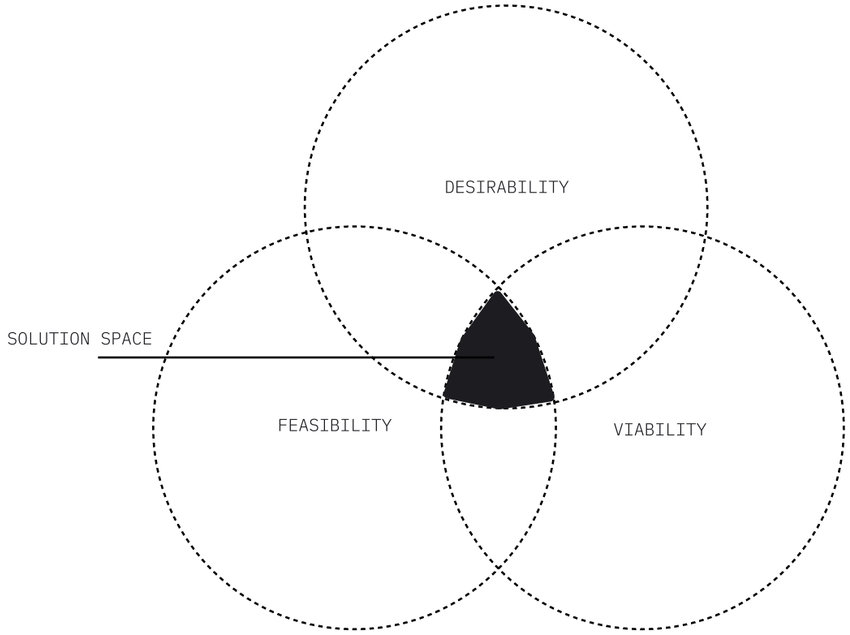


Figure 23 - The DVF model

DESIGNING FOR DISCOVERY

RQ: How Can Underlying Desires Be Discovered?

Before exploring how underlying needs can be discovered and surfaced, it is first necessary to establish what needs are, and how they relate to other expressions of emotion - such as values or desires.

INTRODUCING THE 13 FUNDAMENTAL NEEDS

Perhaps the most well-known need typology is Maslow's hierarchy of needs, the well-known pyramid we all were introduced to at some point in secondary school. However, in a similar way to Kubler-Ross' five stages of grief, it applies a linear, hierarchical structure to an entity that is anything but.

In Maslow's theory, the next 'level' of the need pyramid is not pursued until the preceding level is fulfilled; according to him, this traversing of the levels is driven by a desire to realise our potential. In the case of a incurable HNC patient, whose basic levels are unfulfilled as inescapable consequence of the disease, does this mean they cannot experience any love? Joy? Does their terminality – which strips them of achieving their 'full potential' – render them entirely unmotivated of any attempt at finding happiness? Maslow's theory fractures in the face of complex human realities such as these.

Desmet and Fokkinga (2020), dissent from Maslow's approach in their paper, 'Beyond Maslow's Pyramid', in which they propose a new approach – the 13 fundamental needs. These needs are not presented, or fulfilled, hierarchically, but instead fulfilled in parallel. This fulfilment may not be conscious and is often unnoticed until a need becomes unfulfilled, in which case negative repercussions are suddenly experienced – this also cannot be compensated by the over-fulfilment of another need class. While universal, these needs can translate into people's daily repertoire in vastly differing mediums, based on personality, culture, background, and more. The salience of the ways in which we fulfil these needs will evolve over our lifespans, but their ultimate fulfilment will not waver (Desmet & Fokkinga, 2020).

These needs can be indicated by a range of factors – goals, emotions, values, tastes all are indicators of the underlying needs. They can also be dissected into sub-needs – operalisations of the overarching need. For example, an operalisation of autonomy could be expressions of individuality through style and fashion. In their book 'Emotions by Design' (2025), Desmet and Fokkinga descripe a variety of methods and tools which designers can use in order to discover these fundamental needs, and design to fulfil them. These tools help designers dissect user needs to an actionable insight – for example, if a participant in an interview says 'they enjoy coffee', this does not provide enough depth to meaningfully design. However, if a participant says 'their morning coffee is important as it gives them a moment to reflect and prepare for their goals for the day' the design space suddenly becomes richer.

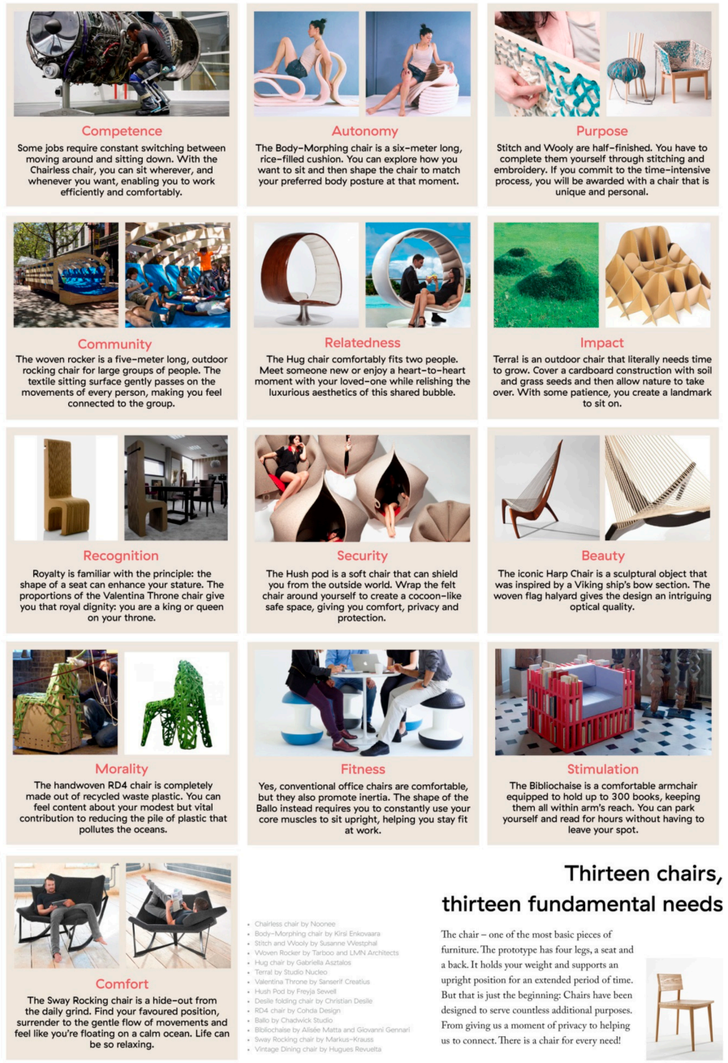
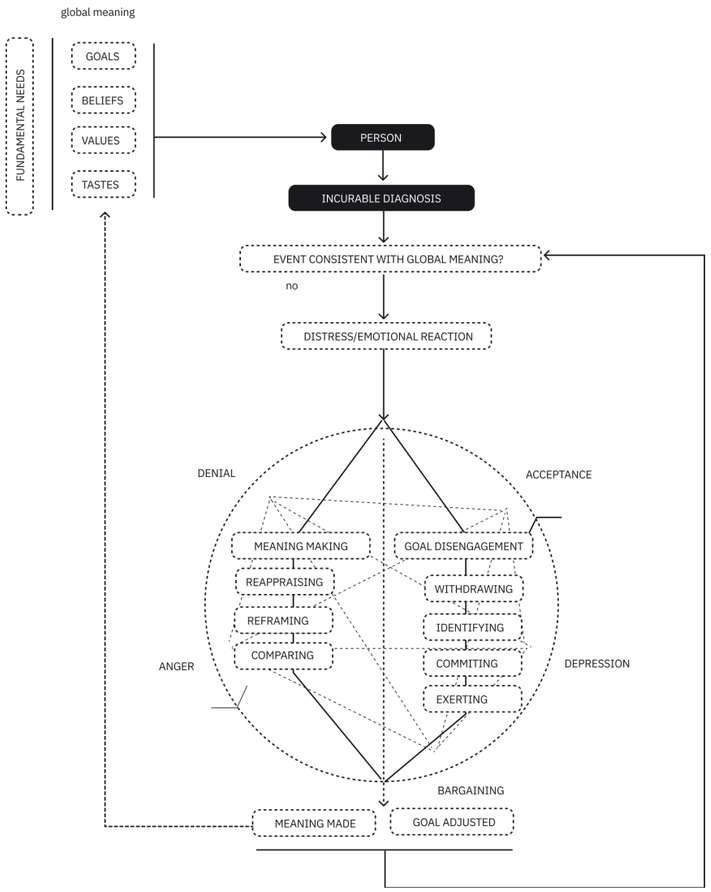


Figure 24 - The 13 FUNDAMENTAL NEEDS (Desmet and Fokkinga 2020)

DEPLOYING THE FUNDAMENTAL NEEDS

In exploring the fundamental need theory, a gradual resonance between the created cognitive model and the fundamental needs emerges. In the meaning making model, ‘global meaning’ refers to the internal belief system we posess, of values and beliefs. Similarly, in the fundamnental needs theory, these components - values, goals, preferences - are seen as manifestations, influenced by our underlying needs. The Basic Model of Product Emotion demonstrates how the collision of fundamental needs with events defines how we appraise, and (emotionally) react - mirroring how the meaning making model shows our ‘global meaning’ defines how we experience situations.

This identification of this relationship enables the positioning of the fundamental needs in the previously created cognitive model. Equally, it opens the opportunity to use the fundamental needs tools - specifically developed for designers to uncover deeper, critical need spaces - as a way to help patients traverse through the cognitive landscape and through the identified solution space towards meaning identification.



The Cognitive Model, with Fundamental Need Theory integrated

THE DISCOVERY TOOLS

PrEMO

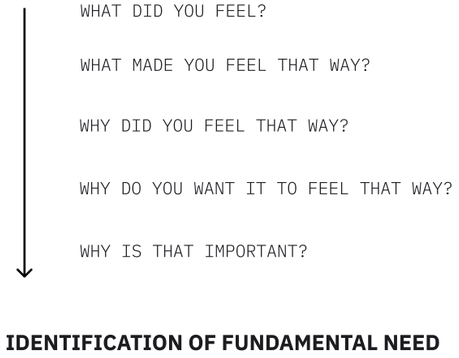
Emotions are subjective and abstract – a characteristic which can make them hard to communicate through words. PrEMO is a visual tool which can be used to facilitate dialogue between designers and users around emotions, through the provision of a visual aid. This can be used in interviews and discussions as a indicative medium for expressing ones emotions, but it can also be used to graphically demonstrate the emergence of emotions, such as micro-emotion scan maps, where the user interaction experience is visualised through granular attention to each minute emotion that arises during product interactions (Desmet & Fokkinga, 2025).

NEED CLASHES

Need clashes is an inspirational approach to designing, where fundamental needs are paired off in order to create rich solution spaces - through compromise, resolving or prioritizing (Desmet & Fokkinga, 2025). While this technique is not necessasarly intended for need discovery, it can be utilitised as a means to present dilemmas to others, and gauge their reaction towards one over the other - this process can be reimagined to facilitate need priorities.

THE LADDDERING TECHNIQUE

One method for discovering underlying needs is the laddering technique; a socratic technique intended for use by designers with users. As indicated by the name, it involves descending a metaphorical ‘ladder’ through a series of ‘Why?’ statements to find meaningful and impactful solution spaces (Desmet & Fokkinga, 2025).



DESIGNING FOR DESIRES

RQ: What Desire Should This Intervention Be Built On?

FINDING UNDERLYING NEEDS

Each and every artefact designed, was designed to fulfil a need; similarly, the artefacts we interact with – particularly those we enjoy interacting with – signifies need fulfilment (Desmet & Fokkinga, 2020). Thus far, this project has been viewed through a lens of discovery; designing something which will help uncover the needs of hospice patients. However, in considering the brevity of patient's lives, it is critical to ensure that the time spent interacting with the intervention, and discovering these sources of fullfillment, is fulfilling in itself. In testimonies, patients recounted their frustration at having to spend their time organising wheelchairs and other resources – time, they said, they would much rather spend on something enjoyable. Consideirng this interaction will likely be recurrent over a number of months during the hospice phase, this consideration towards enjoyment not only through, but from, interaction becomes even more critical.

From the conception of this project, the importance of value was a cornerstone – that patients time is precious and rare, and should be used in as meaningful a manner as possible, one which brings joy and peace to the patient. By considering the 13 fundamental needs, in accordance with the thematic insights established in the research section, areas of particular interest can be found for delineating value directions, with these acting as an inspiration for how to discover value while also delivering value. The intervention should ensure that it delivers not only joy through the improvement of their own care as a result of the interventions outcome, but genuine, authentic happiness from something of intrinsic value to them, during the discovery interactions themselves.

To distinguish these potential values, the 13 fundamental needs were used to cluster insights across literature. These included the thematic insights presented in earlier chapters, such as from Fegg, 2005, which presented patients tendancy to move towards areas of transcendence as presented in the earlier chapter. Further research was also conducted into existing studies which established specific priorities as expressed by hospice [palliative] patients, and also used in this identification.

Based on this exploration, the fundamental needs which emerged as most desirable were autonomy, relatedness, purpose and morality.

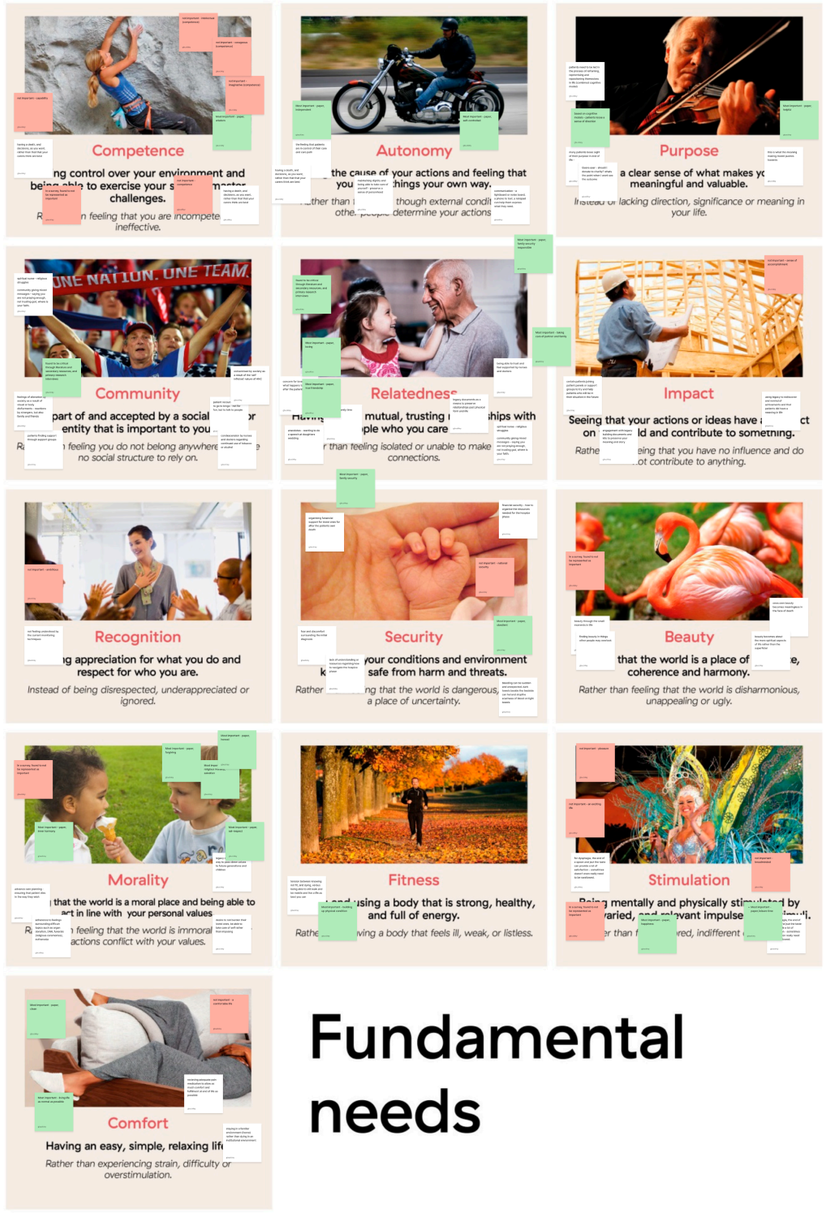
Below: Example of terminal patient wishes fulfilled as part of the three wishes program



A Garden Wedding



A final date night



DESIRABILITY

CHARACTERISTICS AND ATTRIBUTES

In adopting a human-centered design approach, the user should be positioned, and kept central to the design. The perspective of design for emotion calls for designing with, and through, users' needs and emotions, and using them as a source of direction and inspiration.

Blending these two dimensions, I created a concise list of the research insights from the users - the patient - in terms of their emotions. I then translated these into a set of attributes that the design should abide by in response to these insights, and finally into a set of the emotional and experiential affordances that these attributes would facilitate.

These would then be used in the following ideation and development phases as a guide to ensure that the final outcome would remain aligned with the patient, their emotions, needs, and characteristics.

INSIGHT	ATTRIBUTE	AFFORDANCE
FREEDOM	UNRELIANT	EMPOWERMENT
STOICISM	INDIRECT	REFLECTION
NORMALCY	FAMILIAR	COMFORT
DIGNITY	ACCESSIBLE	ACHIEVMENT
CONNECTION	EMOTIONAL	LOVE
ALTRUISM	ASSISTIVE	MORALITY
PURPOSE	TRANSCENDING	PEACE

PURPOSE

When faced with death, a life's purpose becomes hazy - without a future, previous goals become impossible, hopes and dreams disappear. Terminal patients may feel a lack of direction or reason for their existence.

The intervention, though its surfacing of priorities, should help patients in rediscovering their purpose and sources of joy in life, allowing them to focus and find fulfillment from them in the time remaining.

NORMALCY

Patients are already dealing with the burden of accepting their terminality - a thought which likely never fully goes away. Their days are full of reminders of this, from medications, cards and visits from loved ones, pain.

In determining patient's psychological well-being and priorities, the intervention should minimise any reminders of this fate, and avoid causing further distress as a result.

DIGNITY

The physical effects of HNC may force some patients to rely on others for aspects of personal care - such as being fed, bathing, dressing. This strips patients of a sense of dignity, and leaves them feeling powerless.

The intervention should therefore restore a sense of competence and ability, enabling interation at their own discretion in a private, dignitifed manner.

ALTRUISM

While patients face terminality, there was little evidence to show self-pity, and instead much evidence to support patients pre-occupation with the welfare of others. Patients consoled and reassured their loved ones, while others contributed to research out of a desire to help their fellow and future sufferers.

The intervention ideally should bolster this, venturing towards this higher reason.

STOICISM AND TABOO

The most influential finding was patients tendency to withhold emotions. The generational habits and norms of these patients involve a high degree of aversion and discomfort with vulnerable discussions due to learned taboos; that troubles are private and unfit for sharing. This stoicism is also bred from patients fear of causing further worry for their loved ones, particularly considering their pre-existing guilt for the burden of care their carers already endure.

The intervention should therefore be designed to allow patients to share and explore their emotions and feelings in a private, safe space, which overcomes the stigmatized barriers surrounding emotional openness.

CONNECTION

The importance of loved ones was perhaps the most pertinent outcome of the research cycle. Patients want to spend their final months in the company of those they love, finding closure, sharing wisdom, or just feeling the warmth of love. Patients also value this in their nurses and carers, and the support and care that they feel.

The intervention should recognise the importance of relationships and connection, and refrain from causing any fracturing to established relationships, preferably instead facilitating further deepening of trust and love.

INDEPENDENCE

Many of these patients feel stripped of their autonomy; stripped of a future, limitied choices and freedom, reliant on others for care. Designing an intervention that further emphasizes this lack of autonomy by forcing patients to rely on others for interaction (such as group use), or dictates decisions or moments of choice itself would only exacerbate this negative feeling.

Instead, the design should provide a sense of control and autonomy to the patient, ensuring all interactions, choices and action moments are at the discretion of the patient alone.

POSITIONING - MEDICAL SYSTEMS

RQ: How Should The Design Be Positioned In The Reality Of Medical Technologies?

THE FUTURE OF MEDICAL CARE

As both medical and digital technology rapidly progresses, an increasing promise is shown in combing these two realms. ‘Flagship – Consultation Room 2030’ is a collaborative effort between TU Delft, Erasmus MC and Erasmus University Rotterdam which explores the integration of (digital) technologies into the consultation room of the future (Convergence, n.d.). For this project I endeavor to somewhat align with these aspirations – exploring technology that could be plausibly integrated within a decade. Exploration of the domain has illustrated the degree of suffering patients face, with inadequate support, and highlights the desperate, vital, and life-altering opportunity for an ameliorating intervention.

DIGITAL TECHNOLOGIES

In the ‘milieu’ chapter, the digital nature of many monitoring systems were outlined, where patients physical and psychological health are tracked through digital questionnaires and interfaces, and supported by remote check-in’s. This approach is necessitated by multiple factors. First, the time limitations of staff and their need for quick, succinct overviews of patient health and well-being to inform actions. Second, the medical industry requirements, where data protection is critical, and where digital systems can help ensure the safe-guarding and documentation of said data. The nature of health and disease is also very sensitive to time, where delays can cause illness progression or death - therefore the efficiency of digital communication is suited. Additionally, the remote context of hospice, where patients are cared for in the home environment, away from staff, further aligns with a digital communication medium.

In light of this, a digital-component is necessitated if the intervention is intended to be realistically implemented.

Yet, consideration has to equally be made to the populus involved; elderly, lower socioeconomic, incurable patients. This cohort’s digital literacy should therefore be considered to ensure harmony between the medical context’s requirement for digitisation, and the patient population’s need for suitable, age-accessible tools.

DIGITAL LITERACY

Digital literacy for elderly populations has been widely discussed, and its relevancy to this project is clear. As HNC hospice patients are, on average, 70 years old (van den Besselaar et al., 2023), we can estimate that the population who would be using this intervention five to ten years from now, would be currently between 60 to 65 years old. Based on available studies, the most applicable age band is those 50-64.

Of this age group, approximately 50% of (Dutch) adults possessed ‘above basic’ digital skills (Netherlands, 2023). An Irish study into internet and digital usage in the population found that of the 60-74 year old cohort, the most popular online activity was ‘Seeking health related information’ (An Phríomh-Oifig Staidrimh, 2024).

In primary research, insights were found regarding patients own use of technology to help them. As recalled by experts, one patient described using Chat GPT to help him monitor and treat his own symptoms, as well as to upload and have the AI explain his test results, blood work, etc. However other patients did not like AI tools, saying they much preferred having real human connection – this relatedness was described as incredibly important, and impossible to replace with digital means. This perspective extended to other technologies, such as robots, VR, saying they were too ‘cold and impersonal’.

Patients talked about the importance of being seen, and treated, as the same person you were before – with patients expressing frustration when they were treated too delicately. Some patients recounted experiences were particular information was omitted from discussions by consultants. Patients however also described their nurses in a warm light, expressing appreciation for how warm and caring they are, and the hope they bring to their hospice phase.

The design outcome of this project should not avoid digital technologies, but approach them sensitively - preferring more basic interfaces such as apps and smartphones to that of VR. This treads the line between the envisioned integration of further digitalisation and technological advancements into the domain, yet remaining suitable to the cohort involved.

This integration should be approached cautiously, ensuring that the outcome does not become too ‘cold’ or impersonal - retaining close connection, trust, and human interaction with nursing staff and carers.

> *“One of our patients also mentioned that he really enjoys warm interactions with the nurses and it makes him feel better and that he wouldn’t want it replaced by cold technology”*
>
> *– Experts, Interviewed*

POSITIONING - HNC TRAJECTORY

JOURNEY MAP

Human centered design and service design principles both call for the envisioning and simulating of the human experience of a conceptualised design – from first impression, to final use (van Boeijen et al., 2020). Therefore, feasibility, in this context, and consideration the project's adoption of a design for emotion approach, also involves consideration of feasibility in relation to patients emotions and state of mind.

The disease trajectory and its brevity and complexity presents a dense labyrinth of emotions and events - aspects which will have to be acknowledged and navigated in order to situate and design an intervention which can support a patient sensitively throughout these phases. This is also critical considering the context's inclusion of death, and therefore should be mapped to demarcate the intervention's temporal constraints in relation to the disease trajectory and patient death.

To illustrate this, an emotion map was constructed, based on an amalgamation of the trajectories discovered during the research phase to create a general, representative picture of a HNC trajectory, unspecific to any particular institution or culture. It utilises the PrEmo tool to present these on an experiential level, preserving the core focus of emotion.

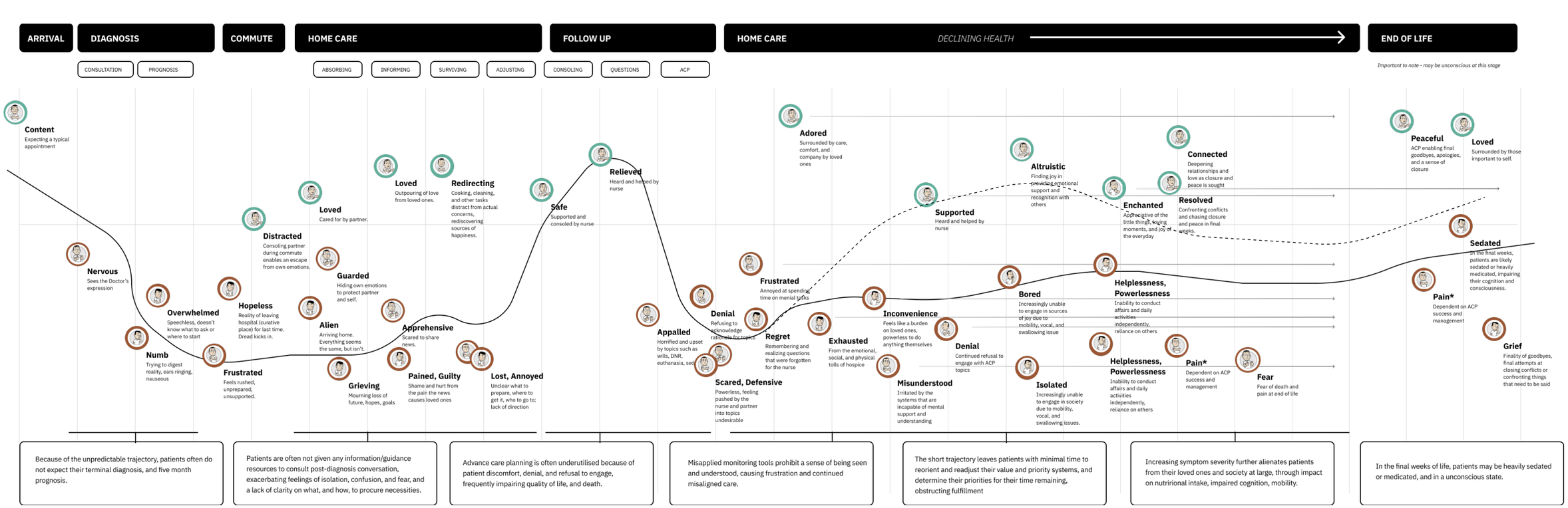


Figure 26 - JOURNEY MAP

PROBLEM DEFINITION

WHO

The primary stakeholder in the problem space is the hospice head and neck cancer patient - who deserves quality of life in their final phase of life. These patients are elderly and majority male, of a lower socioeconomic class, and on average, have a life expectancy of five months. They suffer a myriad of complex physical and psychological complexities - including voice impairments or loss, and a sense of guilt and shame as a result of the percieved self-inflicted nature of the disease (which is often assocaited with excessive tobacco or alcohol use).

The secondary stakeholder is the nurses who aid the patient (and their carers and family) in their final phase of life. These nurses may work as part of a hosptial or hospice, and are overburdened with limited time, yet go above and beyond for their patients.

WHEN

The intervention is positioned throughout the Hospice phase - the final five to six months of the HNC patients life.

WHERE

A large portion of hospice care happens in the home environment, as is preferred by patients and their families, with a mix of remote and/or physical support from professional staff (depending on the care provider/ institution). In these cases, the primary home carer is often the patient's partner or next of kin. In certain cases, complexities may result in the final period of care occurring in a hospice or institution.

WHY

The scientific approach of modern medicine warrants quantitative, succinct monitoring systems. However, these pale in the complex context of psychological wellbeing at end of life, and appear to fail in unearthing richness and nuance needed. Professional staff attempt to glean this missed understanding through conversation, however this is futile in the face of patient's learned aversion towards emotional vulnerability.

UNDESIRED SITUATION

The core goal of hospice care - QoL - relies on a holistic understanding of the patient, and their priorities, values, desires for the end of life phase. This is obtained through the employment of monitoring tools and engagement in ACP, which facilitates the alignment of resources towards the identified sources of meaning.

However, stigmas rampant in the patient cohort results in their aversion towards emotional vunerability and expression, obscuring the surfacing of their needs and the successful deployment of hospice tools and approaches.

DESIRED SITUATION

The barriers surrounding HNC patients resistence to emotional expression are broken or circumvented, enabling the communication of HNC patients' psychological wellbeing and fundamental meanings to nurses in succint, rich manner. Nurses begin to understand and relate to their patients on a deeper level, and are empowered to reorient and readjust care resources in the hospice phase to align with patient's discovered areas of importance. This improves patient's perceived fulfillment and quality of life during the final months, delivering on the core tenant of hospice and palliative care.

PROBLEM STATEMENT

As a result of stoicism, learned taboos, fear and emotional avoidance, patients refrain from sharing and engaging in activities and tools which aim to procure an understanding of their psychological mindset and meaning priorities, impeding nurse's efforts to align resources with patient values and desires, and obscuring achievement of a quality of life, and a good death.

CONSTRAINT DELINEATION

Having explored the body, mind, and environment surrounding the patient, a visual depiction was created which brought the critical dimensional factors and insights together to form a starting point from which to approach the creative phase.

01. HNC patients often suffer voice impairments or loss as a result of treatments.	The design does not rely on verbal interactions.
02. HNC prognosis is unpredictable, and therefore life expectancy and death is uncertain.	The design recogises the brief and volatile life expectancy of HNC.
03. Current systems struggle to obtain a clear understanding of patients psychological space.	The design fosters understanding of patients psychological mindset.
04. Patient's time is valuable as a result of their short life expectancy.	The design fulfills desires during interaction.
05. HNC patients already resent the burden they place on their loved ones and carers.	The design can be used independently.
06. HNC patients struggle to be open about their emotions.	The design can be used privately.
07. Patients feel powerless, and struggle with their lack of independence and autonomy.	The design facilitates patient autonomy in choices and decision making.
08. Discussions surrounding decisions about death and terminality are uncomfortable and often avoided.	The design facilitates meaning surfacing through a comfortable medium.
09. Patients struggle with the taboo and stigma of emotional vunerability and are often stoic.	The design helps break the barriers to psychological wellbeing discussion.
10. Elderly patients have lower literacy skills.	The design interfaces are suitable for the digital literacy of the age group.
11. Elderly populations require additional accessibilty considerations in digital artefacts.	The design is compliant to accessibility considerations required for older users.

01. Patients during the terminal stage struggle to reorient themselves as their future is lost.	The design promotes reasoning and reflecting about patients lives.
02. Grief and trauma are not a linear process, and instead involve frequent regressions and reframings.	The design recognises the non-linear nature of patients reasoning, and does not chase a final 'solution'.
03 The oscillating nature of the cognitive model illustrates the constant reassesment and reorientation of patients.	The design engages with the user throughout the hospice trajectory.

01. Current systems fail to deliver a holistic understanding of patient needs and priorities.	The design surfaces the priorities and needs of patients.
02. The rapid, sensitive nature of medical care necessitates the use of digital interfacing.	The design can communicate with the (digital) systems of medical institutions.
03.Nurses are overworked and overburdened, with extremely limited time.	The design delivers a rich but efficient understanding of insights for overburdened nurses.
04. Nurses aim to align care with the needs of patients in order to deliver QoL.	The design delivers actionable insights which can be translated into care interventions towards QoL.

DESIGN GOAL REFORMULATION

THE ORIGINAL DESIGN GOAL:

PROJECT KICK OFF

Investigate and develop an approach to support the recognition, articulation and monitoring of emotional wellbeing of head and neck cancer palliative care patients, to improve understanding, awareness and support of such within healthcare systems and health care professionals.

PRESENT

Development of an mediating interface, which surfaces and articulates patients meaning sources through an indirect exploration of their desires and needs, and enables responsive care adjustment and alignment towards meaning, fulfillment and ultimately, Quality of Life.

CONCLUSIONS

This chapter researched and answered key remaining research questions regarding method, which needed to be answered in order to position ideation in a grounded, rationalised space. These included the methods to discover needs and desires, and the contextual boundaries which needed to be recognised in regards the evolution of the service.

The chapter cultimated in the identification of the primary tension and problem statement - the conflict between the emotionally avoidant persona at the core of the project, and the project's ambition to design an intervention to surface the emotion based needs of this populus.

CREATING

VI

IDEATING

This chapter presents the initial design phase, and identification of the concept direction.

THE IDEATION PROCESS

In his book, ‘The Design of Everyday Things’ (Norman, 1988/2013), Don Norman (the recognised father of human-centered design) posits that ‘in order to come up with revolutionary ideas, you have to challenge the norm – the only way to do this is to question the obvious and abandon the expected’. However, in this project, the complexity and vunerability of the context makes it difficult to drop all sensibilities and diverge. To bridge this gap, I adopted a layered approach to design, where divergence was broad, then gradually converged through the playful additive layering of criteria, during the ideation stage.

RQ: How Can We Surface The Needs Of The Emotionally Avoidant?

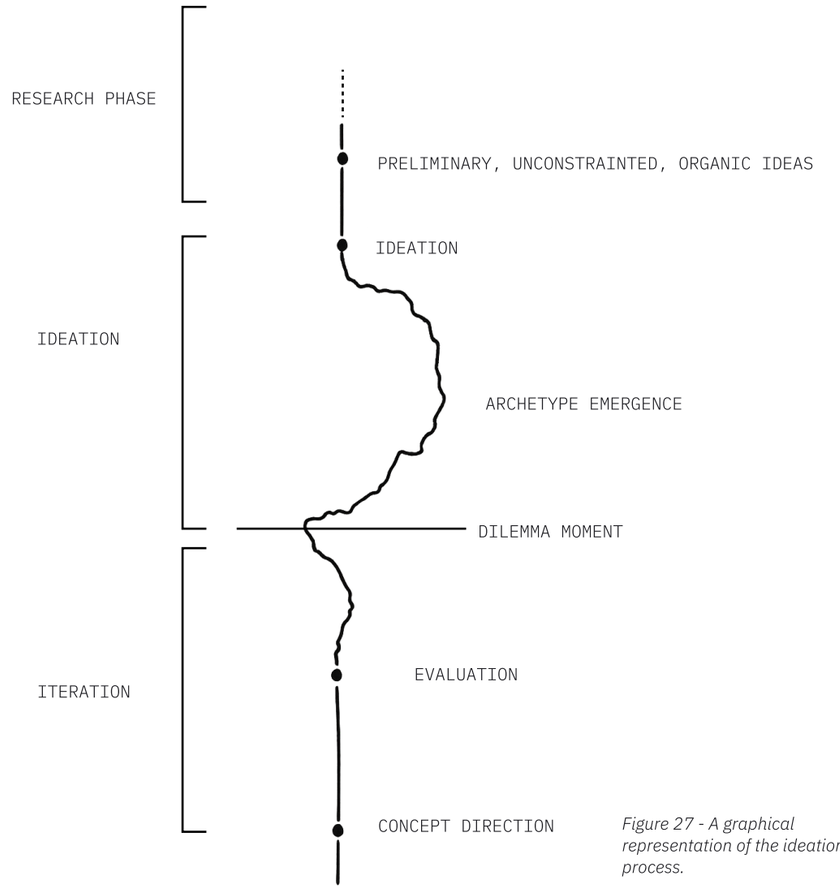


Figure 27 - A graphical representation of the ideation process.

RE-IMAGINING THE FUNDAMENTAL TOOLS TECHNIQUES

During this exploratory process, one of the base cycles was the re imagining of the fundamental tools techniques presented earlier - such as the laddering technique. These discovery tools showed promise in their ability to deepen; however, they had been originally developed to be deployed in the hands of designers as a research tool. In the case of this project - where the techniques would instead need to be able to be self-prescribed - a re-imagining was conducted to explore how to reorient and adapt the tools to enable this.

The outcome of this exploration served as the theoretical basis for the eventual idea archetypes, with each archetype based on one re-imagined tool.

BRINGING COMFORT TO REFLECTION

In therapeutic approaches, a common occurrence is the use of activities as an attention diversion tool, allowing the heart and mind to open through the distraction of the hand and head. Horticultural therapy is a recognised therapeutic approach, where the interaction with plants, nature, soil and the act of physical movement and engaging of the hands enables the head to more freely and openly think and reflect (Hamal, 2025). In a similar manner, therapists often utilise colouring books or jigsaws during conversations to prompt conversation through a methodological, meditative activity (Emanuela et al., 2021) - as well as providing a place for gaze diversion, as eye contact can be confrontational during emotional conversations.

In a similar way, multi-sensory experiences engage the person as a whole - providing a more corporeal, holistic experience, the immersive nature of which increaces enjoyment and insight.

RESEARCH THROUGH DESIGN

Consideration was also given towards a research through design approach, where designs could consciously position the user as a researcher; for example, providing a kit which would guide the patient through a discovery of their own mindset, and finding meaning.

CONNOTATIONS OF TIME

The topic of time arose as a subject that may require avoidance - during exploration surrounding the themes of familiarity and normalcy, artefacts such as calendars, clocks arose. However, the count-down nature of these may spark unwelcome associations. A similar consideration was the presence of anything that a clear level of ‘incompleteness’ could be attributed - such as ‘line a day journals’, as this may cause discomfort and distress. It is acknowledged these are purely assumptions, but their relevance appears apparent.

DILEMMA DESIGN

The definition of the approach to design had created a vast set of constraints, as well as desires, attributes, discovery tools, etc which could be used to inspire. A method employed in this cycle was the creation of inspirational dilemmas (need clashes) which pitched constraints against each other. The dilemma design methods - moderating, triggering, or resolving - were employed in response to spark creativity (Ozkaramanli et al., 2016).

EVALUATION

THE DILEMMA MOMENT

In the process of evaluating the design ideas and archetypes, a series of conflicts arose. One of the evaluation criteria addressed during this stage was the perceived suitability of the ideas for the intended population. For instance, do I believe that the majority of 70-year-old working class men would be interested in sitting down and crocheting? My answer was no. Of course, in cases such as these, it would have been preferable to test this assumption in reality, but due to the project topic and restrictions discussed, this was not possible.

This was not the only disqualifying factor. I found myself doubting the suitability of ideas when evaluated at a realistic level, beyond persona criteria. Many of the ideas felt excessively artistic or critical - considering the vulnerability of the population, and the high degree of real need identified, I wanted to preserve a sense of realism. To me, an artistic statement felt somewhat disingenuous and a betrayal to the emotional reality, vulnerability and critical needs of the population I was coming to know.

In the course of this review, three recurring elimination factors emerged - incompatibility with the reality of institutional systems, the project's focus on discovery of meaning rather than designing for meaning, and patients discomfort and avoidance of emotional expression. These were applied in evaluating and identifying a promising, realistic conceptual direction.

"….I need to know what he wants or how he feels, but he doesn't talk about it"

– Carer, (O'Sullivan & Higginson, 2014)

RESPONDING TO THE DILEMMA

Through the focus on these tension, ideas were dissected and disentangled , with nuanced ideas extracted and preserved, in search of promising conceptual directions. This cycle resulted in the identification of the final conceptual direction which would answer the crevice between the emotionally avoidant and the core project focus of meaning discover - legacy.



FIGURE 28: SOLUTION SPACE

LEGACY

DEFINING THE CONCEPT DIRECTION

Sharing stories about our lives is a tool as old as time when establishing relationships, building trust and love, seeking understanding. As a qualitative research method, life narratives first emerged during Freud's psychoanalytic investigations, and have grown into a widely recognized qualitative research method towards the subjective nature that is the essence of a life (Atkinson, 1998).

Through the employment of the laddering technique, patients can be guided through a story-based exploration of their life and legacy, identifying sources of meaning - and what truly matters.

> *"Story makes the implicit explicit, the hidden seen, the unformed formed, and the confusing clear."*
>
> *– Quote from the Life Story Interview, (Atkinson, 1998)*

INTERACTION DRIVER

Patients are deeply concerned for their loved ones - not only in the present, and the burden of care and trauma they bear, but also in the time following the patient's own death. They express concern at the support they will receive in grief, and their absence and inability to provide support.

This intervention provides a means for patients to answer this concern through the creation of a legacy document - a physical narrative of the patient and their life that their loved ones can hold near after they are gone as a source of comfort and preserved connection.

THE PATIENT EXPERIENCE

Through participation, the framework softly guides the patient in rediscovering sources of meaning through a deepening cycle facilitated by the laddering technique - reminding patients of what matters to them and their sources of joy, and mentally repositioning them to pursue these sources of fulfillment in their remaining time, providing improved QoL.

NURSE

Based on the laddering application and identification of fundamental needs, an aggregated overview of the patient's critical need categories are created, with contextual insights contained within each category. This enables nurses to identify the most important need category, and reference, interpret and translate the insights into care adjusments.

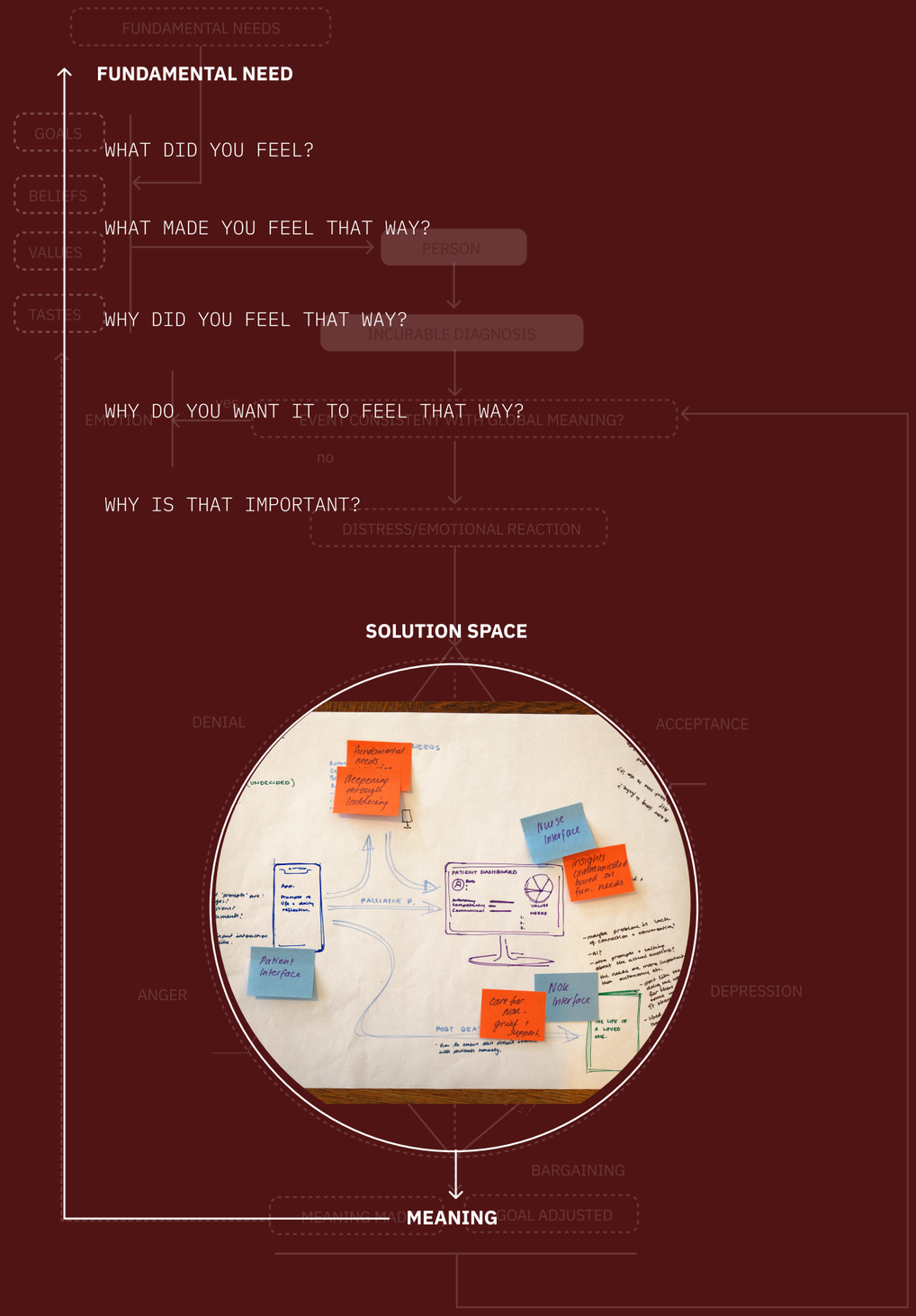


Figure 29 - Concept direction positied in identified solution space

WHY IT SHOWS PROMISE

Patients are afraid of emotion – therefore, perhaps the approach is to avoid referencing emotion directly. The indirect referencing and exploration of emotion and needs through stories and implicit means demonstrated promise in early ideation, inspired by the common legacy building activities that terminally ill populations engage in when approaching end of life - such as the advance of letters for future events such as birthdays, weddings, anniversaries, or recording their voice with emotional messages of love and endearment. These are often constructed in response to patients concern for their loved ones welfare after they passed, as a premade source of comfort, for the future.

This intervention builds on this, answering patients altruism through these shared stories and the knowledge that it will help their loved ones in the future. It also serves another value; rediscovery of purpose. Like the legacy documents, it reminds patients of their achievements, their purpose for living, as well as a sense of life preservation beyond the physical form - providing a sense of spiritual comfort and transcendence.

Their disease and emotions are something they don't want to talk about. Their life, and legacy, they do.

BOUNDARIES

In order to ensure the projects feasibility within the timeframe of 100 days, considerations needed to be made regarding the degree to which each component of the system would be considered and developed in the course of this project. Considering the complexity of the service, attempting to detail it in its entirely would obscure meaningful detailed design of any one component, and would be detrimental to the projects overall outcome.

THE FOCUS

For this project, focus will be on the systematic framework - the systematic process of prompting, reflecting, deepening and documenting – as it represents the core essence of what this project has come to be; discovery through legacy. It represents the core of the research findings, patients stoicism, and shows the most promise for positively impacting patients' lives – potentially beyond solely the domain of head and neck cancer. Detailing embodiments while neglecting this foundational system would render the project as a whole superficial and ungrounded. This conversational dialogue represents the premise of the project – ultimately, the application success of its physical manifestation – whether that be app, book or otherwise – will lie on the basis of the framework underpinnings.

As an aspiring design researcher, this theoretical side of the project also aligns more with who I am, and who I want to be, in my career. As this thesis will likely represent the end of my academic journey, I also want the final outcome to represent who I am as a designer.

Service design, as the design is emerging as, focuses more on the experiential evolution of a user's interactions with a design and the implications of such, rather than the tangiable and material qualities. However, while the primary focus of this project is the framework, conceptual embodiments will also be employed throughout development and final communication as demonstrative means of how the framework could be tangibly integrated. Some of the constraints identified, such as voice impairment/loss, depend on embodiment rather than framework design. These should therefore be superficially explored in order to propose considered interfacing media which provide a preliminary suggestion as to how these considerations could be adhered to. This embodiment is also critical for communications with stakeholders - nurses, patients, NOK - who operate external to the design profession, and with whom schematic, speculative presentations would likely fall short in triggering insightful, rich discussions.

THE PROJECT OUTCOME

The outcome of this project will be theoretically grounded framework, which presents a methodological approach towards the surfacing of patients fundamental meanings and the communication of these with clinical staff, communicated through schematic illustrations and assisted by prototypical embodiments.

CONCLUSIONS

This chapter concluded with the discovery of the project’s design direction and essence - legacy.

It answers the central design tension, by using stories and indirect exploration as an interface between the emotionally avoidant and the act of discovery, surfacing and articulating meaning and enabling the alignment of care.

“when we tell a story from our own life... we increace our working knowledge of ourselves because we discover deeper meaning in our lives through the process of reflecting and putting the events, experiences and feelings that we have lived into oral expression”

(Atkinson, 1998)

02

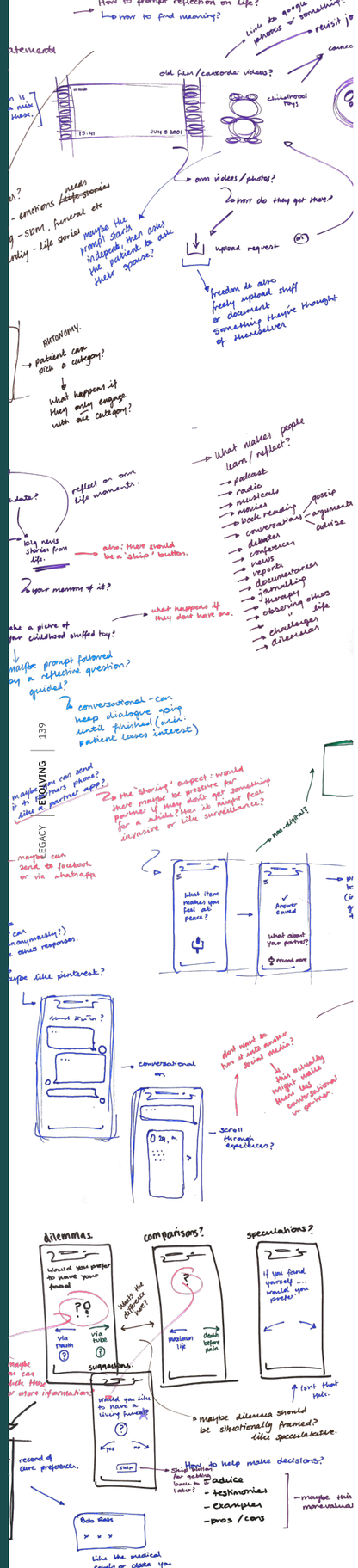
LEGACY

CREATING

VII

EVOLVING

This chapter presents the design evolution process.



UNDERSTANDING THROUGH STORIES

Stories are one of the most ancient arts of being human - defining and teaching us about our world, our position in it, and creating connections from us to that which surrounds us. They help us feel, learn, grow and develop, and act as the basis for many of our daily experiences; conversations, media, reflection. Their importance can be seen in terminal patients common desire to create stories - their legacy - in the time leading up to their death, as a means of preservation and for passing along lessons and values. It is this essence of stories, their instinctual importance to humans, and their ability to create deeper understanding which defines the core essence of this project.

RQ: How Can Legacy Act As A Guiding Medium In Patients Reflection And Reorientation Of Meaning?

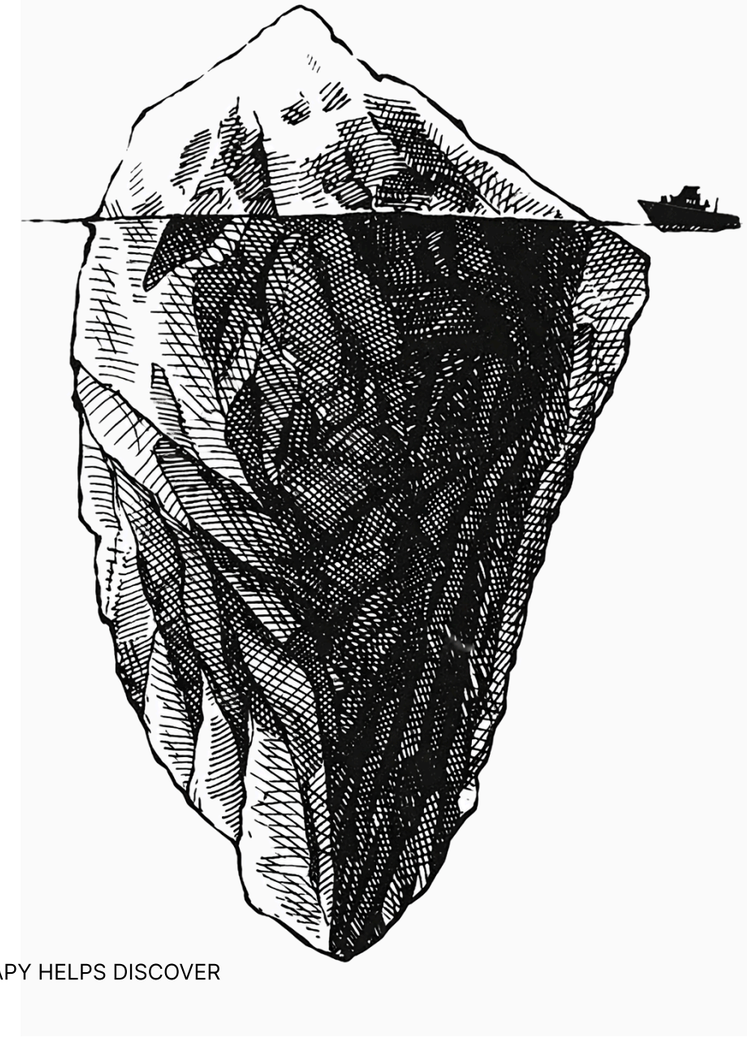
THE APPROACH OF THERAPY

While legacy had been chosen as the lens and essence of the project, the medium through which legacy would interface was still undefined. What triggers learning? What triggers introspection? Avenues included movies and documentaries, short stories, photographs and journals, podcasts, art pieces. While the diversity of media were promising and auspicious, it remained speculative, without a theoretical grounding to confidently state that these ideas would actually trigger reflection, and without patients to reflect and dialogue with.

When therapists and therapy attempt to help you to solve distress, they first have to find the distresses' source. In many cases, patients attending therapy are unaware of the underlying source of their mental suffering – it is therapists jobs to traverse clients minds and discover where unrest originates. Further complications arise from patients who, as a result of societal expectations or their own traumas, struggle to open up and talk about their feelings. As a result, conversations are often about life, with subtext revealing the underlying story and stressors.

Until this point, I was hesitant to enter the realm of therapy. I was acutely aware that the goal of the project was to discover patient's psychological concerns and needs – not to solve them. However in this case, it was an obvious decision. With this in mind, I delved into therapeutic literature – particularly therapy designed for post-trauma and transition periods – to investigate approaches, methods and protocols therapists use when delivering treatment in order to traverse these challenges. I also investigated what tools are currently available which can help hospice patients to navigate their psychological landscape, and what approaches they take. This exploration led to two discoveries which would be instrumental in the remainder of this project.

WHAT WE KNOW



WHAT THERAPY HELPS DISCOVER

The approach of therapy - dignity therapy

DIGNITY THERAPY

Dignity is a multifaceted concept, comprising of self-esteem, respect, independence, and more. For those with incurable illness, dignity can be difficult to preserve, as one's autonomy and existence becomes challenged. (Rosenberg, 2018)

Dignity therapy, by Harvey Chochinov's, strives to counteract these challenges, and reinstate patient's sense of dignity and self.

Dignity therapy is a psycho-therapeutic technique which helps those with terminal illnesses to preserve and document their life story. It comprises of a guided conversation, where through reflection and discussion, patients narrate their life story, providing an opportunity to recount their accomplishments, adventures, roles and experiences (Chochinov, 2012). Through this presentation, patients are aided in acknowledging and remembering the impact and value their life held, and rediscover their sense of self, their essence and in turn, a sense of dignity. (Rosenberg, 2018)

This clinical model composes of an audio-recorded, in-depth session, where a licenced professional guides the patient in reflecting on their life through a series of prompts and questions, and documents their memories as the patient describes; especially those of significant value and meaning to the patient. The session is then transcribed, where collected stories are edited into chronological, coherent passages, prefaced by a representative question from the interviewer, with this transcript given to the patient to review and amend. The session and its stories then exists as a physical legacy document, which is given to the patient for them to share or store in accordance with their wishes, allowing the patient's life and story to survive past their death and pass down through generations. (Rosenberg, 2018)

01. TELL ME A LITTLE ABOUT YOUR LIFE HISTORY; PARTICULARLY THE PARTS THAT YOU EITHER REMEMBER MOST OR THINK ARE THE MOST IMPORTANT? WHEN DID YOU FEEL MOST ALIVE?

02. ARE THERE SPECIFIC THINGS THAT YOU WOULD WANT YOUR FAMILY TO KNOW ABOUT YOU, AND ARE THERE PARTICULAR THINGS YOU WOULD WANT THEM TO REMEMBER?

03. WHAT ARE THE MOST IMPORTANT ROLES YOU HAVE PLAYED IN LIFE (FAMILY ROLES, VOCATIONAL ROLES, COMMUNITY-SERVICE ROLES, ETC.)? WHY WERE THEY SO IMPORTANT TO YOU, AND WHAT DO YOU THINK YOU ACCOMPLISHED IN THOSE ROLES?

04. WHAT ARE YOUR MOST IMPORTANT ACCOMPLISHMENTS, AND WHAT DO YOU FEEL MOST PROUD OF?

05. ARE THERE PARTICULAR THINGS THAT YOU FEEL STILL NEED TO BE SAID TO YOUR LOVED ONES OR THINGS THAT YOU WOULD WANT TO TAKE THE TIME TO SAY ONCE AGAIN?

06. WHAT ARE YOUR HOPES AND DREAMS FOR YOUR LOVED ONES?

07. WHAT HAVE YOU LEARNED ABOUT LIFE THAT YOU WOULD WANT TO PASS ALONG TO OTHERS? WHAT ADVICE OR WORDS OF GUIDANCE WOULD YOU WISH TO PASS ALONG TO YOUR (SON, DAUGHTER, HUSBAND, WIFE, PARENTS, OTHER[S])?

08. ARE THERE WORDS OR PERHAPS EVEN INSTRUCTIONS THAT YOU WOULD LIKE TO OFFER YOUR FAMILY TO HELP PREPARE THEM FOR THE FUTURE?

09. IN CREATING THIS PERMANENT RECORD, ARE THERE OTHER THINGS THAT YOU WOULD LIKE INCLUDED?

Figure # - The dignity therapy question protocol

The approach of therapy - meaning centered psychotherapy

MEANING CENTERED PSYCHOTHERAPY

Victor Frankl was a psychiatrist who established logotherapy – the theory that posits that the primary motivator of the human self is the drive to find ones own ‘meaning of life’; one’s purpose and reason for existence. (Devoe, 2012) Early in his career, he suggested that humans strive to find purpose in life, even in the face of extreme suffering and brutality. Later, he would expand on this hypothesis through his own survival of the holocaust and the unique perspective it provided (Thomas et al., 2014). His experience proved the power and importance meaning provides – the ability to keep us alive (O’Callaghan et al., 2020).

Frankl theorised that humans find and create meaning through a variety of lenses; their career and hobbies, their understanding of their life, past and present, their relationship with life through art, humour, relationships and love, and the way in which they choose to act in the face of challenges. (Thomas et al., 2014) For terminal patients, many of these can be challenged: their job may no longer be feasible, they may have to give up hobbies, certain relationships may be challenged.

Meaning-centered psychotherapy acknowledges these realities of life, and helps patients to navigate them in order to retain and reinstate a sense of purpose – whether that be mending old avenues or establishing new. It follows Frankl’s philosophy, reminding and helping terminal patients to realise that life retains meaning, even when facing its end. (Kissane, 2015) It helps patients find a sense of purpose and meaning through an exploration of patients life story and history – their accomplishments, experiences, relationships and attitudes (similar to dignity therapy), and establishing and accepting one’s self, skills, abilities and limitations. By coming to terms with the reality of one’s self, patients can then begin the process of establishing where and how patients can find and satisfy this identified meaning. (Thomas et al., 2014) It focuses on not only discovering new sources of meaning, but also reconnecting with old, and the enhancement and maintenance of meaning that has been found. Like dignity therapy, meaning-centered therapy heavily touches on the concept of legacy, with sessions exploring identity and the impact of cancer, and how legacy can be left as a gift for others. (Kissane, 2015)

These discussions are facilitated through both individual (homework) exercises and group discussions, and allows patients to help each other realise their purpose. In clinical practice, patients reported being thankful for the opportunity to help one another, and were surprised with how comfortable they were discussing the private matters of one another’s lives – even independently planning meet-ups post 8-week treatment. (Thomas et al., 2014)

IMPLICATIONS

The discovery of meaning centered psychotherapy provides validation in the positing of stories as a successful means towards patients discovery of meaning and purpose, while the dignity therapy provides a structured, rationalised question protocol for documenting a person's life. These approaches provide directive for the further development of this project and provides a grounding for its rationale.

DISCUSSION OF DEATH AND CANCER

Meaning-centered psychotherapy, while not centered around the acknowledgment of death, gently refers to its unavoidable nature. Questions such as 'How has your life changed since your diagnosis?' do not directly reference cancer, but allude to its presence, and nudge patients into reflecting what they have lost. Through this reflective process, and identification of what has changed, the approaches - particularly meaning centered psychotherapy - encourage patients to reframe and reimagine how they could rediscover the source of joy that has been lost, and reintegrate it into their life.

However with this cohort, and its intended experience as one of escape and reflection, these questions will not be included so as to preserve its focus on life - not death. Instead, the intervention will rely on the dignity therapy quesions.

STRUCTURED FREEDOM

While a set of guiding questions are given, dignity therapy advocates for the interviewer to follow the patient; the topics that the patient raises are likely those most meaningful to them (Chochinov, 2012). In one case, a patient engaging in dignity therapy spent a lot of time speaking about his wife, their marriage and divorce – to him, the outcome was hoped to be an 'apology' of sorts. The exercise is ultimately for the patient, and should therefore be directed by them.

UNDERSTANDING, NOT MONITORING

While the project thus far was framed as monitoring patients priorities and emotions – tracking peaks and valleys, as a means for identifying opportunities, this approach instead advocates for a holistic understanding - not segmenting people's life and meaning into individual components, where nuance is lost, but instead understanding them as a whole. Stories capture depth, emotions, context – something which monitoring cannot. Rather than approaching this concept as monitoring through life insights, it should instead be approached as understanding through stories.

DISTILLING A LIFE

One of the factors in this project is the trajectory involved – patients have a life expectancy of approximately five months; in reality, this becomes more like four months when you consider the initial weeks as the 'numb' phase of absorbing their diagnosis, and the final weeks, where patients are heavily medicated, often sedated or uncommunicative. The objective of capturing a life in such a limited time, and creating an authentic, rich synopsis, is difficult. The nine questions in Dignity therapy facilitate an avenue for this – having been specifically developed for deployment with terminal patients, and attaining an understanding in an even further limited time – a single, one to two hour session (Chochinov, 2012). For this intervention, it can be employed to ensure that a deep understanding of patients lives can be attained even in the limited temporal circumstances.

INTERMEDIARY CONCEPT

The discovery of these theraputic provided substanciary evidence and prompted the creation of a protoypical model of the developing framework. It built on the original concept, integrating the theorethical insights and allowed for a schematic illustration to be created, visually representing the relationship and channels between the core components.

QUESTIONING AND DEEPENING

The framework employs the dignity therapy protocol questions in order to prompt patient reflection, and recounting of life stories. This approach is particularly applicable, as the questions have been specifically developed to obtain an understanding of someones live and sources of meaning within a short timeframe - nine questions over a one to two hour interview.

While here it is being employed through a digital interface, this provision of depth in the face of brevity is critical considering the HNC patient's short trajectory.

THE PATIENT EXPERIENCE

INTERACTION DRIVER

The framework speaks to patients' altruism and concern for their loved ones, alluring patients through the delivery of a service which grants patients a means to provide comfort to their loved ones after their death through the creation of a legacy book.

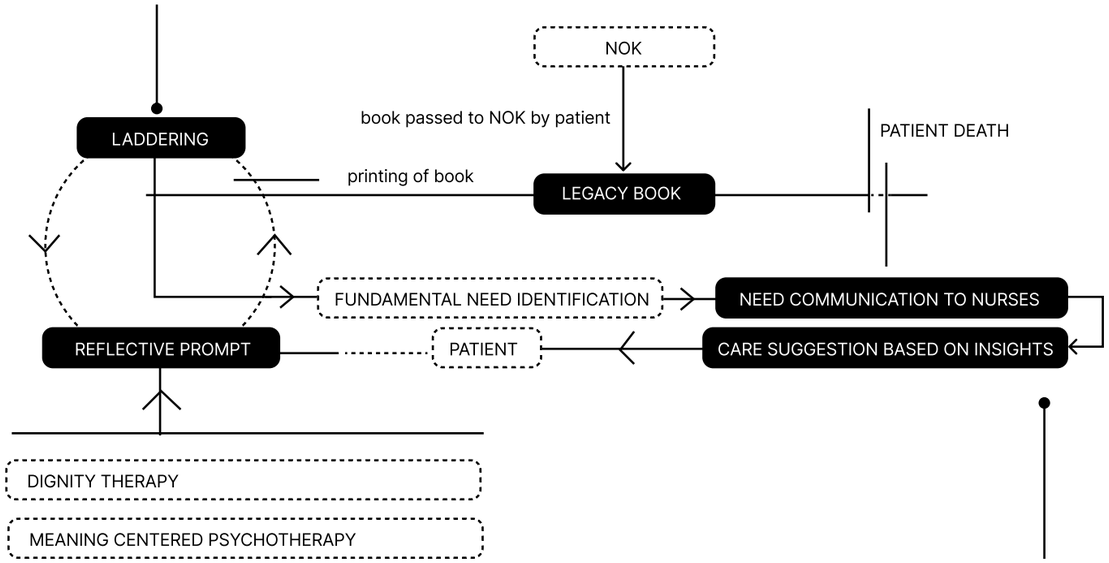
SURFACING MEANING

Through participation, the framework softly guides the patient in rediscovering sources of meaning through a deepening cycle facilitated by the laddering technique - reminding patients of what matters to them and their sources of joy, and mentally respositioning them to pursue these sources of fulfillment in their remaining time.

THE NURSE EXPERIENCE

Based on the laddering application and identification of fundamental needs, an aggregated overview of the patients critical need categories are created, with contextual insights contained within each category. This enables nurses to identify the most important need category, and reference, interpret and translate the insights into care adjusments.

The framework surfaces patients meaning sources through provocative questions about life, legacy and care, enabling discovery through a medium which recognises patients stoicism and minimises disomfort or distress



The framework communicates patients stories in a segmented manner, with each insight statement based on a contextualised source of meaning. This enables deep understanding and interpretation, yet recognises nurses time limitations, and facilitates the alignment of resources towards meaning sources, improving QoL

Figure 31 - A schematic illustration of the initial framework concept as established at the end of the ideation and concept direction cycle

CONSIDERED USERS

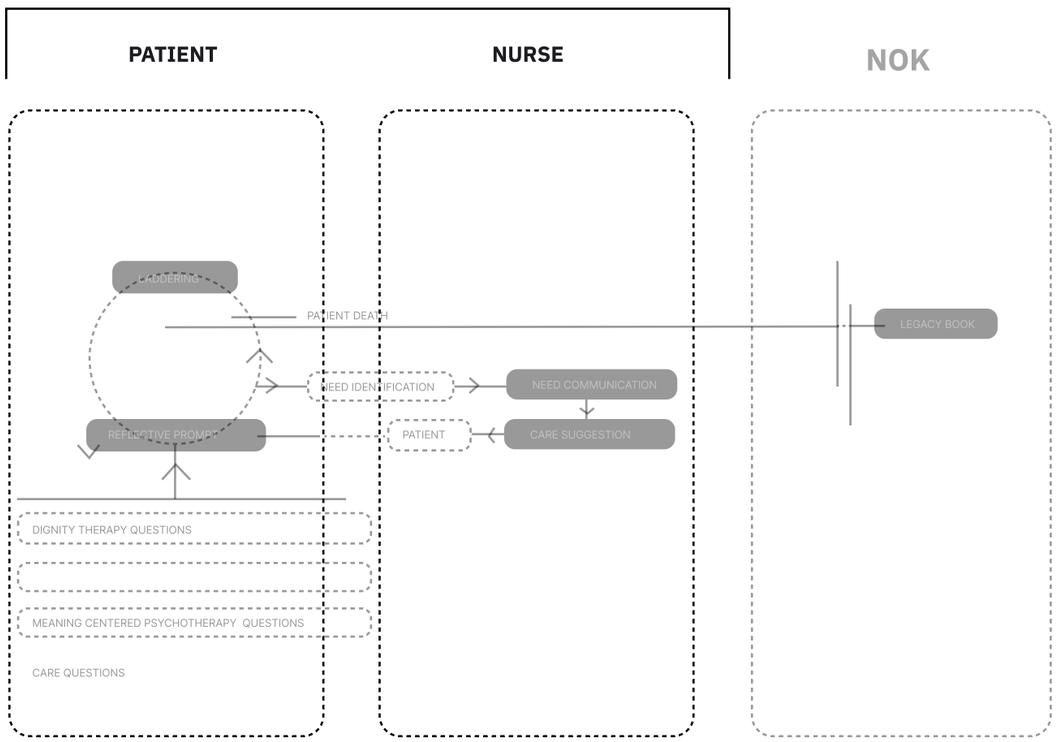


Figure 32 - Identified users

WHO IS THE USER?

A ramification of this design direction is the multi-stakeholder scenario it creates; the central user of the patient, the nurse, who actualises the patients' uncovered needs, as well as the next of kin, who recieves the legacy document.

In this instance, it is important to ensure that the patient stays central – that their experience with the intervention is not compromised. The intervention has to stay true to the patient; the pessimal outcome would be the intervention causing any level of further discomfort for the patients. For instance, the patient should not feel as if they can't share or explore certain memories (and meanings) because of the awareness of future reception by NOK or nurses, and an unwillingness for this knowledge to be shared.

THE NEEDS OF NURSES

At the same time, while the patient should remain central, considerations do have to be made to ensure the intervention's success for all stakeholders involved. For instance, dismissing nurses as a mechanic 'cog' is also ill-advised. With the patients framed centrally – about them, their life story – the nurses are, practically, a means to take the meanings found and align care with them. However they are also human – in order to ensure they also want to engage with the intervention, and help it reach its potential, their values and needs, and designing for such, also need to be acknowledged. What do the nurses want the intervention to deliver to them? What would help them in delivering care? How can it emotionally appeal to them? According to Desmet and Fokkinga (2020), all the artefacts we interact with fulfil some need. In order to encourage repeat interaction – and fulfilment – the artefact therefore also needs to fulfil the need of the nurse. Without this, the nurse may disregard the intervention, ultimately affecting the patients own experience.

FOCUS RATIONALE

For the purposes of this project, framework and embodiment development will be centered around the patient and nurse. While ensuring the NOK also feels considered and included is important, it would be remiss to design the patients interactions around what the NOK desires - the patients freedom to explore, reflect, and find comfort should, as the dignity therapy protocol advises, should be at their total discretion.

Should the project timeframe be longer than the given 100 days, it would be interesting to further explore this avenue, and how the NOK's desires could be integrated without impairing the patient's exploration. However, for the purposes of this project and its available time, this will not be considered as a central constraint and driver.

THE STAKEHOLDER PERSPECTIVE

INITIAL CONCEPT FEEDBACK

With the basic premise of the design concept established and the stakeholders mapped, development and refinement began. This happened on an individual basis, but also through a series of feedback sessions with the varied stakeholders involved in the system.

The insights and discussions surfaced through this process are presented in the following pages, followed by a general reflection and rationale for the interpretation, and consequent inclusion/exclusion and response to the insights.

Disclaimer - as a result of the context involved in this thesis, the participant pools are incredibly low. Therefore, insights regarding general perceptions surrounding hospice care and HNC were not taken singularly or definitively - instead, the insights presented throughout the following pages are those which, when cross-referenced with secondary research, aligned and generated further richness and insight, and validated the secondary research findings. Insights which dissented from all other research, and which could not be corroborated, were not included.

Insights and feedback pertaining directly to the concept were taken into consideration, and a rationale is given as to their inclusion or exclusion from further development.

These interviews were not conducted solely with Erasmus MC, and instead represent the voices of people across institutions, from both the Netherlands and Ireland. All insights have been anonymised and attributable information removed to protect identities.

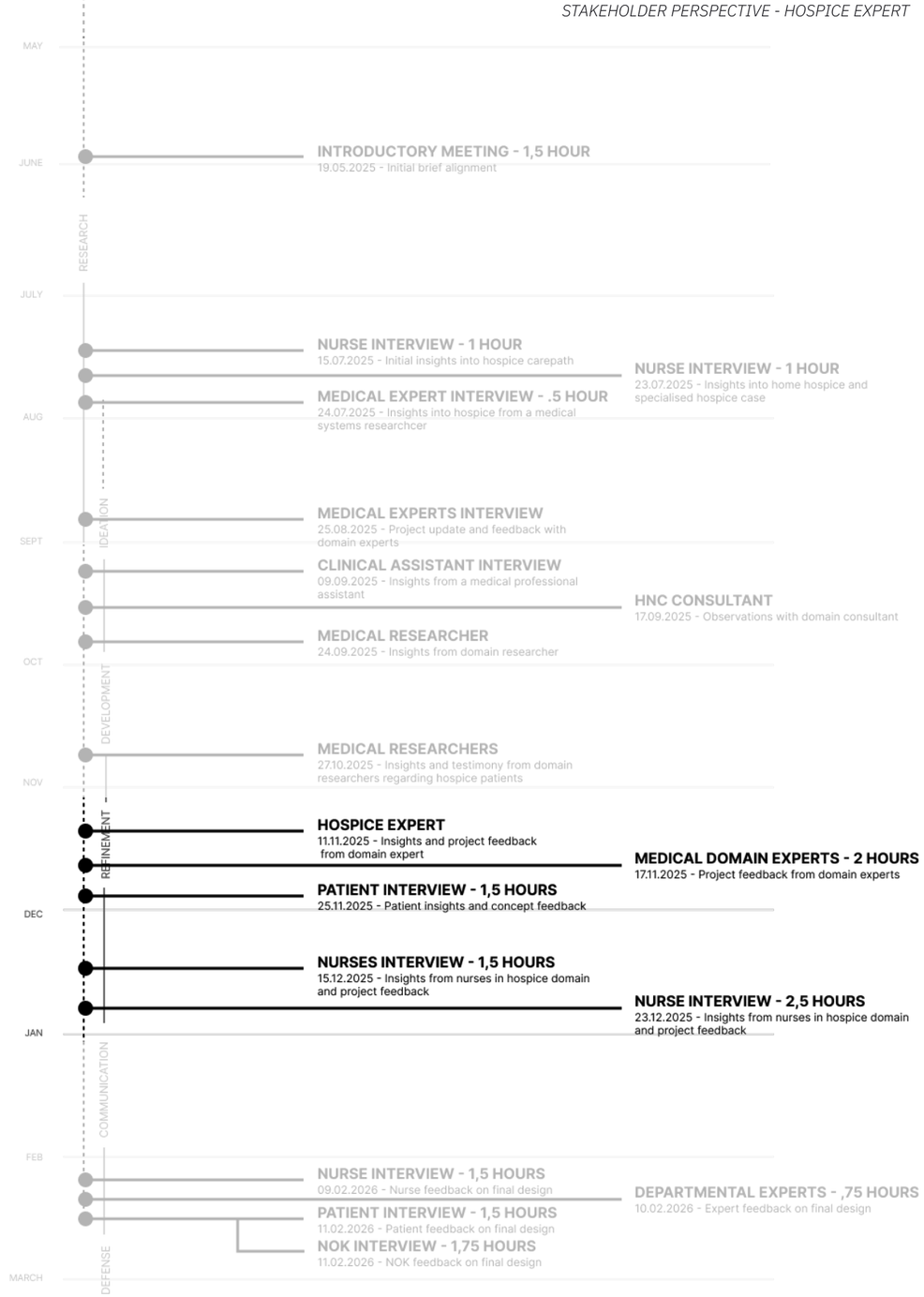


Figure 33 - schematic showing the various interviews and feedback sessions that occurred during this period

THE INSTITUTIONAL PERSPECTIVE

The concept was presented to institutional domain experts in order to ascertain an institutions perspective on the intervention. Rather than focusing solely on one interaction – the patient, nurse, or NOK side – the system was introduced holistically.

A mixed response was recieved. Research insights received praise, with participants assenting interpretations and findings, and expressing their approval at the manner in which research, and the patient insights, were represented. However, the manifestation of these insights, and its coalescence into the initial framework, raised criticism.

REFLECTION VS COLLABORATION

There was an antipathetic reaction to the indirect nature of the questions, instead favouring and soliciting a more direct approach, through interventions which would instead support and encourage patients to become accustomed and comfortable with discussing the loaded, emotional aspects of care. Though patients desire for autonomy and privacy were acknowledged and assented, designing towards these desires was nevertheless met dubiously.

Instead, attendees advocated for a more conversational design, which would encourage patients to share and discuss their concerns and thoughts with carers. Existing interventions, such as conversation cards, were presented as preferable, where gamified approaches helped break the emotional barriers around these topics. This would foster greater understanding when approaching care planning and alignment with patient needs; one HCP recounted a recent experience where a partner wanted to discuss the patients wishes for their funeral arrangements, but were unable to get said patient to open up. This disconnect caused significant distress and anguish for the partner in light of what she knew was a fast approaching event, and where she felt unable to properly accommodate what her partner would want in his final celebration of life.

FEASABILITY

Fears were also raised regarding the feasibility of the intervention, and the resources and time that the institution associated with the development of the app and system, considering the strict protocols and regulations associated with medical device development. One expert recalled the extreme timeframe involved in the development of the existing system the institution employed, and expressed apprehension regarding the development of another digital service.

Interventions should be developed with the reality of the the medical field in mind, such as device regulations and practical constraints.

HOSPICE EXPERT

The concept was presented to an expert in the hospice and palliative care domain, in a similar holistic manner as was presented to the institution.

THE INBETWEEN LAND

Patients find themselves in a strange place - not dead, but also not entirely alive at the same time. They are living, but living with an expectation of death - a strange ‘in between’ state. This place is strange, but it is important to recognise it.

The intervention shouldn’t approach or converse with patients in a way that implies they have already passed. They are still living, they are still making memories - their life story is still happening, it is not over.

A HOLISTIC UNDERSTANDING

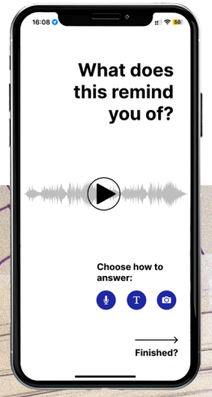
In spiritual counselling, counsellors frequently make A4 summaries of stories and insights that are discussed - these, similarly to the proposed intervention, aim to deliver a more whole, rich understanding of the patient.

However, in order to do so, it is important to not only chase priorities, sources of meaning, but also dislikes. Only focusing on the happy parts could result in a two-dimensional being - instead, like in Desmet and Fokkinga’s (2025) ‘Rich Experiences’ approach, where a negative and positive emotion together create richness in experiences, so too do these poles create more richness and depth in understanding people.

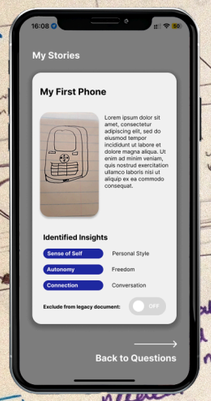
During this conversation, an example also arose, wherein a patient was being asked about her hobbies when younger. The patient began talking about her time in a choir, and was asked if she would like to sing. The patient said no, but as the music began to play - opened up completely.

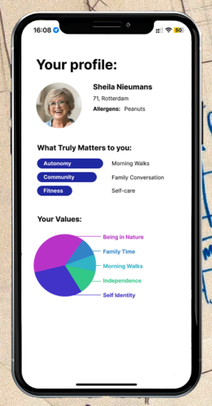
This is quite representative of how I envision my own intervention - understanding through stories, and rediscovering joy and meaning through reflection.















EARLY EMBODIMENTS AS UTILISED IN STAKEHOLDER FEEDBACK SESSIONS

THE PATIENT PERSPECTIVE

STAKEHOLDER PERSPECTIVE - PATIENT

N.B. – The patient interviewed during this project, while not undergoing curative treatment any longer, had partaken in a clinical trial and reacted positively, far outliving typical HNC prognoses (~8 years as opposed to the typical 5 months). Therefore, while insights can be taken from this activity through patient recollection and testimony, their personal ambitions and opinions are not closely representative of the population at large. The patient themselves recognised this, frequently referring to 'their' preferences and their 'peers' preferences separately. This patient is connected with other patients through a support group, and was as a result, able to give insights into their perception of what these patients collectively, would likely prefer.

In this interview, a two step approach was taken. The first part of the interview was open ended questions about the patients life, their own needs, without any influence from existing concepts and ideation insights. This facilitated unbiased insights into the patients needs and desires, without influence from the developed concept. Then, the framework and embodiment was presented to the patient for their feedback and insights. The critical insights are documented below.

'6 months of hopelessness – I'm going to die'

EXPERIENCE OF PSYCHOLOGICAL CARE

When asked to describe their experience with the psychological care they received, the patient simply said 'I don't know – because I didn't receive any psychological care'. Upon further discussion, it did emerge that the patient had interacted with questionnaire-based tools, but described them as meaningless (in regards psychological care) – 'It is really hard to quantify.. yeah what is quality of life when you're dying? ...how do you express that through this?'

Instead, the patient said my question should be how serious patients treat the questionnaire – in their case, they didn't see the point. When asked if there was ever a response to their (psychological-centric) answers, they said 'never'.

'Why do I have to fill this out when nobody ever uses it'

'I do not wish to depend on someone else completely, if that's the case, just let me go'

WHAT THE PATIENT WANTS

STAKEHOLDER PERSPECTIVE - PATIENT

GUIDANCE

When asked what wishes or needs the patient would have wanted when they first entered hospice, the main expressed desire was simply support, a 'coach' – not someone who will do something for you, but simply someone to help. The patient descried being lost, not knowing what to do; wanting to arrange everything - funeral, care preparation - rather than leave husband to do it, but simply didn't know how. They explained that there is a major difference between knowing they needed to source a wheelchair, versus actually sourcing it - however there was no guidance towards either of these. This confusion resulted in days and days being spent hopelessly trying to plan – which the patient said is the last way you want to spend your time when your life is so limited. While nurses clearly did want to help, it would take days for them to respond, time the patient didn't have.

This structure, and organisation of life, the patient said, is what comfort is in hospice care – just knowing everything is taken care of. Someone by their side, someone who understood you and the phases you were going through – 'That's what I really missed'.

'You had to call everyone just to try arrange something… you want to spend your time doing nice things, not 100 days trying to get some help'

INDEPENDENCE

The patient recalled in the latter days of hospice, the distress experienced as a result of physical deterioration - including an instance where her mother had to make bibs for her. She described simple moments of independence - like being able to make your own tea, or shower yourself, as incredibly important, and although simple, had a huge effect on one's psyche.

'comfort is something else when you are in this [hospice] stage – comfort is autonomy, or being recognised'

WELFARE OF LOVED ONES

As clearly illustrated during secondary research, the patient independently brought up the topic of loved ones and their importance. She reiterated the secondary research's finding about avoiding emotional expression for fear of upsetting loved ones, and prioritising time with family and friends.

During this discussion, the topic of preparing loved ones for grief was also raised, with the patient emphasising how important it was to her to know that her loved ones would have access to quality support and grief counselling after death, and knowing it would provide some comfort.

'I would tune things down, say 'oh everything is okay' when actually I feel totally shit'

REACTION TO LEGACY

While directions other than legacy were equally presented in order to gauge an authentic preference, legacy was identified as the preferred direction.

In particular, the direction of conversation was received negatively, with the patient explaining that for her, even if she did feel comfortable discussing care aspects, it would be worthless, as her husband is not able to talk about these things.

> *"I would definitely like to do it on my own… would be useless for me, he just won't discuss it… there's something wrong with his brain"*

> *'the only thing my husband understood was that I [the patient] was going to die and I [the partner] am left here'*

Unprompted, the patient also referenced the earlier topic of grief counselling, and said that an additional attraction towards this intervention is that it provides the patient themselves a means, and a sense, of providing support and comfort to their partner in their grief after passing.

The patient, when first presented the interface screens, reacted positively. The question prompts were described as 'sparking curiosity', and liked that when opening the app, the questions would be like a surprise - she liked the non-monotony, and its novelty compared to traditional medical approaches.

In later screens, when a sample question and answer was shown, the patient immediately became engaged, recounting how they would answer the question themselves without being prompted to - a particularly encouraging interaction.

AUTONOMY

One important consideration raised was that the intervention should facilitate nuance - in particular for the multiple choice or 'swiping' questions, there should be a means to annotate or make an answer conditional, rather than it being so black and white.

They appreciated the ability to edit stories collected at a later date, saying that this was especially important, so that should they interact on a 'bad' day, they could later go back and change the story to reflect a more balanced view.

INTERACTIONS

The patient said that although vocal interactions would not be an issue for them personally, the interaction was well-considered. They particularly liked the journal upload option, as it is what they would use, but questioned whether they were in the majority. At the same time, they recognised that there were alternate methods of interacting in this case, and this flexibility was good.

When asked how often it could be considered that patients would interact, the response was to expect daily - particularly in the early days, where distractions are needed.

EMBODIMENT

The smartphone direction was clearly identified as preferable. Other digital mediums were described as 'just another device to have to carry around'. Artifacts which were not portable were discounted, as the patient said they would much prefer to be able have the intervention on them at all times, so that they could interact, at will, even when outside the house - or for in latter days of hospice, where mobility issues necessitates easy access.

FEASIBILITY CONCERNS

The primary concern raised by the patient was its failure to deliver on care improvements should there be inaction by the nurses, as based on their experience, responses were slow to arrive.

They questioned whether there would be a way to flag particularly important passages to the nurses to increase the chances of receiving a response, or a way to enable the patient themselves to take action once a care adjustment was identified.

These 'efficiency' concerns were also the primary reason the patient preferred the digital medium over others. On this topic, the other mediums were not identified to have any additional benefits that were not, or could not, be integrated into the smartphone version.

THE NURSE PERSPECTIVE

NB. Due to the presence of a language barrier, one of these interviews were carried out by my colleague. I established a question list, activities, and content prior, then explained my intent. In certain cases, where I was able to understand, I interjected where required. The interview was recorded, and a transcript generated and translated in order to ensure full comprehension and extract all relevant insights.

Multiple separate interviews with nurses were conducted. For the purposes of anonymity and protection of participants, these insights have been unattributed and amalgamated.

Interviews consisted of two phases – first, a general introduction, followed by a brief interview regarding nurse's experience of the hospice phase. This was followed by a presentation of the design, which probed into the nurses experience of the concept, as well as discovering parameters to be considered – such as what fundamental needs it should support, how much time they could interact with the system, and how to best communicate and deliver patient stories in order to foster a rich understanding. Printed visualisations were utilised, which represented 'collected stories' from patients.

> *"For everyone, quality of life is different… A patient may say they still enjoy life... he can't eat, can't talk, can't do anything. But then he says yes, I still can have a cup of coffee with my wife. But he doesn't actually drink coffee, he just sits there… he says, I can still enjoy my life, every day, with my wife, drinking coffee"*

> *"I look at where the fear actually lies. Is it fear of what's to come? If so, you actively ask about that. Hopefully you can break though that barrier."*

PSYCHOLOGICAL RESOURCES

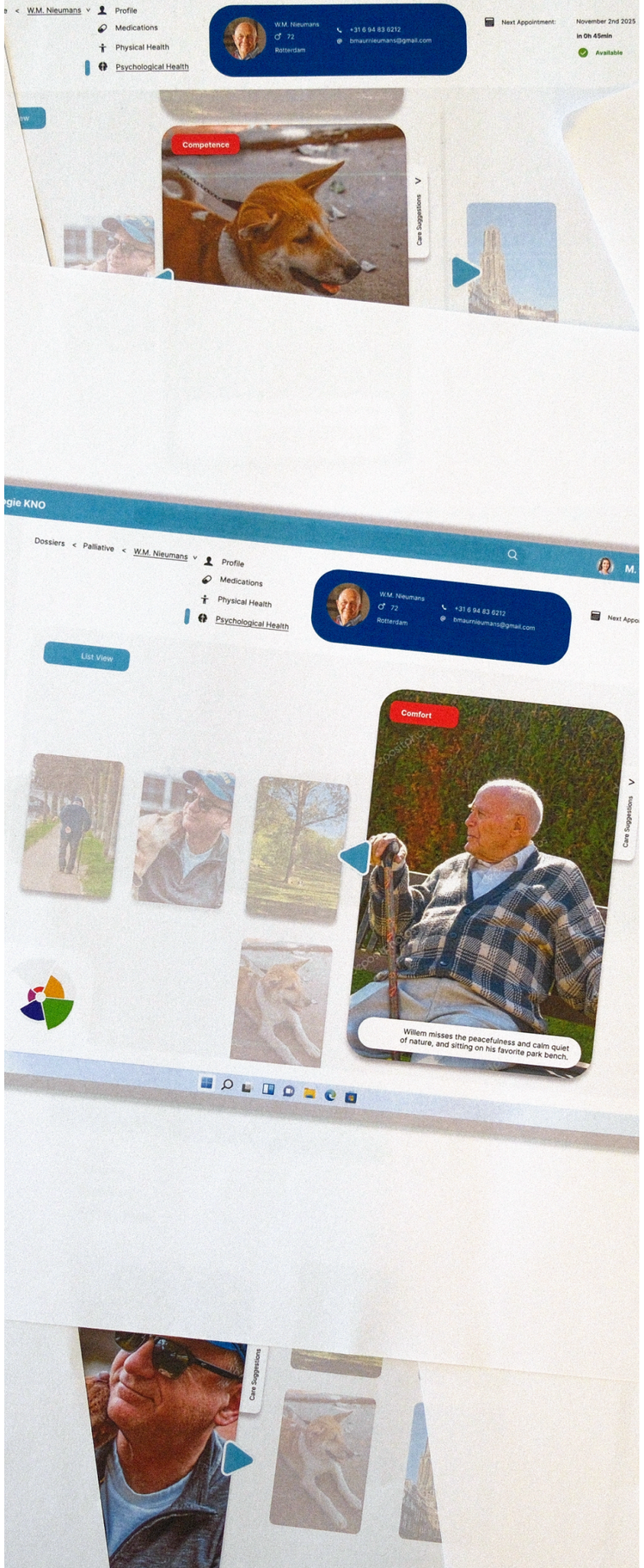
As found in secondary research, nurses expressed opposition to the lack of resources made available to patients in the hospice phase – referencing the absence of take-home materials that guide patients in navigating care in the hospice phase, but also the lack of specialised psychologists. When asked why this deficiency remained, considering how apparent its importance personally seems, discussions seemed to imply that providers generally regard the nurses themselves as the primary source of psychological support.

> *"I was working there for over 20 years… we repeatedly called on upper management to provide therapists or something, but they just never responded… I never heard anything back"*

While willing to fill this gap in care, nurses expressed feeling of ineptitude and guilt in the quality of care they could deliver patients - both in terms of psychological skill, but also time. While they underlined their constant availability to patients - taking patient calls as frequently as twice a week - their overburdened workload was restrictive, and wished patients could instead access the quality, expert care they deserved. The tools employed in the institutions these nurses worked in were perceived as 'meaningless', lacking depth and emotion, and fail to offer actionable insights, wherein they instead elected to talk to the patients themeslves.

> *"…What they go through in the hospice [palliative] phase is no small thing. So you want to respond to those people and guide them…"*

> *"You really try to play an active role – You don't have to, but you should."*



CONCEPT FEEDBACK AND REACTION

ASSISTIVE FEATURES

In the proposed concept, a ‘care suggestion’ feature had been integrated, which based on AI or previously documented nurse responses, would give suggestions about actions to the nurses. I questioned whether this could be found to be paternalistic or skeptical of the nurses skills.

Instead, the nurses appreciated its inclusion, describing it as a ‘good way to get a second opinion’ in addition to their own instincts and ideas. As long as it would not dictate responses, they did not find it intrusive.

DEEPENING TRUST

During the concept presentation, the nurses brought up their prediction that this provision of personal insights and stories would deepen trust - saying that simply being able to ask a patient ‘How is Betsy [the patient’s imagined dog]’ would make the patient feel more seen and understood, increase trust, and potentially make the harder conversations about death more accessible.

DEPTH OF INFORMATION

The most important question that needed to be established during these feedback sessions was what the needs and desires of the nurses was in regards information and communication of patient insights.

To ascertain this, different levels of information were presented - from the vague ‘William is sad’, to the granular ‘William feels disconnected from his grandchildren as he can no longer read them bed time stories’. During the initial presentation, the nurses said that they would have to ask ‘why’ in order to discern action - reflecting the laddering techniques intent and application.

In response to the deeper levels, nurses began making suggestions themselves, unprompted, such as the provision of speech therapy, suggestions to ‘act’ stories instead of tell them, or questioning whether the distance was compounded by children’s fear of mutilations.

The more granular information was found to be preferable - higher levels were perceived as inactionable. However, the nurses also said that this should be presented as briefly as possible - a couple of sentences at most - due to their limited time. Scrolling through the ‘ladder’ was unlikely to be utilised as a result. They also appreciated the inclusion of pictures, saying they helped create an understanding from a quick glance.

> *“Grandpa is just different… a special grandpa.”*

A PERSONAL REFLECTION

‘You will be dead in five months’

I cannot imagine what these patients go through when they are diagnosed as terminal. No matter how much research is conducted, triangulated, interpreted, it is impossible to put yourself fully into their shoes; I realise that. I can speculate on how I would react in any given situation, or really, how I would want myself to react, but none of us can really say what we would do if we suddenly found ourselves in such an unimaginable and unnatural situation; knowing when, and how, you will die.

What I do know, is how I feel I, as a designer, should help these people. They already have an unimaginable burden on their shoulders; grieving their futures, saying their goodbyes, consoling their loved ones, rearranging finances, planning their own funerals. I don’t think we should design something which places, or requires, further change on their parts. I don’t think we should attempt to change their innate behaviour. I do think we should do whatever we can to make their lives easier. I am a designer. I would rather design around them rather than force them to change.

In the course of this project, the academic mindset of what is ‘right’ was challenged repeatedly – for example, the popular approach of participatory design, while generally preferable, becomes unethical considering the brevity of patient’s lives and the trauma they face. At this stage in the project, another academic-to-actuality reflection moment emerged – reacting to feedback.

Part of being a designer is advocating for your users – using your understanding and skills to create something that you truly believe will improve their lives. During this project, I found myself repeatedly questioning my expertise and knowledge – struggling with the degree of isolation from real users, and treading the line between my designerly instincts and the scientific mindset and needs of medical experts and institutions.

This moment in the project required me to take a stance. What did the project mean to me, what did I envision it meaning to the patients.

I have spent hundreds of hours reading about these patients lives and experiences. I have heard their testimonies through personal blogs, forums, videos. I have read posts of patients, days after being told they have five months to live, reaching out on forums begging for advice on what to do. I have seen patients say their goodbyes to online communities, and read the follow up posts, days later, from their grieving spouses. As a graduating designer, soon to return to the workforce, I have the skill, capabilities, and expertise to make these decisions – to back my design and decisions, even if it means briefly disagreeing with institutional stakeholders, and to be confident that as the design and rationale progresses, it’s merit will be seen and understood.

Being a designer is to go against the grain, to challenge norms and expectations, to create tension and upset in chase of innovation. Being a designer is defending your design, and protecting the users and lives it will help improve. Being a designer is making these sometimes hard decisions - which in this project, I learned to do.

> *“I like to have control… if I got to a stage where… my brain (and body) had started to go… I would do something about it… I would NOT want anyone looking after me and I would probably kill myself… I mean I would do it happily”*
>
> *– (O’Sullivan & Higginson, 2014)*

COMPILING INSIGHTS

STAKEHOLDER PERSPECTIVE - FEEDBACK

This section gives a reactive recap on the primary feedback points discussed during stakeholder feedback, and a rationale on their inclusion or exclusion from further development. Insights that underlined appreciation or the perceived suitability of integrated aspects are not discussed, as these insights were taken as validation and not necessitating a course of action.

FOCUS ON LIFE, NOT DEATH

INSIGHT

Discussions with hospice experts emphasised the importance of recognising the patient as ‘still living’, and avoiding questions that refer to their life in the past tense.

RATIONALE AND RESPONSE

While dignity therapy and meaning centered psychotherapy do allude to death, it is important to recognise that the people engaging in these services and appraoches are people who have selected, and are likely open to, therapy and emotional expression and discussion. In this project, the audience is vastly different - specifically targeting people who are uncomfortable with therapy and emotional expression and discussion, and unwilling to discuss the realities of cancer and care decisions, therefore it is best to avoid these approaches.

Questions should focus on people’s lives - their experiences, what they did, where they found meaning. This intervention’s core essence is that of life – not death. It serves as a welcome escape from their approaching death, instead looking to life, their purpose, achievement – by interspersing it with references to cancer – to death - it again becomes another source of trauma in daily life, rather than a respite, attracting negative associations in patients minds, decreasing their desire to interact. In the same recognition of life and legacy, the phrasing and language used in reflective prompts should recognise the patients as still living, and avoid use of past tense.

Patients will be unable to rediscover sources of meaning from their past if the intervention holds them in their present. If during reflections, patients wish to explore cancer-related changes, they can – however, this should be purely at their discretion.

A final important consideration is that should the intervention include direct questions about death and cancer, it will dissuade the stoic persona from interacting with the framework. As hypothesised previously, patients who are comfortable with these topics likely already engage directly with nurses - who confirmed this assumption - and therefore do not need this intervention; so to include these direct questions is ultimately designing an intervention where the stoic persona will not use it due to discomfort, and the open persona will not use it due to lack of need.

CONDITIONALITY AND NUANCE

STAKEHOLDER PERSPECTIVE - PATIENT

INSIGHT

When reviewing interaction styles, the patient expressed the importance of allowing for nuance and conditionality to be attributed to various answers.

RATIONALE AND RESPONSE

In the course of this refinement cycle, it became clear that stories - an authentic take on legacy - should become singularly central - that direct care references or interaction styles only detract from the emotionality and richness of legacy.

Therefore this insight will be intregrated through the sole focus on stories as a medium - giving patients full control over narrative, interpretation, language.

CONSTRAINT

The design should accommodate nuance and conditionality in patients expression.

NURSE’S FUNDAMENTAL NEEDS

INSIGHT

Feedback and discussion with nurses clearly highlighted their care and consideration towards their patients - going beyond the call of duty to support them out of genuine sympathy and compassion.

RATIONALE AND RESPONSE

Through these discussions and, nurse feedback, ‘competence’ was the identified fundamental need that should underscore the nurses interactions with the framework. Nurses appreciated the inclusion of the care suggestion feature as an additional means to improve the care they could provide, and experienced it supportively rather than paternalising.

CONSTRAINT

The design should provide nurses with a sense of empowerment and competence in their delivery of care to patients.

INFORMATION COMMUNCIATION

INSIGHT

In communicating insights to nurses, a balance between brevity and depth should be met - richness through visuals and a succinct description. Clear, contextualised actionable statements were preferred.

RATIONALE AND RESPONSE

In order to provide nurses with the ability to act on patients insights and deliver quality of life to the patient, the inclusion of the whole laddering process was deemed unnecessary. Instead, insights can be framed around the fundmanetal needs, delivering context and a clear underlying problem, enabling nurses to act swiftly.

As found in research, nurses have limited time available, and efficient, succint communication is necessary in order for the intervention to be feasible.

CONSTRAINT

The design delivers a rich but efficient understanding of insights for overburdened nurses, minimising extraneous information.

CARE SUGGESTIONS

INSIGHT

The patient expressed apprehension regarding the efficiency with which responses would be recieved from nurses, questioning whether there would be a way to ‘flag’ important insights, or allow the patient to react and organise care themselves.

RATIONALE AND RESPONSE

While these fears are acknowledged, the ‘flagging’ system would be hard to integrate considering the new decision to avoid direct care references.

In reference to the direct communication of care suggestions to patients, the insights from secondary research - as well as the patient themselves - would point towards this being seen as yet another burden - where the patient now has to spend their precious time trying to organise the care adjustment.

Instead, it is recommended that the framework is initially deployed without these integrations to test the responsiveness of the nurses and staff - and should this issue arise in reality, adjustments made.

THE ETHICS OF INTERPRETATION

INSIGHT

There were concerns raised regarding the systems interpretation and communication of patient’s thoughts, rather than letting the patient communicate with the nurse directly.

RATIONALE AND RESPONSE

It is acknowledged that using a systemic approach to ‘interpret’ patient’s needs and meanings, rather than have patients identify them themselves, feels somewhat paternalistic. I also initially considered whether this direction was somehow unethical or immoral in essentially enabling a system to interpret and communicate on behalf of a patient.

However on further reflection, I realised that demanding these people to change and become comfortable with conversation, in the midst of what are already huge, demanded changes, is more unethical than simply designing with them. It also should be considered that the system in no way changes the voice of the patient – instead, it simply summarises the insights.

Moreover, the essence of the design is the exploration of legacy - disconnected from any direct reference to illness. Expecting patients to directly communicate with nurses changes this experience to another medical ‘chore’.

A final consideration: in therapy, patients often don’t know what the source of their problems are, or how to interpret their thoughts - the therapist helps them interpret it. While an assumption, this may also apply in this case, where patients can’t discern their meaning sources themselves.

BEHAVIOUR CHANGE

INSIGHT

Suggestions were made that instead of circumventing conversations around care, instead an intervention should be integrated which would encourage patients to open up.

RATIONALE AND RESPONSE

In most cases, designing for behaviour change can be revolutionary, challenging and changing unwanted behaviours and attitudes, and encouraging users to instead adopt preferred behaviours. However, in the context of this specific project, this approach warrants reconsideration.

While the desire to have patients feel comfortable with conversing about these topics is valid, and preferable in an ideal scenario, it does not change the fact that expecting patients to change their behaviour and become comfortable with these discussions – particularly considering how much other change they are already being forced into - is a massive expectation. This expectation becomes even more loaded when this behaviour and attitude change is required within as limited a time period as the HNC trajectory, and with time to spare in order to actually engage in the conversations that the patient has now been made comfortable with having. A further limitation is the limited access to the patient population, and the difficulties that would arise when attempting to validate whether the behaviours your design is attempting to change has the intended effect.

While this is an interesting design problem, pivoting the project approach so intensely at such a late stage in the project is inadvisable.

DEVELOPMENT FEASIBILITY

INSIGHT

Hesitation was expressed regarding the realistic implementation of the framework (and embodiment), with references made to previous time frames digital interventions required.

RATIONALE AND RESPONSE

The complexities associated with design in the medical field are irrefutable, and it is important to recognise the realities and regulations the medical field entails - such as the consideration given towards the reliance on digital communication for efficiency and data protection and handing. However, the context in which the project was proposed was an expressed desire to explore how digital technologies could be used to imagine the future of hospice care.

The project was conducted aligned with this vision – freely exploring the opportunities digital technologies may afford. While the system may seem speculative now, the rate at which the involved technologies – particularly AI – are progressing shows promise for their feasibility. While this is a valid consideration, considering the initial framing of the brief, and the projects coherence with such, as well as the point of the project wherein this discussion arose, pivoting entirely away from these technologies would jeopardise the outcome of the project at large.

AUTONOMY VS COLLABORATION

INSIGHT

In tandem to the insight pertaining to behaviour change, suggestions were made to reposition the design as a collaborative activity rather than an individualised interaction.

RATIONALE AND RESPONSE

Creating an intervention centered around conversation and discussion not only strips patients of the autonomy and privacy they desire, but reinforces the lack of autonomy they experience – presenting another interaction which requires reliance.

As identified in interactions with the patient participant, even if the patient is (or changes themselves to be) comfortable with engaging in these topics of conversation, if their partner is not comfortable doing so, it means they cannot benefit from the intervention whatsoever.

Instead, this insight will be considered as a preferential implication of the frameworks deployment - exploring means to spark conversations as a side effect of engagement, rather than a central tenant.

> *"I would definitely like to do it on my own… would be useless for me, he just won't discuss it… there's something wrong with his brain"*

There was one consideration, which while initially integrated, was later removed.

HOLISTIC UNDERSTANDING

INSIGHT

It is important to get a whole picture of a person in order to understand them - not just the positive aspects, but also the negative. It is equally important to obtain stories across their life, rather than a subsection.

RATIONALE AND RESPONSE

In response to the recommendation by stakeholders to ensure a holistic image of patients life, the fundamental needs were considered as a means for the system to track which needs were surfaced, and which were not.

As stories were gathered and fundamental meanings surfaced, the system keeps tabs on how many times each fundamental need is identified as a basis. As gaps are identified, in response, the system could push patients towards questions that it hypothesises will surface insights related to the missing need, and hopefully fill the gap.

However, on further reflection, this was not included in further development - one of the primary recommendations in the dignity therapy protocol is to let the patient lead, and embedding this feature directly fractures this. However, should further work on the project commence, this direction would be valuable to pursue further, and explore a way of integrating this aspect without causing interference on patients freedom to reminisce.

REFINING THE DESIGN - THE FRAMEWORK

In response to the identified considerations, a further refinement cycle began, with methodological, granular consideration given towards the systematic processes - the intricacies of how the initial question would be generated, the theory behind how the nurses' summary would be created, how the laddering technique would progress.
Through diagramming what aspects and interactions needed to be facilitated when and where, these maps were used to identify what assets from the accumulated theoretical approaches could contribute where. In tandem, embodiment interfaces were developed, to respond to framework adaptations and further considerations.

This 'jigsawing' process resulted in both a final schematic, and visual understanding of the concept, detailing the interactions and interfaces involved, as well as the systematic, methodological processes supporting these interactions.

COMMENCING

DIGNITY THERAPY

REMOVAL OF MEANING-CENTERED PSYCHOTHERAPY QUESTIONS, AND DIRECT CARE QUESTIONS

The basis of the initial reflective prompts was reduced to only the dignity therapy protocol - in reflection, the meaning-centered psychotherapy questions were too cancer-orientated considering the interventions stance as life-centric.

In addition, the process employed by the meaning-centered technique was quite reminiscent of the laddering technique - posing questions, then prompting further reflection through questions which are identical to the 'Why' laddering employed by the laddering technique.

COMMUNICATING

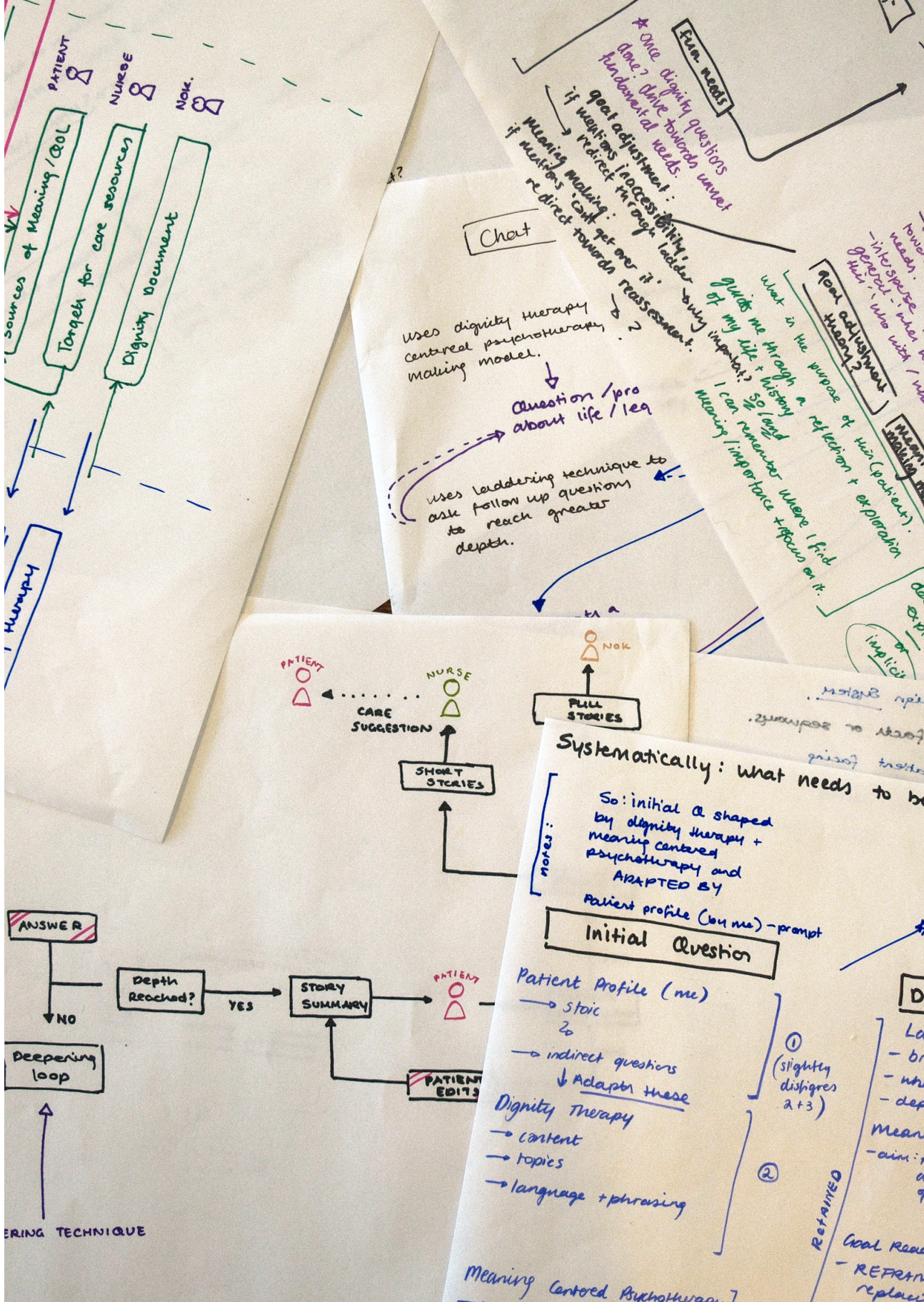
FUNDAMENTAL NEED MONITORING

When communicating insights to nurses, rather than basing this synopsis on the laddering outcome, the insights will be segmented based on the fundamental needs.

For example, rather than a holistic story - 'I really enjoy walking my dog in the local park... the fresh air helps me me relax, but I also enjoy meeting my neighbors' it would segment the insight into two seperate components; 'Being in nature helps William relax' and 'William enjoys talking to people'.

This facilitates brevity and clarity, without removing emotional depth.

This is a simplistic example for audience understanding - it is assumed actual stories would be significantly more complex than this example.



CONSIDERATING INTERACTION DRIVERS

During this exploration, consideration was also made towards the reasons that users would interact with the framework - two additional pathways were integrated based on these insights and included in future framework deployments.

In intial patient research, it arose that patients find a huge amount of joy in the ‘normal’ and familiar - taking extra time to see beauty in the mundane. Considering their awareness and consideration of the present, it could be assumed that they may be quite sentimental during this phase, with sounds, smells and tastes triggering memories, nostalgia and sentimentality.

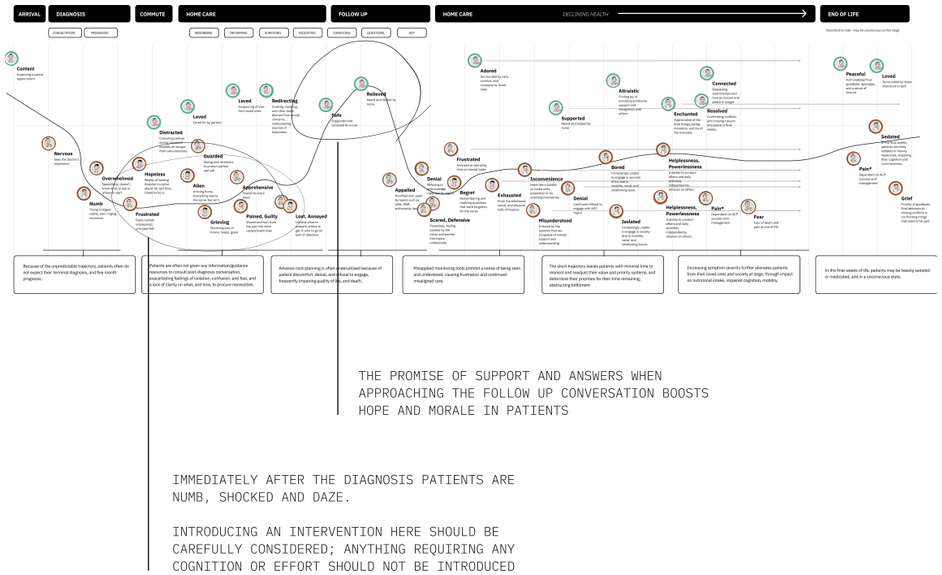
The intervention should accomodate this, providing a channel where patients can document stories of their own accord - not in response to the framework-defined questions. Once their story is told, the standard framework returns, prompting a deepening cycle based on the patients own story.

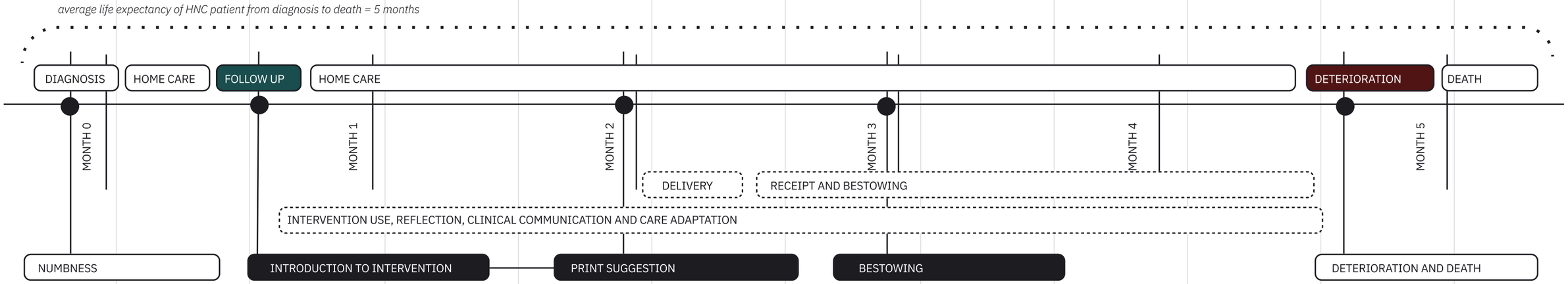
Based on the intensity of distress and references to struggles in the silent of the night, notification controls were integrated, the frequency and timing of which could be controlled in app by the patient. This would allow the patient to define particularly hard moments of their day (eg. at night) that they expect distress, and allow the app to send a notification to them during these moments to hopefully provide a diversion.



SITUATING THE INTERVENTION

Considering the service nature of the developing framework, it is necessary to establish the temporal parameters each phase of the framework should commence, and conclude within, in order to deploy various interaction cycles at opportune times. For example - when should the service be introduced? When, and how, does the patient begin reflecting? When should they stop?





NUMBNESS

In the days following their incurable diagnosis, patients are overwhelmed and numb, dealing with the trauma and intensity of the transition. They are not in a mindset where they have the capacity to reflect on their life - they are still dealing with the loss of their future. It therefore would be inappropriate to introduce the service at this stage.

INTRODUCTION TO INTERVENTION

Patients have had some time to navigate the initial trauma and shock, and are now better positioned to receive the intervention. They have begun reorienting their life, and likely have a number of questions about what to expect, what to do, etc. They will have been breaking the news to loved ones, beginning to grapple with their reality and meaning, and the other hardships of hospice.

Introducing the intervention provides patients with a resource to turn to and feel supported, a medium to reflect on their life and meaning, and helping them rediscover sources of joy to focus on during their final months. It facilitates increased clinical understanding and care adjustment, improving quality of life and fulfillment from tailored alterations towards identified sources of meaning.

It also reassures patients concerns for their loved ones welfare after their death, by providing a means - the legacy book - for them to contribute towards their future consolation.

During this check-in, the ‘What Matters’ system is presented to patients, described as a way for patients to reflect on their life and sources of meaning, and to better align clinical care, and provide a source of comfort for their loved ones after they pass.

Patients are briefly introduced to its intention, and send home with a flyer where they can download and explore the app in their own time. It provides a means of diversion and expression when they are stressed, and makes them feel supported simply by having a resource at their disposal – rather than none at all.

PRINT SUGGESTION

Considering the average life expectancy of five months, the aggressive nature of the disease, and patients likely reduced cognition during the final weeks, consideration needs to me made towards the conclusion of story collection to allow for sufficient time for patients to bequeath their legacy to their loved ones, and discuss their life story together.

At this stage, the most critical stories and insights should have been documented through the dignity therapy protocol. Equally, these identified sources of meaning and their communication of such towards nurses should have permitted action towards the identified meaning sources.

While the document is printed at this stage, patients are welcomed to continue interacting - any further collected stories can be printed, and added to the legacy book. This ensures patients don’t feel trapped or forced into abandonment of the intervention. Ideally, the intervention at this stage has grown to become a source of comfort, and it is paramount that this comfort can continue to be accessed until the end - rather than suddenly stripping this source of comfort away.

BESTOWING

Patients, having now recieved the printed legacy document, have the opportunity to bequeath the legacy book to their loved ones, at a time and moment that suits them. It provides a moment to reflect, converse, and provide a moment for any final conversations or conflicts to be resolved.

In the meantime, patients can continue engaging with the intervention, collecting and printing stories and adding them to the legacy book, allowing it to grow with them.

DETERIORATION AND DEATH

By now, patients have likely concluded their use of the app, and have handed the legacy book over to their loved ones. At this stage, patients are likely to be in a cognitively impaired state, from medication, pain, and potentially as far as palliative sedation.

Therefore it is essential that, in order for patients to have time to bestow the legacy book to their loved ones, and find comfort, closure and solace in final conversations and sharing of stories, it should be ensured that the book is delivered in ample time prior to this period to facilitate this.

ADAPTING TO THE AMBIGUITY OF THE HNC TRAJECTORY

In response to the positioning of the framework within the disease trajectory, estimatory calculations could be made to determine the number of reflective questions required to ensure reflective interactions could be adequately sustained. This calculation was critical to ensure that patients who (hopefully) had come to find comfort, solace, peace and fulfillment through reflection through the framework would be supported by an ample number of prompts and questions to reflect through.

CONSIDERING MINIMAL INTERACTIONS

For the minimally-interacting patients, the dignity therapy protocol's nine questions already sufficed, as they were specifically developed obtain a complete understanding of terminal patients lives within a limited time. These questions will be pushed to the foreground during patients initial interactions, to ensure that a maximal, of the patient's life is documented as early as possible, so that in the case of premature passing, the patients most pertinent memories and stories have been preserved.

CONSIDERING MAXIMAL INTERACTIONS

For patients who engage intensely with the intervention, or survive beyond the average prognosis, considerations should be made to ensure that they can continue interacting with the intervention and seeking the solace it provides. It would be remiss to present an intervention for a patient's comfort, but then strip them of this comfort in the midst of hospice care - particularly as it is hoped they will have grown fond of, and found peace, meaning and fulfillment through its presence. The embodiment of the intervention should also reflect this, and provide a means for stories to be added to the book, even after initial printing.

In this case, the dignity therapy protocol is insufficient, as can be seen from the calculations. As a result, a brief research cycle was conducted to identify further theoretically grounded approaches to legacy making.

ASSUMING ~5 INTERACTIONS PER WEEK ON AVERAGE, AND CONSIDERING AVERAGE PROGNOSIS:

PROLONGED SURVIVAL ACCOMMODATION = 50 WEEKS

50 X 5 = 250 QUESTIONS NECESSITATED

250 - 9 (DIGNITY THERAPY) = 240 ADDITIONAL REQUIRED

PATIENTS WHO ARE ACCOMODATED BY THE DIGNITY THERAPY PROTOCOL QUESTIONS

PATIENTS WHICH THE FRAMEWORK SHOULD CONSIDER AND ACCOMODATE

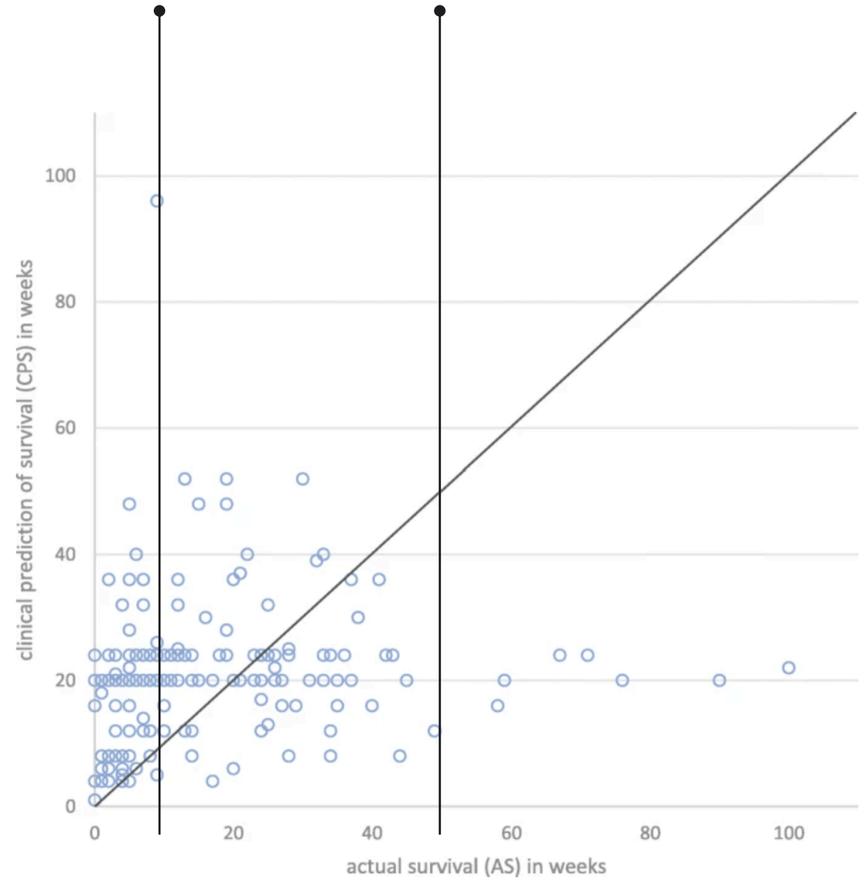


FIGURE 34 - Chart showing the predicted vs actual survival of HNC patients post incurale diagnosis (Hoesseini et al., 2020)

ADDITIONAL REQUIRMENT

Based on the actual survival of HNC patients post incurable diagnosis as outlined in Hosseini et al,. 2020, a majority of patients are encompassed if the system is designed to support patients who survive up until 50 weeks.

As a result, brief research cycle was held to source academically validated research questions which would sufficiently accomodate and support these patients in their continued reflection and engagement, and ensure they could reap the benefits of what hopefully has become a source of comfort and value.

THE LIFE STORY INTERVIEW

The dignity therapy protocol is designed to be administered in a single session, and is developed for such - using a set list of questions which were specifically developed to prompt stories about the most important (to the patient) parts of someone's life.

The Life Story Interview is also designed as a guide to procuring someone's life story - but rather than a concise set of questions which are intended to all be employed during the interview, it gives a large, comprehensive list of prompts, segmented into 'categories', which can guide the conversation. In the same way as the dignity therapy approach, the interview is recorded and transcribed, with the final outcome from the interview being a sort of 'mini autobiography', narrated through the words of the interviewee (Atkinson, 1998). The only difference in this output is that in the life story interview, the narrative reads as a mini 'novel', while in dignity therapy, representative interviewer questions are preserved in the final document as a means of navigating the stories (Chochinov, 2012).

There are 11 main chapters with over 250 questions total branched across 'Birth and Family of Origin', to 'Historical Events and Periods', which asks participants about their memories regarding major historical or political events during their life. These chapters are shown below, along with some example questions.

There is one chapter - vision of the future - which certain questions would be rephrased as a result of their unsuitability to the cohort in question.

```
01 BIRTH AND FAMILY OF ORIGIN
02 CULTURAL SETTING AND TRADITIONS
03 SOCIAL FACTORS
04 EDUCATION
05 LOVE AND WORK
06 HISTORICAL EVENTS AND PERIODS
07 RETIRMENT
08 INNER LIVE AND SPIRITUAL AWARENESS

         HOW WOULD YOU DESCRIBE YOURSELF AS A CHILD?
         DO YOU THINK YOU HAD A HAPPY CHILDHOOD?
         WHAT WAS IT LIKE TO TURN 30,40, 60?

09 MAJOR LIFE THEMES
10 VISION OF THE FUTURE
11 CLOSURE QUESTIONS
```

SUDDEN DEATH

The default framework operates based on the average lifespan - prompting patients to print their life story at the three month mark, allowing patients a month of consciousness in order to hand over the book. This month also facilitates some cautious flexibilty towards patients who may deteriorate earlier, wherein patients could hopefully gift the legacy document earlier.

However, there will inevitably be patients who die prior to reaching this three month mark - and designing the intervention to notify all users to print the document earlier is impreferable, as it is yet another reminder of paitents of their terminality, an aspect which the intervention specifically avoids directly referencing.

Of course, patients can request a print of their document at any time, but considering the aggressive nature of HNC and its unpredictable nature, this cannot be relied upon.

In the case where patients do suddenly pass, a failsafe is integrated to ensure that the NOK can still access the stories that hae been collected. During initial account creation and setup, the patient will be asked to provide contact details for their NOK. This NOK will then get a link that will enable them to request a printing of the book (with redactions as the patient intended) in the eventuality that their loved one does pass unexpectedly.

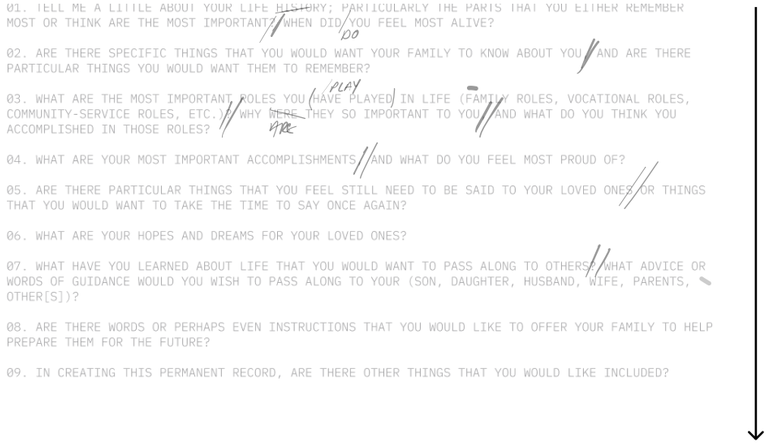
PHRASING AND LANGUAGE

While the dignity therapy questions, meaning centered psychotherapy questions, along with the life interview questions, collaborate to obtain a broad understanding of patients lives, some further review was needed to ensure their alignment with the context and constraints established throughout the project - phrasing, approach, language, and ensuring the sentence structure, and length, was suitable for an self-prescribed manner, rather than being posed by a trained professional in a conversational setting. Similarly, the laddering questions should also abide by these regulations - originally intended as a designers tool, they are equally being employed in a self-directed context.

Requirements were developed based on research and the framework's intent - such as the avoidance of direct refernces to emotion, as the intervention had been specifically delevloped to be used by people who were uncomfortable with discussing this. It should also avoid directly referencing cancer, as it is supposed to be experienced as a comfortable reflection on life, rather than another reminder of cancer and death - it is hard to reflect on life and find peace if interacting through a medium about death and disease.

In the framework, this protocol would be systematically applied across the dignity protocol questions, as well as the life story interview questions. While this systematic encoding is outside the boundaries of this project, an excerpt is shown as an example of how the dignity therapy questions would be adapted to suit the framework, based on the created protocols.

01 QUESTIONS SHOULD NOT REFERENCE CANCER OR TERMINALITY DIRECTLY.
02 AVOID PHRASING SUCH AS 'REFLECTING ON YOUR LIFE' WHICH IMPLIES THAT PATIENTS LIVES ARE
03 ALREADY OVER.
04 IF QUESTIONS USE PAST TENSE PHRASING, ENSURE RECOGNITION IS MADE TO THE PRESENT TENSE
ALSO.
05 ONLY POSES ONE QUESTION AT A TIME; IN THE CASE OF TWO TIER QUESTIONS, ASK THE QUESTIONS
ONE AFTER ANOTHER, UNLESS THE PATIENT HAS ALREADY BEGUN CHANNELING TOWARDS A MEANING.



01.
01. TELL ME A LITTLE ABOUT YOUR LIFE.
02. WHAT ARE THE PARTS OF YOUR LIFE THAT YOU REMEMBER MOST?
03. WHAT PARTS OF YOUR LIFE DO YOU THINK ARE THE MOST IMPORTANT?
04. WHEN IN LIFE DID/DO YOU FEEL THE MOST ALIVE?

02.
05. ARE THERE SPECIFIC THINGS THAT YOU WOULD WANT YOUR FAMILY TO KNOW ABOUT YOU?
06. ARE THERE PARTICULAR THINGS YOU WOULD WANT YOUR FAMILY TO REMEMBER ABOUT YOU?

03.
07. WHAT ARE THE MOST IMPORTANT ROLES YOU HAVE PLAYED IN LIFE (FAMILY ROLES, VOCATIONAL ROLES, COMMUNITY-SERVICE ROLES, ETC.)?
08. WHY WERE/ARE THESE ROLES SO IMPORTANT TO YOU?
09. WHAT DO YOU THINK YOU ACCOMPLISHED IN THOSE ROLES?

04.
10. WHAT ARE YOUR MOST IMPORTANT ACCOMPLISHMENTS?
11. WHAT DO YOU FEEL MOST PROUD OF?

05.
12. ARE THERE PARTICULAR THINGS THAT YOU FEEL STILL NEED TO BE SAID TO YOUR LOVED ONES?

06.
13. ARE THERE THINGS THAT YOU WOULD WANT TO TAKE THE TIME TO SAY ONCE AGAIN TO YOUR LOVED ONES?

07.
14. WHAT ARE YOUR HOPES AND DREAMS FOR YOUR LOVED ONES?

15. WHAT HAVE YOU LEARNED ABOUT LIFE THAT YOU WOULD WANT TO PASS ALONG TO OTHERS?
16. WHAT ADVICE OR WORDS OF GUIDANCE WOULD YOU WISH TO PASS ALONG TO YOUR (SON, DAUGHTER, HUSBAND, WIFE, PARENTS, OTHER[S])?

08.
17. ARE THERE WORDS OR PERHAPS EVEN INSTRUCTIONS THAT YOU WOULD LIKE TO OFFER YOUR FAMILY TO HELP PREPARE THEM FOR THE FUTURE?

09.
18. IN CREATING THIS PERMANENT RECORD, ARE THERE OTHER THINGS THAT YOU WOULD LIKE INCLUDED?

Figure 35 - The dignity therapy question protocol

PRESENTING

VIII

FINAL DESIGN

This chapter presents a summary of the final design.

FUNDAMENTAL MEANING FRAMEWORK

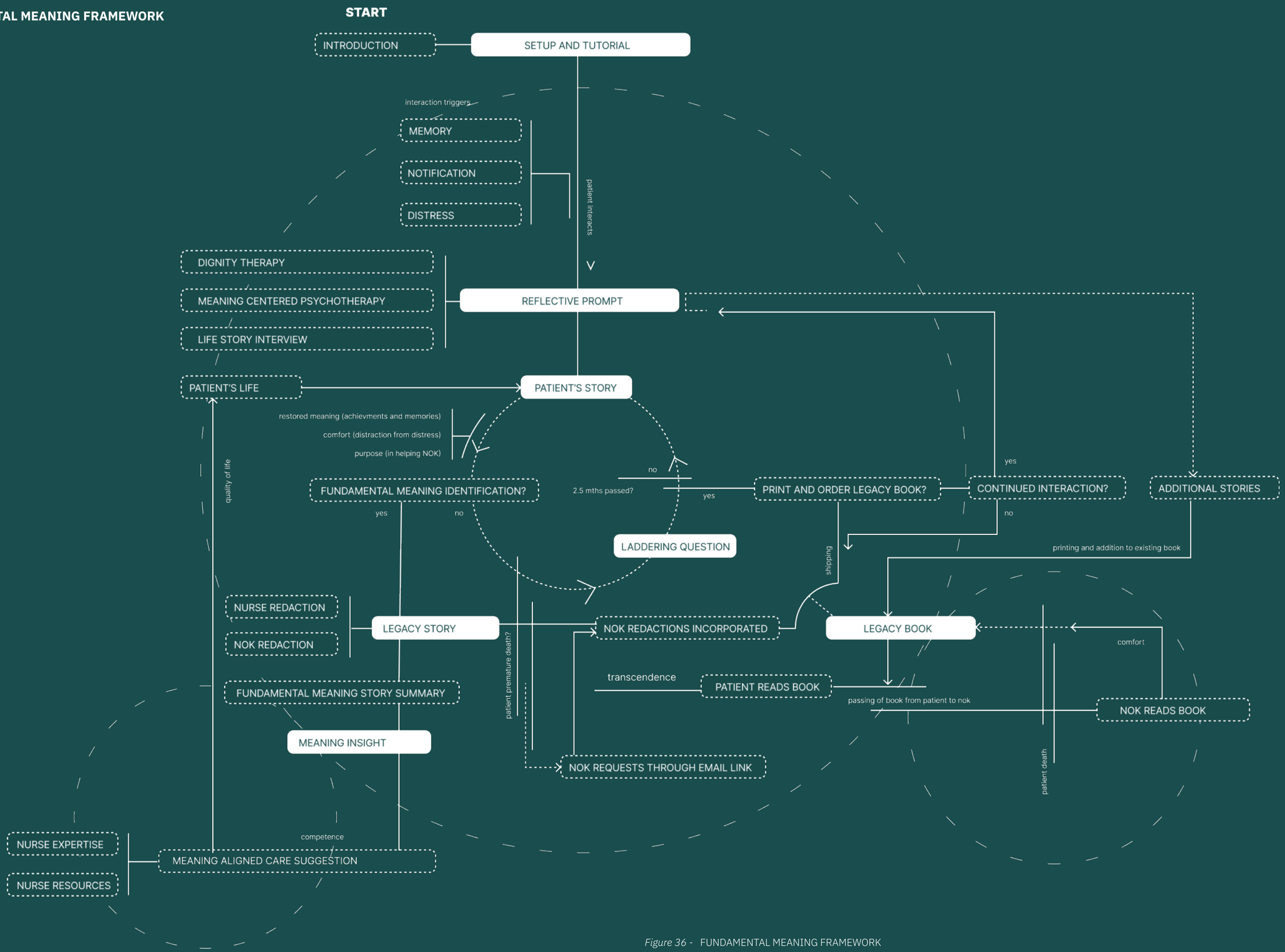


Figure 36 - FUNDAMENTAL MEANING FRAMEWORK

FUNDAMENTAL MEANING FRAMEWORK

CONCEPT STATEMENT

The fundamental meaning model presents a theoretically grounded framework, which utilises the lens of legacy and life stories to act as a mediating interface between patients and clinicians, surfacing fundamental meanings and facilitating the alignment of care resources towards QoL through a shared understanding. In tandem, it answers patients desire to prevent suffering in loved ones after their death through the creation of a legacy document, which they can bequeath and which will provide comfort and a preserved sense of relatedness even after death.

PATIENT STATEMENT

> *Guides me through a reflection of my life and legacy, helping me to identify where meaning and purpose lies, and documenting these stories to create a legacy document to provide comfort to my loved ones after I am gone.*

NURSE STATEMENT

> *Provides support in my alignment and delivery of care to patients through deep, emotional insights about patients meaning and needs, enabling responsive action and adjustments.*

NOK STATEMENT

> *Takes the pressure off asking confrontational questions to my loved ones prior to their death though its topics and presence, and provides comfort and a preserved sense of connection after they are gone.*

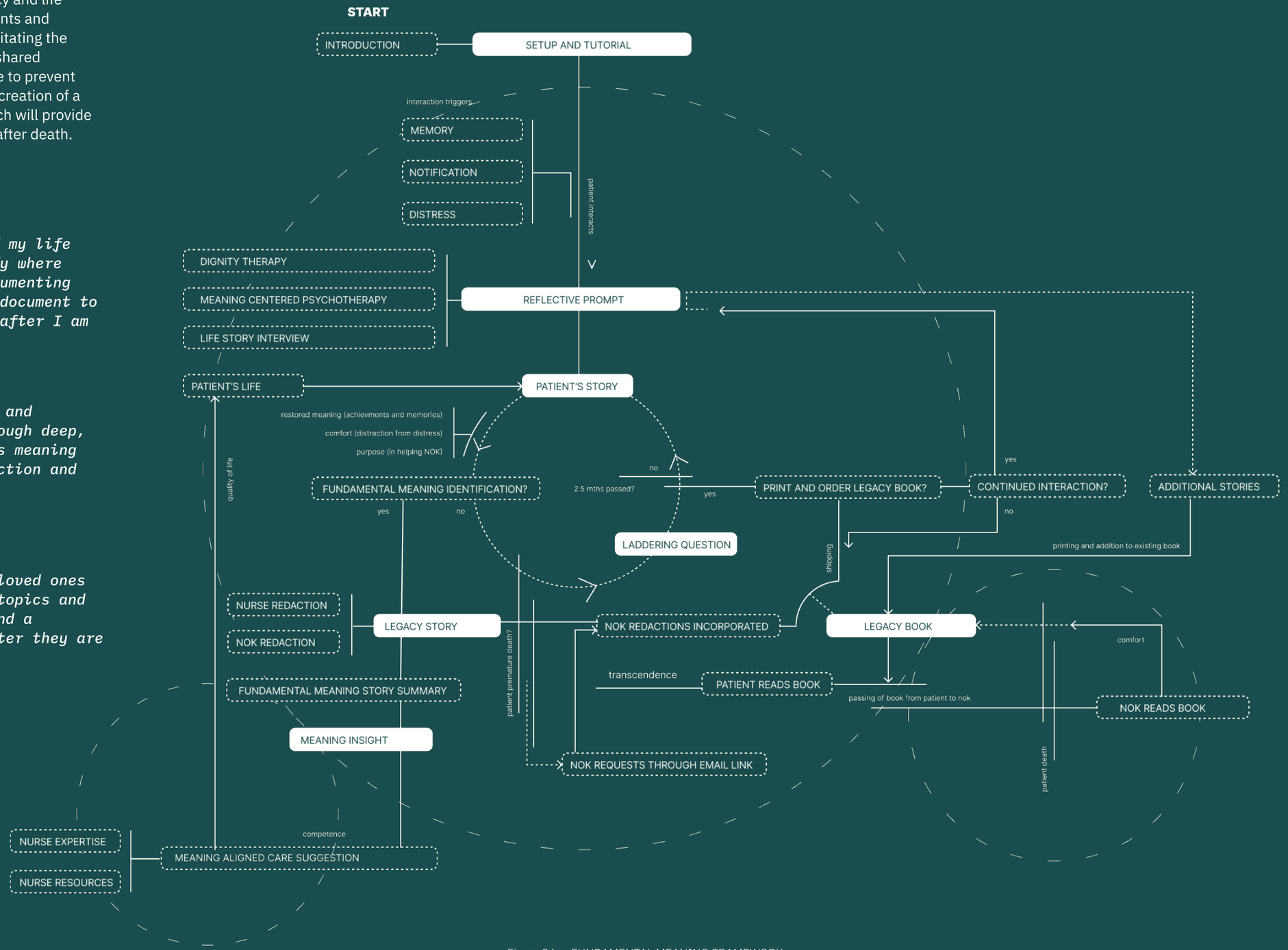


Figure 36 - FUNDAMENTAL MEANING FRAMEWORK

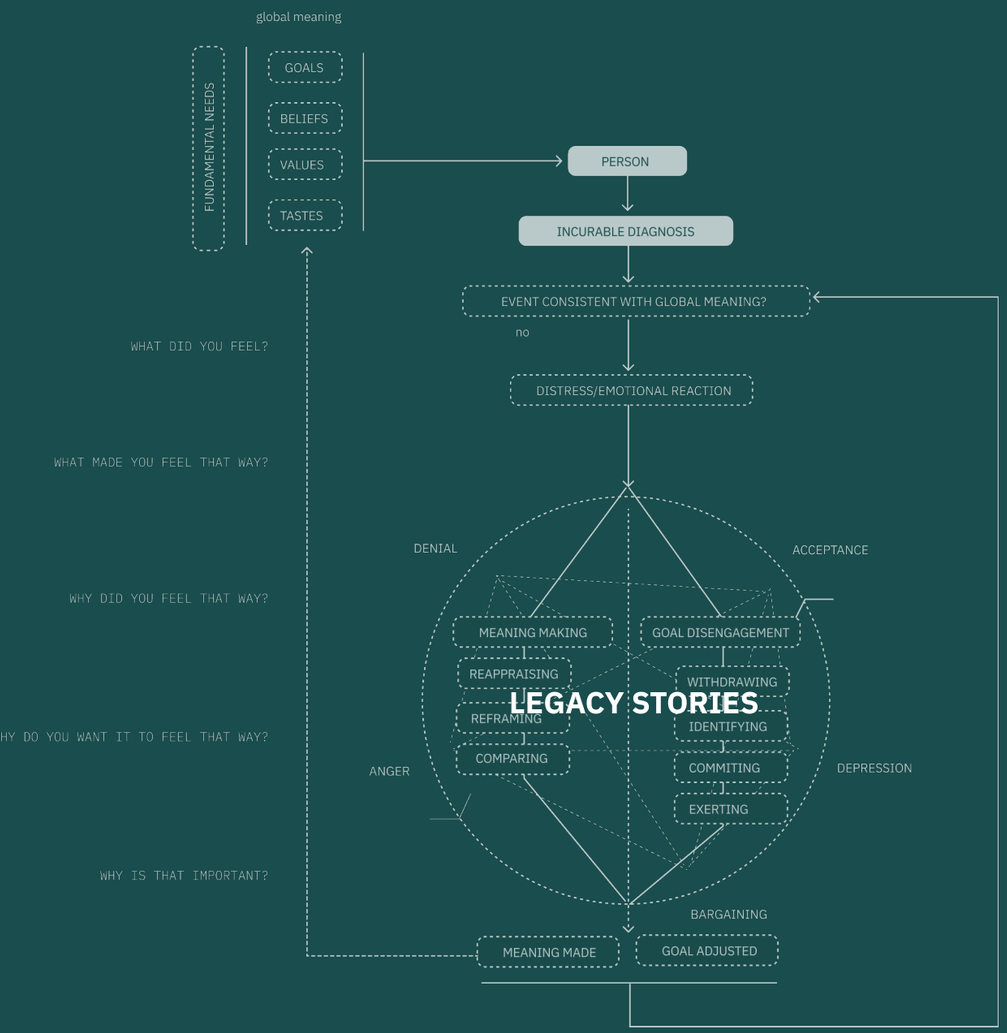
HOW IT WORKS

The fundamental meaning framework is based on on the qualitative research approach of life narratives, and utilises a combined question protocol based on the dignity therapy and life story interview techniques to ensure a holistic interpretation of the patients legacy is explored and obtained, even in the face of termporal limitations.

This cycle of prompting and reflecting - aided by the laddering technique - through the lens of legacy and life, enables patients to rediscover purpose and meaning - similarly to the meaning-centered psychotherapy approach - presenting a pathway and direction for patients in seeking fulfillment and QoL in their final months. These meaning sources are contextually communicated to nurses through their institutions native interface, empowering them in care and resource alignment towards these surfaced meanings.

The framework speaks to patients altruism and concern for their loved ones welfare, providing patients a means to answer their worries through the preemptive creation of a comforting medium to hold dear after they have passed, and the preservation of their relationship, even after death.

ASSUMED IMPLICATION	MEDIUM
RESTORED SENSE OF PURPOSE	REFLECING ON ACHIEVMENTS OF LIFE
IMPROVED SENSE OF SUPPORT	PROVISION OF A TAKE-HOME RESOURCE
MITIGATING DISTRESS	PROVIDING COMFORT AND DISTRACTION THROUGH REFLECTION
FULFILLMENT AND JOY	THROUGH SENTIMENTAL, NOSTALGIC REMEMBERANCE
RESPITE FROM REALITY	ESCAPE FROM TOPICS OF OF DEATH AND CANCER
SHARING OF LIFE STORIES	BARRIER-BREAKER FOR LEGACY CONVERSATIONS
DEEPER NURSE RELATIONSHIP	PERSONAL REFERENCES MAKE PATIENTS FEEL SEEN AND UNDERSTOOD
IMPROVED ACP ENGAGEMENT	DEEPER RELATIONSHIP INCREASES COMFORT IN ACP
SPIRITUAL TRANSCENDENCE	PRESERVATION OF SELF BEYOND THE PHYSICAL FORM
CLOSURE AND COMFORT	DOCUMENTING FINAL THOUGHTS AND REFLECTIONS ON LIFE



FUNDAMENTAL MEANING FRAMEWORK - EMBODIMENT PROTOCOL

The primary component of the ‘What Matters’ system is the fundamental meaning framework, which incorporates and recognizes the majority of the constraints and considerations an intervention positioned in this context must adhere to.

However, the reality of HNC and terminal disease involves the presence of complex, potent symptoms and squelae, the impacts of which can cause profound physical impairments. The practical and regulatory constraints of the medical industry equally entails its own considerations which must also be considered. These constraints relate to the embodiment of the framework, and are critical in ensuring the eventual manifestation of the framework is feasible and considered.

The ‘Fundamental Meaning Framework - Embodiment Manual’ provides a textual set of recommendations that should be recognised when conducing framework embodiment. These are presented alongside a conceptual, demonstrative embodiment of the framework, which provides a preliminary, prototypical suggestion as to how these considerations could manifest and enable suitable inferfacing between users and the framework.

HNC EMBODIMENT PROTOCOL

01 In the case of digital embodiments, interfaces must respect the digital literacy of the elderly population, ensuring clear affordances, interaction flows.

02 In the case of digital embodiments, interfaces should be designed with accessibilty in mind, including, but not limited to, text sizes, sans-serif fonts for readability, colour blind considerations.

03 Interfacing mediums should be multifaceted, and consider the needs of the population. For HNC cohorts, a critical consideration is the presence of voice impairments or loss. Therefore, interactions should not rely on vocal interfacing.

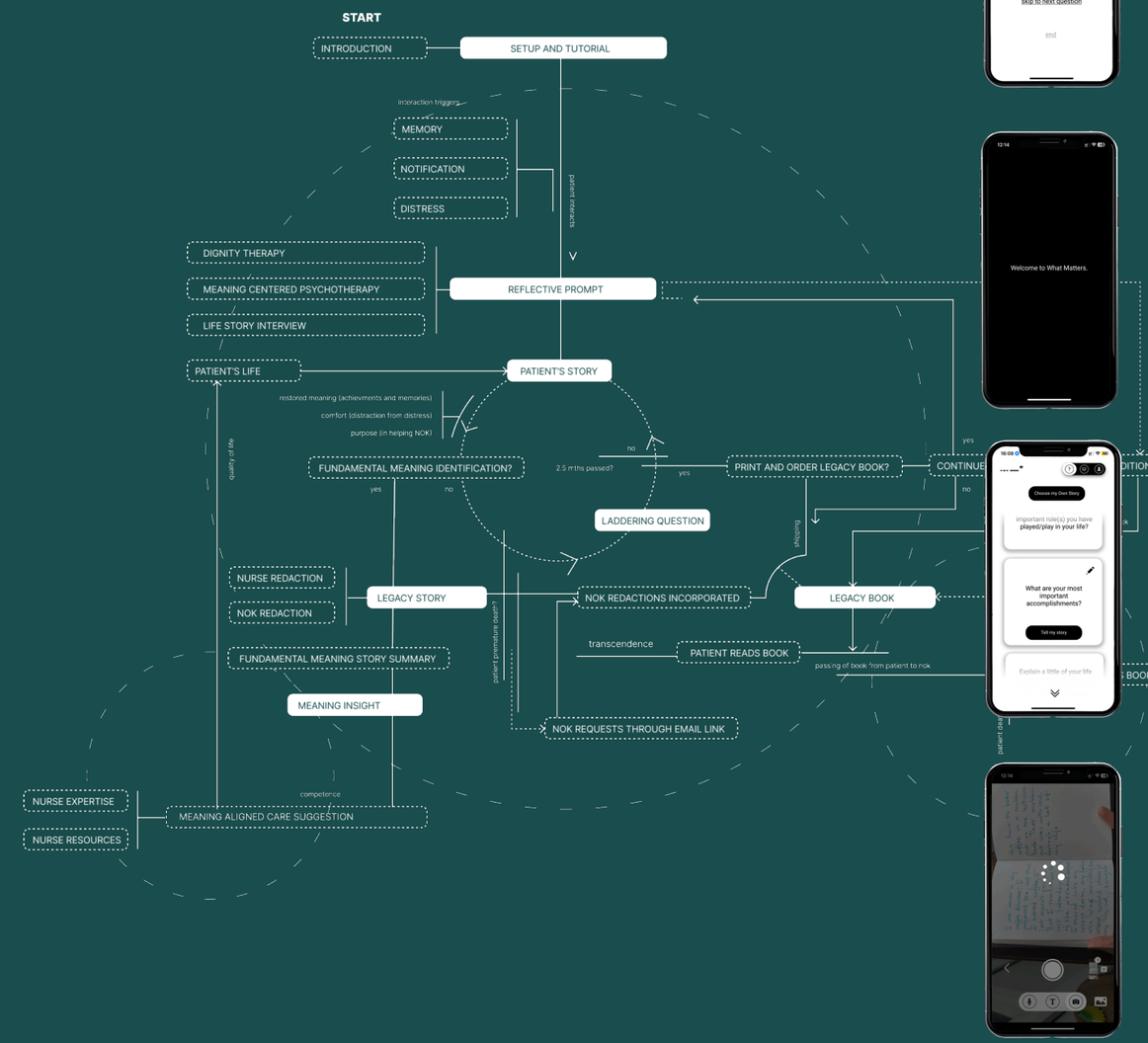
04 Embodiments should acknowledge the typical operations of medical institutions and their use of digital technologies to monitor patient health.

05 Embodiments should consider the sensitive nature of the patient medical data being handled. Communication flows, particularly if analogue, should integrate safeguards to ensure that sensitive data is protected when being transferred from patient to nurse.

06 Embodiments should recognise the importance of efficiency in medical contexts. In the context of terminally ill patients, life expectancies limit time to deliver fulfillment and quality of life, therefore dialogue between patient interfaces and nurse interfaces should be expeditious to ensure prompt response and care adjustment.

07 For nurses and care providers, efficiency and readability should be priortised to ensure that there is no additional mental burden on overworked staff, and insights can be extracted expeditiously

08 Embodiments should ensure the patient is preserved as central - that inclusion of other stakeholders is not at the expense of the patient experience. For example, patients should retain control over where, and how, information is shared with others.



APPLICATION BEYOND THE HNC DOMAIN

During this project, the application potential grew beyond that of solely HNC hospice patients, and towards the wider domain of hospice and the terminally ill. Therefore, embodiment protocols were also delineated for application beyond the original HNC population.

CONTEXTUAL PROTOCOL

01 In the case where the framework is being applied to non-HNC cohorts, consideration should be made regarding disease timelines. ‘Print and Order’ gates should be moved to correspond to the trajectory, ensuring that accommodations are made for patients to receive the physical book, bequeath it to their loved ones, and engage in consequent conversations prior to their passing prior to significant deterioration or death.

02 Consideration should be made towards the needs of the care staff of the cohort and the specific challenges they face.

EMBODIMENT PROTOCOL

01 In the case of digital embodiments, interfaces must respect the digital literacy of the elderly population, ensuring clear affordances, interaction flows.

02 In the case of digital embodiments, interfaces should be designed with accessibilty in mind, including, but not limited to, text sizes, sans-serif fonts for readability, colour blind considerations.

03 Interfacing mediums should be multifaceted, and consider the particular (physical) requirements and impairments of the population which may render certain interactions unsuitable.

04 Embodiments should acknowledge the typical operations of medical institutions and their use of digital technologies to monitor medical information and communicate with patients and care staff.

05 Embodiments should consider the sensitive nature of the patient medical data being handled. Communication flows, particularly if analogue, should integrate safeguards to ensure that sensitive data is protected when being transferred from patient to nurse.

06 Embodiments should recognise the importance of efficiency in medical contexts. In the context of terminally ill patients, life expectancies limit time to deliver fulfillment and quality of life, therefore dialogue between patient interfaces and nurse interfaces should be expeditious to ensure prompt response and care adjustment.

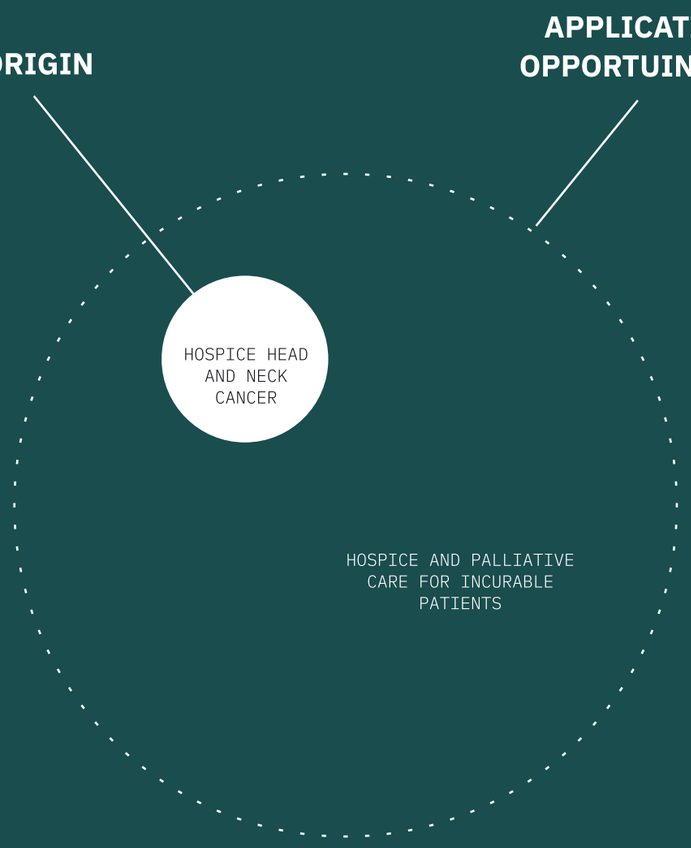


Figure 37 - Showing application potential of framework

WHAT MATTERS - INTERFACE SUMMARY

Although interfacing and embodiment was not the core outcome focus of this project, it was investigated in a secondary manner in order to facilitate project conversation and communication with stakeholders.

REDACTIONS EMPOWER PATIENT IN CONTROLLING THE SHARING OF INFORMATION

MULTIFACETED INPUTS - VOICE, TEXT, VISUAL

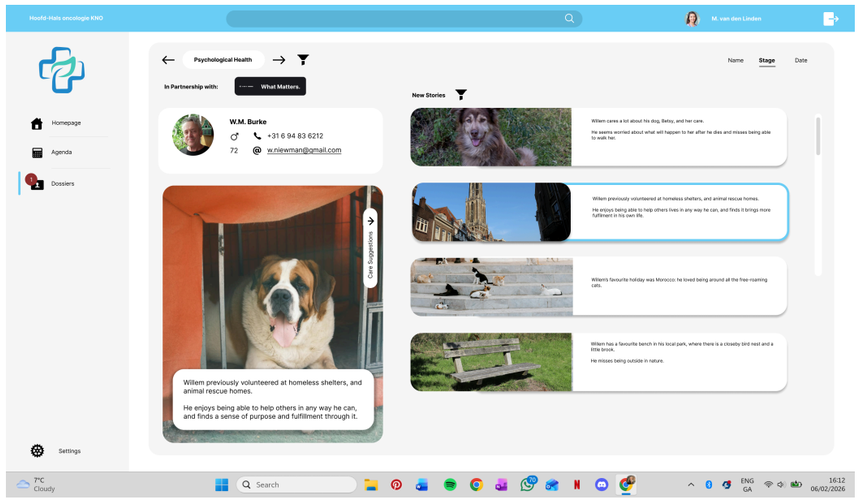
CONTROL TO SKIP QUESTIONS OR END REFLECTION

CLEAN, ACCESSIBLE DESIGN, SANS SERIF, AND CLEAR COLOURING FOR ELDERLY POPULUS

PATIENT RETAINS CONTROL IN NOTIFICATION SETTINGS AND LEGACY PRINTING

SPIRAL BINDING ENABLES THE ADDITION OF STORIES AFTER INITIAL PRINTING

IMAGE SHOWING CONCEPTUALISED NURSE DASHBOARD AND INSIGHTS





COMMUNICATING

TX

PROMPTING DIALOGUE

EXPLORING IMPLICATIONS

This framework was developed to deliver a design in response to the core brief - the surfacing of patients fundamental meanings, and the communication of these meaning sources to clinical support staff to align resources and deliver quality of life.

In this process, certain design choices were made with expected implications in mind. While these assumptions and intentions were based in research and theoretical understanding, a level of speculation remained regarding whether they would be experienced in reality.

THE INTENTION OF THE VIDEO

In order to explore these assumed implications, a short video was created, which depicted an (imagined) use scenario, from start to end, across stakeholders and interactions. Rather than focusing on the theory and framework, it illustrated a human-centered interaction story, triggering emotions and reactions through human-human and contextual understanding.

The video was not intended as a stand alone explanation, but rather as a complementary instrument to the rest of the project. When presented to audiences, it was first premted with a brief explanation as to the underscoring theory and intents.

This video focused on depicting the interactions themselves, rather than the (expected) implications – allowing audiences to interpret, imagine and share their own impressions and predictions regarding the intervention's impacts, allowing for rich, authentic insights, rather than biasing audiences towards my own expectations.

The story narrative depicted in the video, while reimagined, was created through the amalgamation of real stories from the generativity documents in the Dignity Therapy and Life Interview books. This allowed for a speculative, yet representative dialogue, rooted in reality.

Considering the context depicted in the course of the video – an approaching death – certain scenes would be difficult to convincingly portray through acting, due to the intense emotions and vulnerability that would be present. Therefore certain scenes focused instead on communicating context through props and body language, avoiding dialogue and facial expression. This allowed for further personal interpretations and impressions.

The video was staged in order to explain the context of use through storytelling rather than narration. The only dialogue which was used was that narrating the patients story – this also ensured that this story was experienced centrally, and would have further impact and a lasting impression on audiences.





In the opening scenes, we are introduced to the home of a recently diagnosed HNC hospice patient. Cards, medicine bottles and a plethora of insurance letters and notes are strewn across a table.

We are introduced to the patient who is working through a to-do list, which includes a comment about downloading the What Matters app.

The patient picks up the flyer his nurse gave him during his follow-up meeting, and using the QR code, downloads the app.

The app introduces itself, asks the patient to introduce himself, and then gives the patient a tour of the app and its functionality.

Depending on the scenario, the patient may also download the app in the presence of the nurse during the consult. This can be at the nurses discresion, but would be particlarly applicable in cases where the patients digital literacy is lower, or avoided in cases where the patient has too many questions to dedicate time to in-person explanation.





Some time passes, and the patient makes himself a small cup of coffee, aware the time is soon coming where he will likely not be able to drink it anymore as a result of the disease progression.

He walks outside to his favourite spot, intending on sitting down with a book for a little while and enjoying the outside air.

As he sits down and takes a sip, the taste of the coffee reminds him of the first time his father taught him to make coffee in a mokka pot. He sits in the nostalgia for a moment, then remembers the What Matters app he downloaded earlier.

Putting down the coffee, he picks up his journal and begins to write. We listen as he reminisces on memories with his father.

This scenario is based on an instance where the initial interaction is triggered by a memory - facilitated by the 'choose my own story' feature in the app. However, patients may also be driven to the app through moments of boredom, distress, or a need for distraction, in which case the patient will likely use the given prompts to trigger reflection. These interactions can also be triggered by the patients receipt of a notification, the settings of which is controlled in app by the patient.



SYSTEM
PATIENT
NURSE
NOK

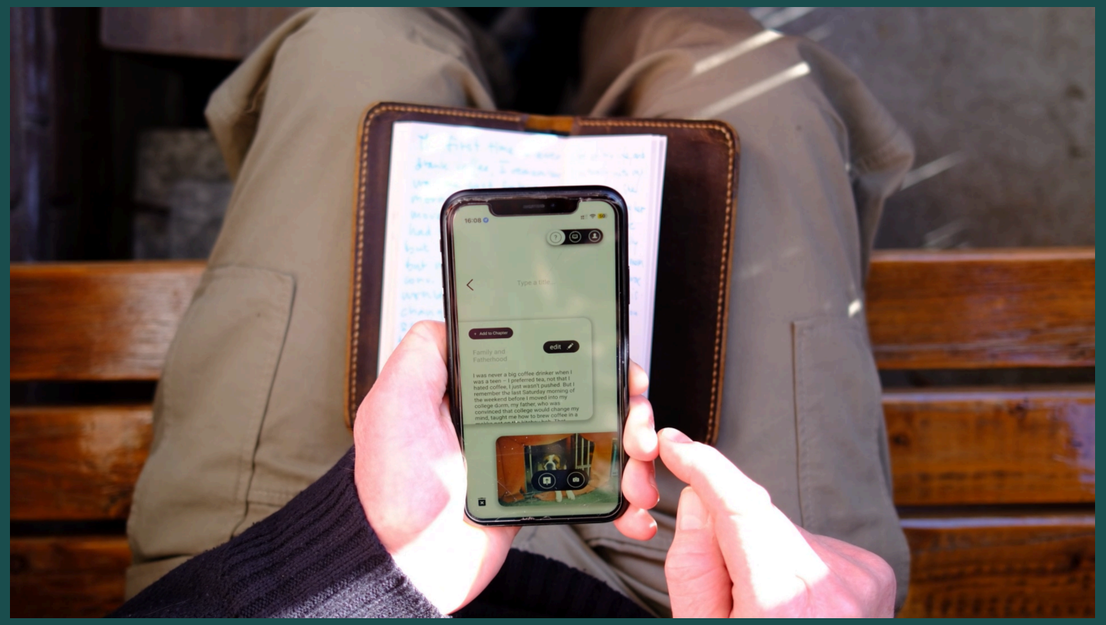


At the end of the reflection, the patient picks up his phone, clicks ‘Choose my own story’, and takes a picture of the writing in his journal.

The app processes the text, then prompts further reflection - asking ‘Why was this important to you’, referring to his joy at his daughers inheriting of his mokka pot.

At this stage, the patient picks up his pen and starts writing again.





As the patient ends his reflection, he once again repeats the process, taking a picture of his journal, and waiting for the system to process.

Based on the patients answer, the system was able to identify ‘community’ and ‘purpose’ as underlying fundamental meanings. It posits a further question to deepen the reflection in another direction.

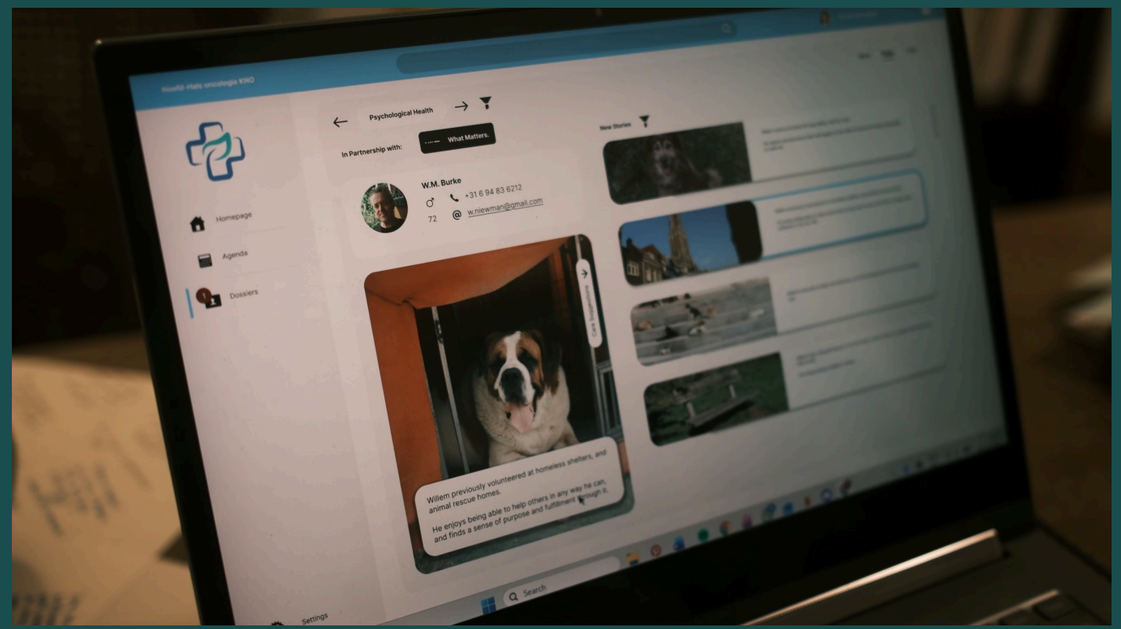
However the patient, eager to read his book, and content with the reflection, clicks ‘end’. The app takes a moment, then presents the patients story for review.

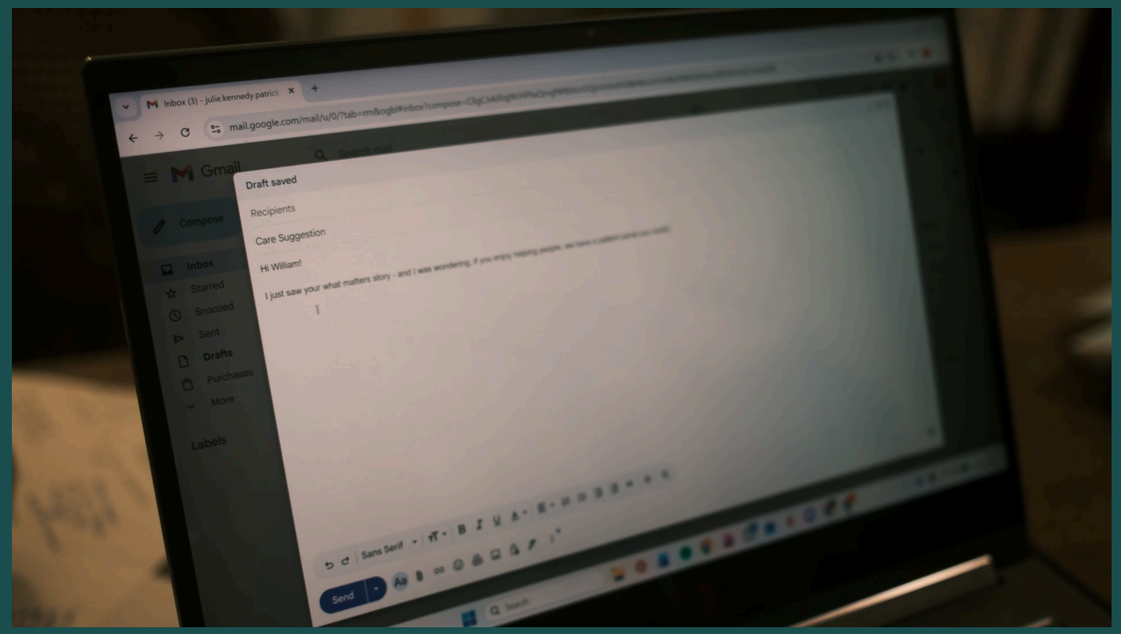
It is at this moment that the patient can make redactions should there be information shared that he doesn’t want his nurse or loved ones to see. In this case that doesn’t apply.

Before closing, the patient attaches an image of his favourite shelter dog to the entry.

The patient then sets the phone and journal aside, and sits back to return to his enjoyment of the sun and breeze.

SYSTEM
PATIENT
NURSE
NOK

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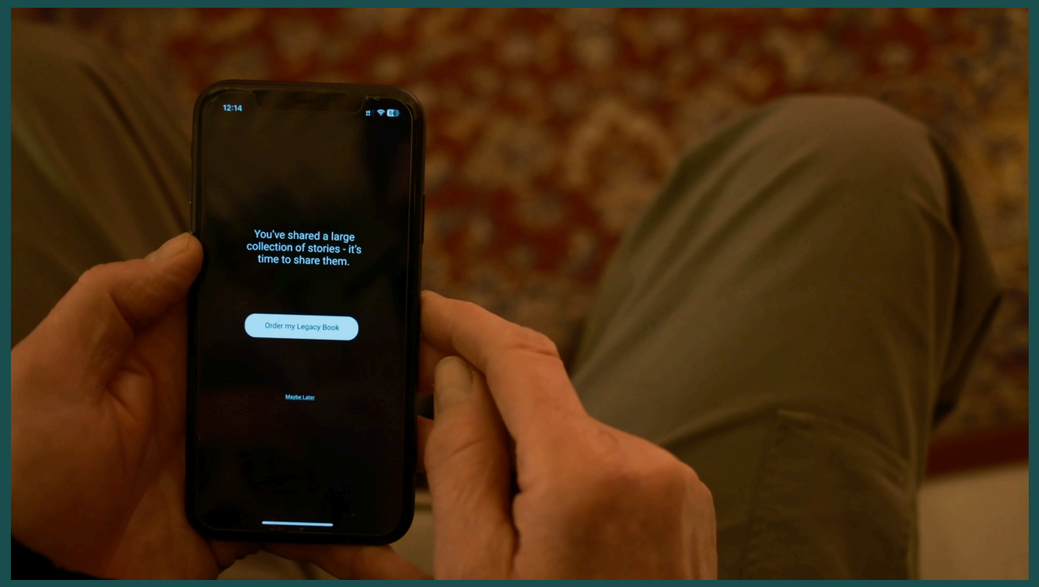
NURSE
NOK





After some weeks of interacting, the app prompts the patient to print their legacy book. The book arrives several days later, allowing the patient to revise it and come to terms with its reality.

SYSTEM
PATIENT
NURSE
NOK



After some time with the book, the patient bequeaths the book to their loved one.





The patient passes. We see the NOK, now in the grieving period. reading the book. After some time, they set it in their book case - preserving the stories of the patient for time to come.

REFLECTING

X

EVALUATING

This chapter provides an overview of thematic insights which arose during final feedback sessions, and concludes with a reflection on their validation or dissention with the speculated implications of the frameworks deployment.

DISCUSSION AND REFLECTION

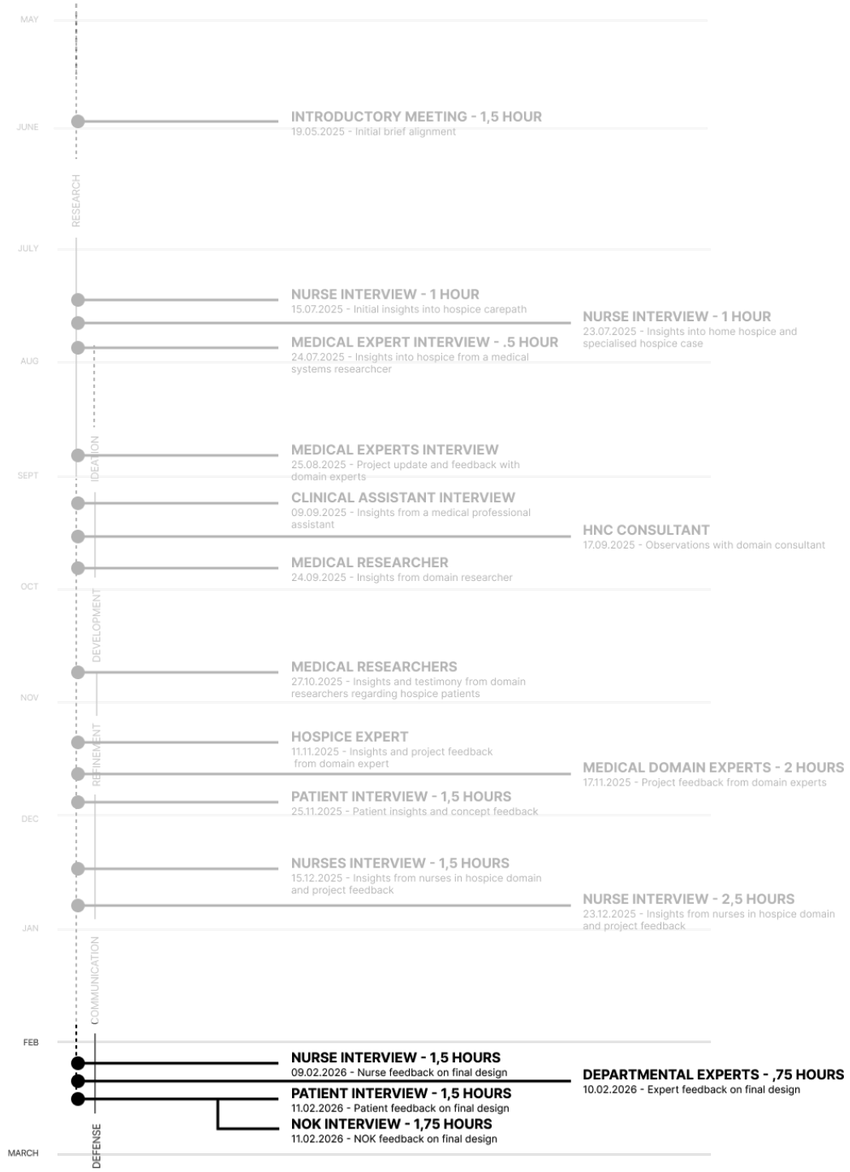


Figure 38 - schematic showing the various interviews and feedback sessions that occurred during this period

(INSIGHT SOURCE)

PATIENT

NOK

NOK

REPRESENTATION OF A PERSON

During these discussions, an interesting theme that emerged was the legacy books ability to exist as a representation of the deceased.

In discussions, the patient recounted the steps she had already taken in ensuring her husband was cared for after she died. One of these was a list of instructions she had made, which told her husband where, and who, to go for grief counselling; chosen speicifcally as a result of her own familiarlity with the counsellor. She explained that in this way, her husband could grieve through the support of someone who knew who she (the patient) was, bringing further understanding into the conversations without him having to try explain to a stranger who his loved one was.

The patient hypothesised that this legacy book could, in a similar way, act as a means of ‘bringing’ the deceased loved one into grief conversations, helping familarise the therapist as to who the loved one was, and creating more deep, trusting conversations.

Another similar train of thought uncovered was the book standing as a memorial of the person. For instances where a deceased loved one was cremated, or without a headstone or physical memorial for whatever reason, the book could fulfil this role.

Throughout the project, a lingering concern remained regarding the potentiality that the intervention’s collected stories could be quite negative considering the patient’s context. I speculated whether this outcome may cause further distress to loved ones should they inherit a document narrating the deceased’s struggles with their disease, rather than providing comfort.

Yet, during discussion, this topic was raised, unprompted. The participant expressed their desire to actually have insight into their loved one’s thoughts during the hospice stage – how they experienced it, an insight into their mind as it was something that they themselves didn’t have the opportunity to hear before their loved one (patient) passed. In their case, their loved ones life pre-diagnosis was already well documented; however this final phase was not. While this insight would likely cause some level of distress and sadness and they recognised its confrontational nature, an aspect I had been concerned about in the creation of this intervention, they expressed that they would like it regardless – that knowing, and feeling a level of sadness, is better than not knowing at all.

PROVISION OF COMFORT AND DISTRACTION

NOK

One of the primary hypothesis throughout the project was that the provision of a life-centric intervention, where focus is taken away from death and cancer, would provide the patient with a safe haven to reflect. It also would act as a medium for comfort and distraction in moments of distress – such as in the late night silence. During an earlier presentation, this assumption was challenged in its positioning of the framework as a replacement for a human conversation; an understandable doubt.

NURSE

However, the nurse expressed that she thought it would indeed provide some comfort during these moments as a distraction or diversion - but only to a certain extent. For these patients, the thought of cancer and death never really goes away – it's always there. Even in the case of cancer patients who have been cured, that thought it always there that it might return.

PATIENT

The patient themselves echoed this sentiment, saying that it would help as a distraction to have on the side and engage when you need - particularly when someone is not there physically to talk to you instead. It may not help 100% of the time, but potentially 50%, they said.

NOK

The intervention will likely not provide a total mental cleanse, however, it likely will provide some distraction, however small.

The interventions presence was also perceived as a means to provide support at the moment of diagnosis - while it may not provide everyone what they need, or want, the simple provision of something specifically intended for their population at the very minimum provides patients with a sense that they are still being cared for, and considered. Considering the current scenario, where patients are sent home with nothing, this would be a vast improvement alone. The patient echoed this feeling, saying that just having something you can physically touch would be of great help in moments of need.

ENCOURAGING CONVERSATION

One of the pivotal moments in this project was a feedback moment where there was a strong recommendation given to pivot the project towards a more conversational design. While this was not incorporated as a direct consideration of the design development, it was considered in a secondary role - as an implication of the design.

NURSE

While the framework doesn't specifically refer to an intent to encouraging conversation, its simple presence and prompting of interesting stories and sentimentality would likely encourage users to ask their own partners and loved ones the questions the app gives them – particularly if they are questions they don't know the answer to.

NURSE
NOK

The moment of bequeathing the legacy book itself, and its continued presence, would likely also trigger conversations surrounding the contents of the book – breaking the confrontational barrier next of kin may experience in attempting to raise these questions prior to death. The book provides a prompt towards these topics instead, making the process more natural and comfortable for all involved.

It may also be interesting to provide a guide of sorts alongside the legacy document, which helps patients and NOK's in navigating these conversations in the most valuable way possible.

NOK

Regarding ACP and care conversations, the assumption that the conversations about life and shared stories would deepen trust and relatedness was raised and assented. The nurse also hypothesised that these shared insights would likely build comfort in patients engagement with harder topics, working towards better, direct ACP. An interesting consideration may be to investigate creating reciprocity within the system – where the nurse has the capacity to respond with their own stories related to that which the patient shared. This way, it doesn't feel like a trial, where the patient is constantly being questioned, instead turning it into a human conversation, and where commonality and relatedness is built.

This approach would likely also further deepen the patient-clinicial relationship and trust, and potential opening the doors to ACP discussions.

NURSE

The provision of a safe space to reflect and ponder also enables patients to say things that they wouldn't otherwise say; things that they want to say, but can't say while looking in their eye. Some brief discussion was held surrounding the potentiality of patients redacting everything, and what would happen in these cases. Naturally, the patient's wishes are paramount, and their redactions should be kept confidential. However, fears were expressed about cases where the patient may begin sharing information indicating a danger to life, or other aspects.

While consensus was not reached regarding this latter point, a speculation was made that the system could potentially flag patients who were heavily redacting information – or not engaging at all, saying that limited, or little interaction can also indicate and say a lot.

FEASIBILITY AND REALISM

NOK

While theorethically the framework is an interesting proposal, it may exist in too utopian a world. Because of how aggressive HNC is, these end of life phases rarely go as expected, and the realistic ability of the patient to engage in the framework as intended would likely be impaired.

INSTITUTION

The topic of feasibility was also raised regarding the practicalities of the framework and embodiment, its interfacing with the institutions, adherence to the regulations surrounding innovation in the medical sphere, and the real-world success of the envisioned system. In this project, the nurse communication channels are envisioned integrated into the native dashboards and systems of the institutions themselves. This translation from system to system requires further consideration and practical assessment on a software level in order to validate its feasibility. It also would need to be investigated as to nurses success and experience in reacting to given insight statements, and whether they would provide enough actionable information, or would be too abstract. This is critical, as the nurses act as the main translator of insights into QoL. Additionally, their cognitive load should be studied during this process, to ensure that it is not overburdening.

These fears cannot be refuted; it is indeed impossible to say whether or not the framework and the presented embodiment would be 100% successful. While it is based on thorough theorethical research into established therapeutic and systemic approaches, the blending of these together into the final framework is a novel approach.

It is also worth mentioning these theories and approaches – the life story questions, the dignity therapy protocol, the laddering technique, are validated in the hands of a human – their translation into algorithmic applications does warrant further investigation.

PATIENT

This point - regarding the interpretation of meaning - was also raised by the nurse, who was hesitant as to whether the system would be able to accurately interpret and extract meaning sources from patient stories, particularly in the face of the ambigious and implicit.

Should further research and development ensue, one recommendation would be to conduct further research into the guidance given in both the dignity therapy, life story interview, and meaning centered interview towards interviewers. In these books, a clear set of considerations are set out, guiding interviewers on how to interpret patient stories, how to balance the line between creating a coherent, chronological story and preserving the patients voice and authentic narrative (Chochinov, 2012). As technologies progress, these considerations may be able to be embedded into the digital system and adhered to as a first step towards investigating the integration and assurance of understanding.

The creation of a validated working model would indeed provide further clarity and validation into it’s applicability, however this was unfortunately outside the development potential of a thesis project. Instead, based on the 100-day project timeframe, it presents an interesting direction for further speculation and development within which further validation could be sought.

DATA PROTECTION

In the final design phase, proposals were made towards how the intervention should conclude – considering patient life expectancy and the importance of allocating sufficient time for legacy book bequeathing. However, considering the aggression of the disease, failsafes were implemented should the patient die prematurely – the provision of a link to the NOK to request printing. This results in the data being held past the patient’s death.

NURSE

GDPR and personal information is a heavily policed and protected data type, particularly data as sensitive as medical information. It therefore should be considered further as to what should happen to the data after the patient passes, and how long it should be retained for, to ensure it doesn’t get into the wrong hands.

In reflection, I would speculate that data should be retained in the system for a period of a year – this ensures that during the confusion and turmoil of early grief, loved ones are not under pressure to arrange the delivery of the legacy document. It also avoids a scenario where, in the hectic days that follow a patients passing such as the funeral, or selling a patient’s house and assets, the legacy document is misplaced and cannot be replaced – only causing further distress and anguish.

However, further consideration should be made towards this recommendation, to ensure both NOK support, as well as adherence to regulatory conditions.

REFLECTING

XI

RECOMMENDATIONS

LIMITATIONS

CONCEPTUALITY

The framework has been created based on a grounding of theoretical rigor, however the real-world success of its deployment is speculative. Further development and embodiment of the framework is necessitated to fully validate its realism, including on the technological and software architecture.

One of the primary questions that remain in this regard is an automated systems ability to interpret and communicate the nuanced, implict and abstract nature that stories often contain - aspects which are naturally understood by humans, but may be hard to encode in a digital system.

A potential response towards this problem is the application of AI, and training it using the protocols set out in the dignity therapy, life story, and meaning centered psychotherapy manuals. However this deployment also raises questions about the ethics surrounding AI and sensitive cohorts, and how these risks could be mitigated. In this case, the risk is lowered by the non-conversational nature of the system - there is no risk of hallucination or the AI agent making dangerous suggestions; the questions it poses are strictly those from the aforementioned theories.

However, there could be a risk of the AI making inaccurate statements on behalf of the patient when communicating with nurses, based on inaccurate interpretations. There may also be a risk that the AI could misrepresent patient stories when presenting them for redaction and review, which may cause patient upset.

Should further development be undertaken, these aspects of the system should be a priority, to identify merits and faults early, and adapt the system in response.

CONTEXTUAL TESTING

While mitigated through extensive secondary research, one of the primary limitations of the project is the limited contact with the reality of the context. This was as a result of the aggressive nature of the disease, and the populations limited time, rendering contact with the population regarding the project unethical.

However, in order to test the feasibility and effectiveness of the framework and project outcome, some population contact is necessary. This could potentially be deployed initially with other populus - such as patients with head and neck cancer who are still in the curative phase - in order to validate the meaning surfacing and fundamental operation, or with incurable populations who do not face the same aggressively limited life expectancy as the HNC populus.

RECOMMENDATIONS FOR FUTURE DEVELOPMENT

TECHNOLOGICAL IMPLEMENTATION

Further exploration should be conducted into the feasibility and realistic deployment of the framework. This should not initially be on an embodiment level, but rather a basic encoding of the fundamental network to test and validate technologies capabilities regarding interpretation. A first step towards this could simply be the creation of a chat bot, trained on the protypical conditions and recommendations laid out in the Dignity Therapy, Meaning-centered psychotherapy and Life Interview books, where a simple story is presented and observations made regarding the AI's ability to determine fundamental meanings.

Further reactive development could then occur based on these findings.

NURSE EXPERIENCE

While nurses reacted positively during presentations, real life feasibility and testing should be conducted to determine nurses capabilities and experience in reacting to insights and translating them into real world care adjustments. These insights should range from the concrete to the abstract, and could potentially be based on insight statements generated by the techological prototype outlined above. Conclusions should be drawn regarding 'abstraction limits' a threshold where further abstraction becomes inactionable for nurses, and this constraint embedded into the framework protocols.

In addition to testing nurses capabilities, cognitive load testing should be conducted to ensure that this system does not signify excessive additional cognitive load. This intervention is aimed at helping the nurses deliver care, and therefore should not be experienced as a further burden.

ETHICAL AND REGULATORY CONSIDERATIONS

Innovation within the medical realm requires significant regulatory adherence and consideration. In this project, these were not explored in-depth. Further research should be conducted into regulatory restrictions that may apply and constrain the further development and deployment of this framework, particularly should AI be involved in the systemic embodiment.

Consideration should be made regarding data protection additionally, and the protection of sensitive data in transfers from patient to nurse, and from patient to legacy book. It also should be considered how long after patient death data is stored and destroyed, both considering NOK needs as well as laws and restrictions.

REAL WORLD TESTING

The development process of this framework was based on extensive literature - however, it is never truly possible to predict how it would translate in the real world. Concerns remain about its success in a real HNC scenario, where although the average trajectory was five months, the aggressive nature of the disease results in many patients passing before this point.

While considerations were made in response - early prompts to print, the provision of printing on demand, and the allowance of NOK print requests in the case of sudden death, it is unclear how the real, raw realities of the HNC trajectory would impair the intended interactions.

CLOSING REFLECTION

In the final presentation to the patient, a simple statement was made - ‘When I am diagnosed again, I would ask for this.

While this framework shows significant promise to both the HNC domain, significant doubts remain as to how it would interface with the real world considerations. Considering the complexity and unpredictable, aggressive nature, and the conceptual nature of the intervention, further in-context exploration is required.

However, the experiential and theoretical aspect of the framework shows promise - both in regards the general feedback received, and the rigor which it was built upon. It answers the core tension between stoicism and emotional expression, in a way that is sensitive to the populus, and designs with, rather than for. It delivers a sense of purpose, comfort and distraction, and provides patients with some sense of comfort, knowing that they have contributed towards the welfare and consolation of their loved ones after their death. It preserves patients stories and lives, and provides a survival of the self, and their relationships, past the earthly form.

Most importantly, it acknowledges the lived realities of these patients, and works with them, rather than against them, during the toughest period of their lives.

Its potential application beyond the HNC domain, towards alternate diseases and potentially broadening throughout the palliative phase illustrates the flexible nature of the framework and its ability to be further explored, and delivering value beyond the sphere of origin.

PERSONAL REFLECTION

This thesis challenged me in ways I never expected – nor, particularly wanted to be challenge. In a sense, the completion of this project was a sort of therapy in itself.

As a chronic perfectionist and over-analytical, anxious person, I have never been comfortable with a sense of loosing control. This thesis was, at times, very much out of my control.

From the offset, my mindset was challenged. I have always loved the research stage of design – particularly interviews and getting to know users. I love hearing their stories, their opinions, their insights – perhaps that’s the Irish in me. Within days of starting this project, major barriers arose that made it clear interviews would likely be impossible, something I struggled with, not only because of their absence from my final thesis, something I wanted to showcase as an integral part of what I see as my designerly self, but in its contesting of the worn in lesson of participatory design being paramount. Lessons such as these arose continuously throughout the thesis, challenging the lessons of academia in the face of reality, and reintroducing me to the reality of real-world design in sensitive spaces.

It also challenged my social skills as a designer – learning to communicate my design to various stakeholders, and at times, take a defensive stance. This confrontation, equally, is something I am not typically good at, or comfortable with. It also taught me not to do things just because I think I should – for example, deciding I had to physically prototype, and almost attempting to code a working chatbot a week before my greenlight (Thank you Pieter and Deger).

But I think most of all, this thesis sent me on a reflective process of my own. In the midst of stories of these patients and what they go through, I did come to know them, even though we never met face to face. Their stories, at times, brought me to tears, and their perspectives made me consider how much of my own life I take for granted. It has prompted me to begin asking my own loved ones more about their lives, and has, on many occasions, sent me down random daydreaming spirals about the story behind that Texan school bus I saw driving around the Utrecht suburbs one morning, and how many other school buses like it ended up in scrap heaps instead, and the people and their stories they carried for years and years.

It’s 11pm on a Tuesday, and I’m not sure how to end this, but if you read until here, I hope this thesis might have taught you something too; to listen, and look, a little more at the stories around you.

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XII

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XIII

APPENDIX

DESIGN FOR our future

TU Delft

Personal Project Brief – IDE Master Graduation Project

Name student Gráinne Buckley **Student number** 5,866,278

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT

Complete all fields, keep information clear, specific and concise

Project title What Truly Matters: Exploring Emotional Awareness and Support in ENT Palliative Care

Please state the title of your graduation project (above). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

Palliative care is described as when treatment broadens from solely curing a disease to disease management - prioritising quality of life over longevity. Patients enter palliative care under varied circumstances - patient election, terminal diagnosis, or in addition to curative treatment. For some diseases, palliative patients can live healthy, fulfilling lives for years – however, for those with Head and Neck Cancer (HNC), the average survival rate is only five months (Hoesseini et al., 2024).

Considering this brevity, patient comfort is crucial in order to maximise perceived fulfilment during their remaining time. While palliative care aims to achieve this, the myriad of aliments HNC patients face during this phase poses significant barriers. Traditional somatic symptoms such as fatigue and nausea are accompanied by speech impairments, nutrition deficiencies and anorexia (Henson et al., 2020), facial disfigurements, and more. These exacerbate patients` psychological and emotional distress experienced as they confront their end of life and are forced to reevaluate what truly matters in their new reality.

While both psychological and physical symptom sets require attention to facilitate true comfort and quality of life, psychological complaints are often neglected (Ferri et al., 2024). The palliative experience of HNC patients is unimaginable and complex, resulting in misaligned, insufficient care. With inadequate opportunity for needs to naturally emerge considering the palliative timeframe, this failure renders the primary goal of palliative care - fulfilment and quality of life - to ultimately be left unmet. Some institutions have begun attempting to rectify this problem - an example of this is the healthcare monitor questionnaire employed by Erasmus MC. However, its composition is considerably oversimplified, and precludes any meaningful insights and improvements.

Annually, there are 890,000 new diagnoses of HNC, with 450,000 succumbing to the illness (Barsouk et al., 2023); half a million vulnerable patients deprived of a comfortable end of life. This is a major opportunity to improve the support which defines the final and most sacred months of life of a global population, and deliver true, complete palliative care.

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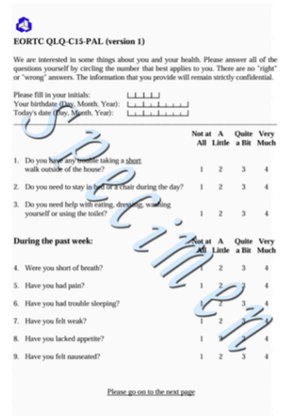
introduction (continued): space for images


EORTC QLQ-C15-PAL (version 1)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: [ ][ ][ ]
Your birthdate (Day, Month, Year): [ ][ ] [ ][ ] [ ][ ][ ][ ]
Today's date (Day, Month, Year): [ ][ ] [ ][ ] [ ][ ][ ][ ]

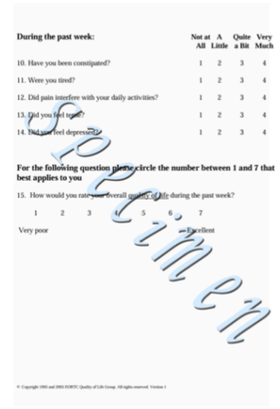
	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
2. Do you need to stay in bed or a chair during the day?	1	2	3	4
3. Do you need help with eating, dressing, or washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
4. Were you short of breath?	1	2	3	4
5. Have you had pain?	1	2	3	4
6. Have you had trouble sleeping?	1	2	3	4
7. Have you felt weak?	1	2	3	4
8. Have you lacked appetite?	1	2	3	4
9. Have you felt nauseated?	1	2	3	4

Please go on to the next page

Specimen

image / figure 1 Sample Monitoring Questionnaire as employed by Erasmus MC


During the past week:	Not at All	A Little	Quite a Bit	Very Much
10. Have you been constipated?	1	2	3	4
11. Were you tired?	1	2	3	4
12. Did pain interfere with your daily activities?	1	2	3	4
13. Did you feel tense?	1	2	3	4
14. Did you feel depressed?	1	2	3	4

For the following question please circle the number between 1 and 7 that best applies to you

15. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor — Excellent

Specimen

© Copyright 1995 and 2001 EORTC Quality of Life Group. All rights reserved. Version 3

image / figure 2 Sample Monitoring Questionnaire as employed by Erasmus MC - Single psychological question seen Q15

DESIGN FOR our future

TU Delft

Personal Project Brief – IDE Master Graduation Project

Problem Definition

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)

Palliative care is intended to address both physical and psychological comfort, however, their differentiating attributes often results in disproportionate attention - somatic symptoms are recognisable and measurable, while psychological complaints are abstract and individualised. In palliative and traumatic contexts, this divide dilates - emotional complexity renders generalised approaches ineffective, and external parties struggle to even approach the patient's internal experience.

In fact, patients themselves struggle profoundly to understand, recognise, and articulate their own emotions and needs. They are suddenly forced to reevaluate, reconfigure, and reprioritise their life, in an attempt to find fulfilment in a confrontational, uncomfortable reality. Compounding this challenge is the urgency imposed by the short prognosis associated with HNC, which diminishes the time within which the patient can conclude what truly matters to them.

Without a clear understanding of what is important to patients, healthcare professionals (HCP) cannot truly align care, undermining patients ability to find meaning at end of life. This project seeks to explore the emotional landscape of HNC palliative patients, how they navigate this transitional period, and identify patterns and topics that arise. Insights will be used to inform intervention(s) supporting patients in articulating their emotions and enable HCPs to support their emotional and mental wellbeing through an improved understanding.

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:

Investigate and develop an approach and intervention to support the recognition, articulation and monitoring of emotional wellbeing of head and neck cancer palliative care patients, to improve understanding, awareness and support of such within healthcare systems and health care professionals.

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

This project requires balancing sensitivity and empathy; in a domain as laden as this, only patients themselves can offer authentic insight into their emotional experiences - external parties can ultimately only speculate. Research with patients will be formulated to be minimal, efficient, comfortable, and unobtrusive. Contingency plans will recognise and account for the context's unpredictability, and minimise potential disruptions.

Three key stakeholder groups will be recruited across the Netherlands and Ireland: patients, families, and healthcare professionals. Secondary research will include journal articles, support groups and forums, and video testimonials. Primary research will focus on qualitative data, with activities guided and framed in the 13 Fundamental Needs (Desmet & Fokkinga, 2020) and the triggering and moderating strategies from design for dilemmas (Ozkaramanli, 2016). Methods such as sensitising workbooks, experience diaries, and probes will help explore daily realities and provide insights into the typical emotions/concerns of participants. Semi-structured interviews will address key questions while enabling participants to naturally lead conversation. Key insights will be used to direct idea generation focus points in methods such as brainwriting, and evaluation will include emotion mapping, informed by theories such as acceptance and commitment theory.

Project planning and key moments

*To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting**, **mid-term evaluation meeting**, **green light meeting** and **graduation ceremony**. Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).*

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting	8 Jul 2025
Mid-term evaluation	10 Oct 2025
Green light meeting	8 Jan 2025
Graduation ceremony	20 Feb 2026

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	✓
For how many project weeks	34
Number of project days per week	3,0

Comments:
Actual project days per week 3.5

Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.
(200 words max)

I chose to return to education and pursue a masters in Design for Interaction as a means to approach the social/humanitarian design fields – I similarly wanted my thesis project to reflect this. Social design is a undefined field in many ways – to me, it refers to design projects which focus on complex topics in neglected, unprofitable sectors, and often have a layer of political or emotional entanglement, and are sensitive in some way – mentally, culturally, or otherwise. This project attracted me for these same reasons – vulnerability, sensitivity, complexity, ambiguity and emotionality. Having worked in med-design before, I have had the opportunity to develop designs for those with niche needs and have seen firsthand how quickly design can improve patients lives in unaddressed needs. Shying away from projects simply due to a perceived impossibility, to me, goes against everything we are taught as designers – people who are supposed to be able to see beyond the surface, work around problems, and consider things from new perspectives. This project aligned with my priorities and morality regarding what I want to use my skills towards.

I also saw this project as a means to develop and test my research competencies – during my masters, I have realised that my skills and interest lies primarily in the research area, and I wanted to take the opportunity to conduct a project that had research as its primary focus.

Project Timeline

