Enhancing Emotional Support for Families of Head and Neck Cancer Patients in Palliative Care

Master Thesis
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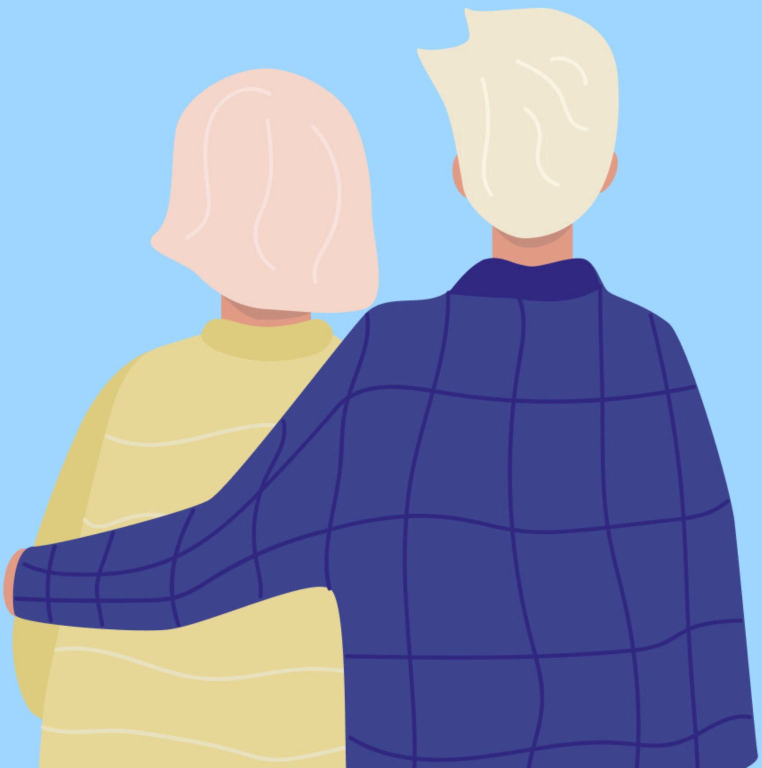

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AI Statement

The completion of this thesis were supported by the use of AI tools, which contribute to enhancing its quality and efficiency. In particular, ChatGPT, developed by OpenAI, was employed to ensure the clarity and accuracy of the writing. The tool not only facilitated the translation of important interview materials, but also strengthened the coherence of the paper.

Moreover, elicit was utilized to systematically identify and gather relevant literatures, thereby increasing the effectiveness and comprehensiveness of the literature review.

The integration of these AI tools was highly beneficial, helping the research remain centered on its key goals while did not diminish the researcher’s own contributions to the work.

Abstract

In an effort to improve treatment for palliative head and neck cancer (HNC) patients, this project is being carried out in collaboration with Erasmus MC, with a focus on value-based healthcare. The project is part of a larger collaboration between IDE, TU Delft, and Erasmus MC, all of which share a common framework based on the thirteen fundamental human needs (Desmet & Fokkinga, 2020).

In the Netherlands, palliative patients generally prefer to stay at home, where family, nurses and general practitioners would take the main responsibility to take care of them. Although psychological support is provided to patients, limited attention has been given to supporting next of kin (NoK), who not only face financial strain but also experience significant emotional and mental stress.

This project focuses on understanding family caregivers fundamental needs and improving the the overall palliative care for the next of kin. First, the researcher identify the key fundamental needs of family caregivers and pain points for them in the current palliative care system via qualitative interviews with nurses and healthcare professionals . Second, we conducted a focus group study, in which we mapped out the journey of NoK and ideal scenarios for supporting them through palliative care. In addition, we presented practical implementation and future strategy to the stakeholder.

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Glossary

At the beginning of this project, because many understandings of “palliative care” came up from both literatures and feedback from the client, it is crucial to clarify the definition of the terminologies used in this report based on the implementation in Erasmus Medical Center.

The following glossary lists some of the key words and their intended meanings applied to this report.

Term	***Intended Meaning***
Palliative care	*Different from the normal cancer patient who goes through palliative care, palliative care here refers to when curative measurements have been unsuccessful. Head and neck cancer patient can no longer or not willing to take curative treatment because of the pain, but still seek for medical attention to improve their quality of life.*
Family caregivers (the next of kin, NoK)	*When head and neck cancer patient enters palliative care phase, most of the patients in the Netherlands prefer to stay at home and receive remote care. This leaves the next of kin, usually their partners or offsprings, to be their main family caregivers.*
Curative care	*Curative care is defined as a model in which all interventions are aimed at diagnosing and treating every problem that arises, with the primary goal of achieving a cure and prolonging life. (Swagerty, 2017)*
End-of-life care	*According to Nation Cancer Institute of the United States, end-of-life care refers to care given to people who have near the end of their life and have stopped treatment to cure or control their disease. This includes physical, emotional, and spiritual support for the patients and their family. End-of life care may include palliative care, supportive care and hospice care.*
Aftercare	*Here specifically refers to care taken place for the family of head and neck cancer patients after the patients passed away. The aftercare aims to alleviate the depression and sorrow of losing the beloved ones and support the family to come back to their own life.*

INTRODUCTION

The introduction provides background information of the project, outlines the project approach, and highlights the project's contributions.

1.1 Project background

Head and neck cancers, mainly squamous cell carcinomas (HNSCC), are a significant global health issue, with over half a million new cases diagnosed each year worldwide(Starzyńska et al., 2022). Patients with head and neck cancer (HNC) often face severe symptoms, such as pain, difficulty breathing, fatigue, and problems with speech and nutrition, which significantly affect their quality of life (Tinti et al., 2020; White et al., 2025).

Although there have been improvements in treatment, HNC patients who entered palliative care only survived for 5.1 months in average after diagnosis (Tinti et al., 2020). A hybrid approach to palliative care, including remote care options, has shown promise to increase their end-of-life living qualities, but there are still major gaps, especially in discussions about life expectancy and providing enough emotional support (van den Besselaar et al., 2024).

Barriers to starting palliative care earlier include misunderstandings about palliative care being equivalent to giving up and ineffective communication between healthcare professionals and patients (White et al., 2025; Satija et al., 2019). Randomized clinical trials demonstrate that early palliative care improves quality of life, mood, symptom management, patient satisfaction, and resource utilization (Glare, 2013). Professional organizations like ASCO now recommend integrating palliative care from the time of metastatic cancer diagnosis (Gaertner et al., 2013).

Family caregivers often experience significant emotional distress and uncertainty during the transition to palliative care, and remote care solutions alone frequently fall short in addressing their emotional needs (van den Besselaar et al., 2024). Research shows that the highest-priority needs for caregivers include being kept well-informed about the patient's condition and feeling reassured about the patient's comfort (Wright & Dyck, 1984). Beyond clinical updates, caregivers also seek a sense of **security and trust**, **partnership** in care, and **ongoing emotional support** throughout the caregiving journey.

The next of kin's daily routine is often disrupted, they experience major role changes, and they frequently face emotional distress as they adapt to caregiving responsibilities (Fronczek, 2015). While caregivers value external support, they specifically highlight a need for practical strategies to manage daily caregiving tasks and personal well-being (Zeng et al., 2022).

Because the impact of illness extends beyond the patient, affecting the entire family system (Kristjanson & Aoun, 2004), it is important that we recognize the crucial role the family is playing and include their needs in the palliative care.

However, in the Netherlands, EORTC-QLQ-C15-PAL questionnaire and regular calls are scheduled to only check on the patients physical conditions. Barely no questions are referred to either patient or family's mental well-beings.
Hence, this project is brought up as part of a collaboration between TU Delft and Erasmus MC, specifically designed to create meaningful value for patients and their families. The primary goal is to better understand the challenges family caregivers face and develop solutions to support their fundamental needs.

1.2 Project approach

This study employs the Double Diamond design framework (Elmansy, 2023), which shifts between divergent exploration and convergent synthesis (Figure 1).

To identify and prioritise what is most meaningful to patients' families, the research also integrates the Fundamental Needs framework from user-centred design (Desmet & Fokkinga, 2020).

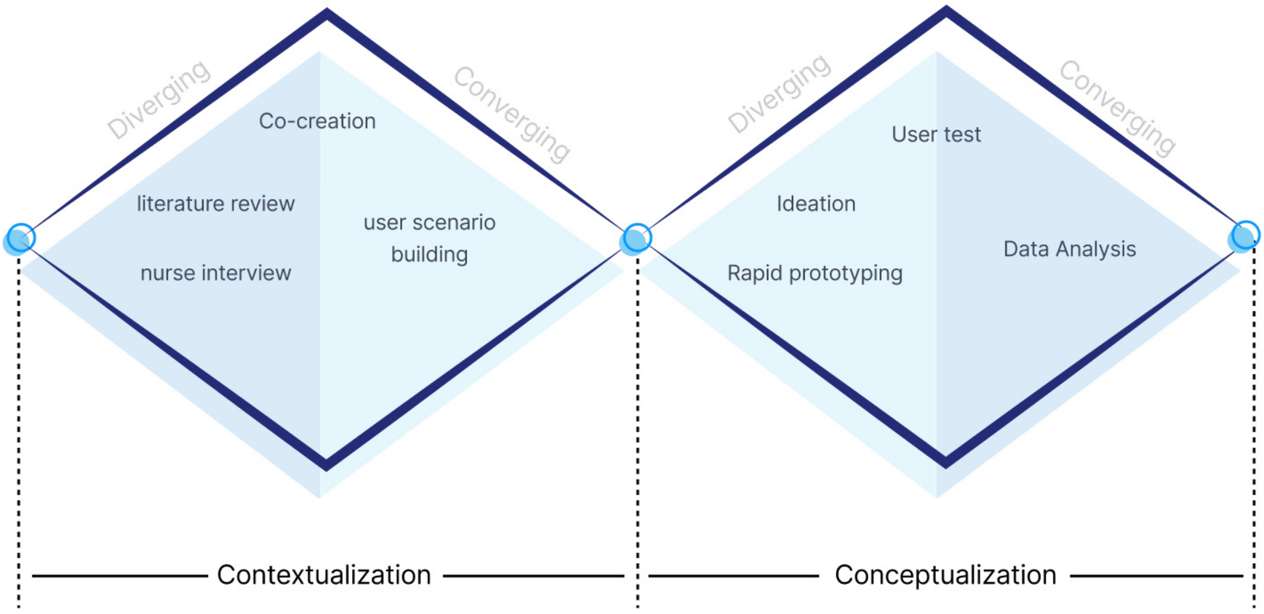


Figure 1. Project Overview

a. Contextualization

In the preliminary phase, literature review and interviews with oncology nurses were undertaken to build a contextual understanding of the situation patients and their families are confronting. Next-of-kin journey map and personas were applied to clarify which kinds of support the families need . Because needs shift across stages of palliative care, a set of stage-specific user scenarios was then developed to steer ideation.

b. Conceptualization

In the second part of the project, based on the persona and user scenarios, prototype was developed through multiple rounds of testing and iterations. The final evaluation is based on two sources, one through connections with elderly people in the same age group, the other through EMC with next of kin of former HNC patient.

1.3 Project contribution

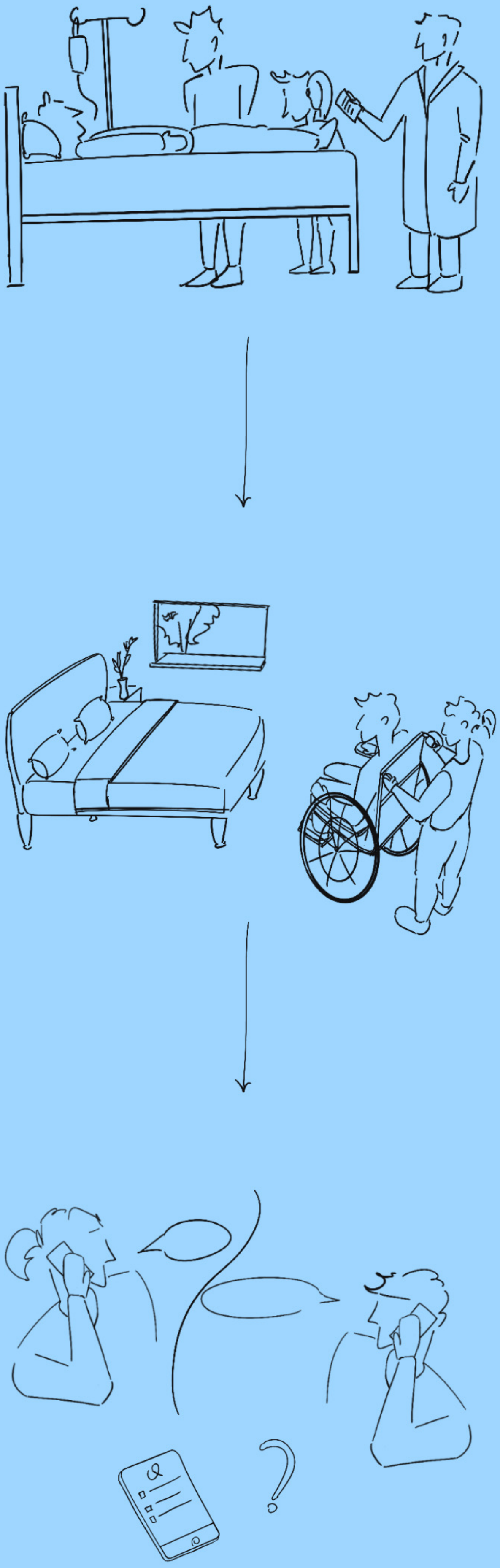
The project aims to design a meaningful intervention for the family members of head and neck cancer (HNC) patients who are currently undergoing or have previously undergone palliative care, with a focus on supporting their own well-being.

Building on the existing remote monitoring solution for palliative care patients of HNC, the study envisions a next generation monitoring system that not only track their physical condition, but also actively promotes the mental well-beings and communication of patients and their relatives.

Transitional support and design interventions

Two key themes emerged from the literature review: first, the next of kin often experience **insecurity and uncertainty about what lies ahead**, reflecting a lack of accessible and clear information about palliative care; second, they tend to **put their own lives on hold**, neglecting their fundamental needs for peace and emotional balance. This is especially evident during the so-called “blank period”—a period typically lasting 6 to 8 weeks—when no routine check-in calls from healthcare professionals are made. During this time, families are largely left on their own unless a serious issue arises.

To address this gap, the project proposes a design intervention specifically for the next of kin during the “blank period”. By raising awareness of their own fundamental human needs, the intervention aims not only to support the caregivers’ well-being but also to empower them to provide better care for the patient in return.



LITERATURE REVIEW

The project initiated from searching for literature about palliative care protocols, conditions of palliative care HNC patients, experience of next of kin, both patients and families mental welling-beings in palliative care , and their feedback on palliative treatment. The goal of the literature review is to gain as much insights as possible from other experts and studies to understand the challenges and difficulties the families are facing without overwhelming them with duplicated research. By learning the experience of families that has been through palliative care, we aim to identify the fundamental needs of the next of kin. The literature review is done in sequence to answer the following research questions (see in figure #)

Research Questions

RQ1: What is palliative care?

What kind of HNC patient will receive palliative care?
When do they receive it?
What are the protocols of palliative care?
Who are involved in the palliative treatment?
What is the impact of palliative care interventions on quality of life and symptom management?
How palliative care is implemented in the Netherlands verse other countries?

RQ2: What challenges and difficulties are confronted by patients and families?

How do they describe the emotional, practical, and communicational related difficulties?
How do the challenges and difficulties impact the patients and families life?
What are the factors affecting their mental well-beings?
How do they cope with the challenges?

RQ3: What would be their prioritized needs and what they have done to met the needs?

Figure #. Research questions followed by literature review

2.1 Palliative care for HNC patients

It is crucial to understand what is palliative care and how it is carried out before creating user scenarios in the next stage. Therefore, the first main research question is:

RQ1: What is palliative care for HNC patients?

In order to grasp the full context revolving around palliative care for HNC patients, this part of the review will also includes the protocols of palliative care and 5W2H of the implementation.

2.1.1 Definition of palliative care for HNC patient

"Palliative care" is interdisciplinary care that provides support for the physical, emotional, and psychological suffering of patients with any advanced illness—typically defined as a serious or life-limiting condition that may be incurable or is approaching the end-of-life phase—regardless of age, diagnosis, or life expectancy(Goldstein et al., 2008). The treatment has evolved significantly over the past five decades, expanding from end-of-life care for cancer patients to a comprehensive approach for various complex illnesses (Meghani, 2004; Guo et al., 2012).

Palliative care has been shifted over decades from highly specialized, hospice-based approaches for terminal cancer patient to models that integrate care across hospitals, communities, and broader health systems.

Higginson (1993) describes early practice as centered in specialized hospices and limited support teams. Later, Barbero and Diaz (2007), document an expansion that incorporated hospital and community services, addressing palliative care for chronic illnesses. In recent years, Lohman et al. (2022) and Robinson et al. (2014) report a global consensus on integrating palliative care into universal health systems, with advances in technology and a strong emphasis on individualized, patient- and family-centered approaches.

Table 1. Evolution of palliative care in three domain

	1990 - 2000	2000 - 2010	2010 - current
Care Mode	• Specialized hospices/support teams for cancer patients; • limited integration with hospitals	• Inclusion of pediatric palliative care globally; • Care from diagnosis to death; • non-cancer and chronic disease focus	• Global consensus on **integration into health systems**; • Universal health coverage; • Advanced technologies in hospitals
Practice Scope	• Focus on terminal care, mainly cancer; • Limited to dying patients	• Expansion to chronic illnesses; • Early pediatric palliative care; • Broader patient populations	• Inclusion of pediatric palliative care globally; • **Care from diagnosis to death**; • Non-cancer and chronic disease focus

	1990 - 2000	2000 - 2010	2010 - current
Patient-family-centered Care	• Emphasis on symptom control and quality of life; • Limited family involvement	• Increasing attention to **communication, decision-making, and family support**	• Holistic, individualized care; • **Interdisciplinary teams**; • Focus on **patient/family experience** and hospital environment

2.1.2 Common symptoms of head and neck cancer patient

For head and neck cancer patients, various symptoms could cause living difficulties and pain through the stages of their illness. Through the storytelling with a patient, Goldstein et al. (2008) has categorized the symptoms into the following kinds regarding the different impacts they have on the patients life and provides a detailed description for each. These symptoms are recognized as common or frequent among head and neck cancer (HNC) patients; however, this does not imply that all patients will experience the same symptoms or share the same illness trajectory.

1. General Pain

The pains are usually as results of radiation and chemotherapy. The patient will feel the pain from multiple areas, such as chin, neck, infected skins and lips. Moreover, the pain in the mouth and neck may be an indicator of recurrence of tumor. While the treatment plan of pain for HNC patients is similar to that of the other cancer patients, the other symptom, for example, the swallowing issue, may affect their intake of medications.

2. Lack of Saliva

Another problem mentioned by the patients is the difficulty of controlling and producing saliva. The symptoms often occur because of the malignancies for patients that gone through radiation therapy. The loss of normal structure of the patient’s mouth results in the inadequate amount of saliva to cleanse and fill in the cavities of the mouth, affecting the patient’s ability to eat and speak. Palliation for the symptoms is constantly moisturise the mouth by water or ice chips.

3. Eating and Swallowing

Multiple symptoms could lead to eating and swallowing disorder. Difficulties in swallowing is the most common symptom for head and neck cancer patients. Mucositis causes inflaming sensation in mouth, while Dysphagia and Odynophagia obstruct the patient from eating normally, can only absorb nutrition via gastrostomy tube. Not only the hydration and nutrition for HNC patients have to be carefully selected, they also face the challenge of traveling because of the amount of food needed per day.

4. Difficulties in Speaking

Another major challenge for patients with head and neck cancer is the potential loss of normal spoken communication. Owing to the anatomical involvement of the disease, treatment often requires surgical modification or reconstruction of the lips, tongue, or dentition, which can produce irreversible changes or injury to speech. Consequently, many patients must rely on assistive devices to communicate after surgery.

5. Anxiety and depression

Head and neck cancer patients experience significant psychological distress throughout their treatment journey. Anxiety is prevalent at diagnosis, while depression tends to increase after treatment (Gil et al., 2012; Wu et al., 2016). Common sources of distress include pain, social and communication difficulties, and fear of recurrence (Mäkitie et al., 2024). One of the main factor that creates anxiety is the patient's fear of recurrence of the painful symptoms (Goldstein et al. , 2008).

6. Quality of Life

HNC patients experience significant impacts on their quality of life (QoL) due to treatment-related side effects and disease progression (Weymuller Jr & Bhama, 2007). Factors such as feeding tubes, tracheostomy, chemotherapy, and neck dissection are associated with decreased QoL (Terrell et al., 2004). Facial disfigurement and self-image anxiety resulting from surgery and treatment negatively affect patients' self-esteem and overall well-being (Bhandari et al., 2024).

QoL typically deteriorates most within the first three months of treatment, with surgery combined with chemoradiotherapy being the most debilitating modality (Sharma et al., 2019), But may improve with targeted interventions (Hortense et al., 2020).

7. Body Image and Self-confidence

The patients often experience body image disturbances due to visible disfigurement and functional changes resulting from treatment (Rhoten et al., 2013). Studies show that 56-68% of patients report positive self-image (Henry et al., 2022), while others experience negative body image and self-consciousness (Neba, 2024).

Body image concerns are associated with increased depressive symptoms and decreased quality of life (Bhandari et al., 2024).

8. Guilt

Patients often engage in self-blame due to the association with risk factors like tobacco and alcohol use (Thamm et al., 2023). Stigma and self-blame can influence positive health changes, particularly in tobacco consumption (Lebel et al., 2013). Psychosocial problems may worsen over time, reflecting potential "patient burnout" (Rapoport et al., 1993).

In conclusion,

common symptoms can be categorized into the three domain: physical pain, psychological stress, and impact on social life (see in figure 2). These challenges are interconnected and affect multiple aspects of patients' lives (Roe, 2008). The impact of the disease varies among individuals, with some viewing it as a past event and others experiencing ongoing difficulties (Isaksson et al., 2016).

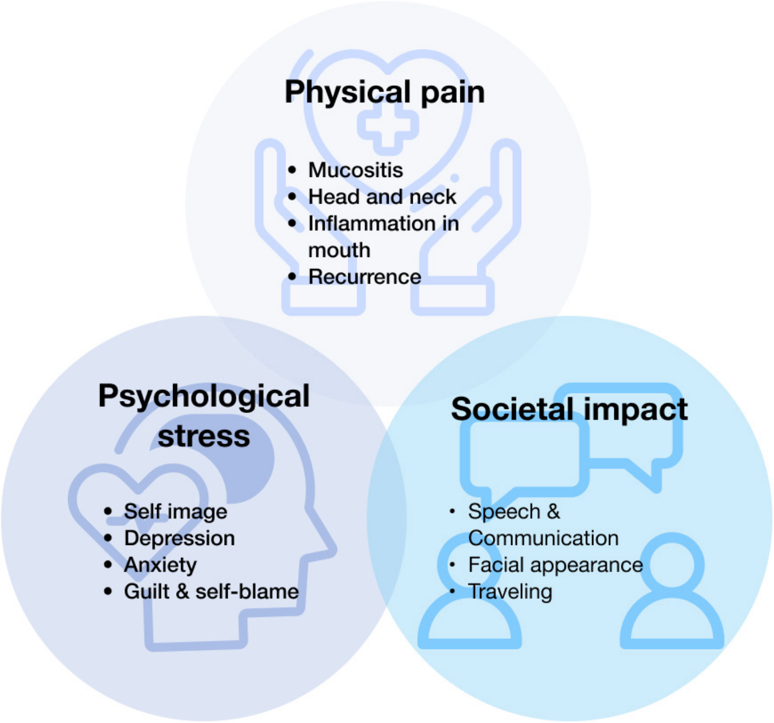


Figure 2. Three aspects of difficulties the patients face

2.1.3 Cure Rates and Treatment Challenges

Approximately 3% of HNC patients enter the palliative phase at diagnosis, with a median survival of 15 weeks (Hoesseini et al., 2024). Within 12 months, 68% of palliative patients die, compared to 9% in the curative group (Mayland et al., 2020). Although there is a huge gap of expected mortality for palliative care and curative oncologic treatment, they are not mutually exclusive. Rather, they can coexist and offer complementary benefits. Palliative care focuses on alleviating pain, treatment-related side effects, and psychological distress, whereas curative therapy may prolong survival or reduce tumor burden. Accordingly, there is a clinically meaningful zone of overlap in which integrated approaches help patients transition between—and adapt to—different treatment pathways (Figure 3).

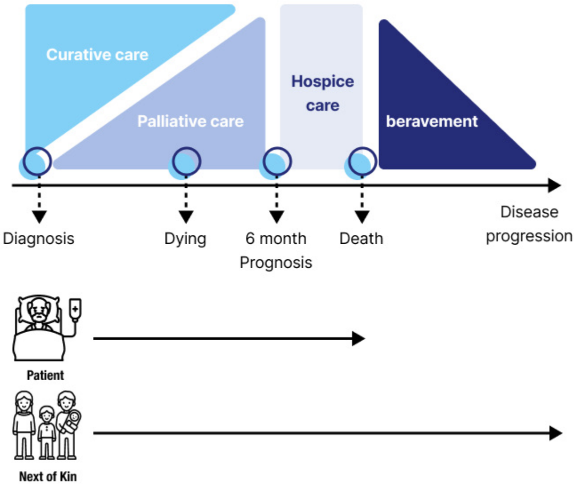


Figure 3. Model of palliative care adapted from 'the integrated model of care' proposed by World Health Organization (WHO), 1990

Since the World Health Organization (WHO) introduced its staged model of palliative care in 1990, scholars have reconsidered where palliative services should sit across the overall course of illness. For HNC patients, earlier integration of palliative care is associated with better quality of life, stronger symptom control, and improved treatment outcomes (Figure 4). Early palliative care (EPC) has been shown to reduce hospitalizations, increase care planning discussions, and improve treatment completion rates (Chen et al., 2024).

The target population for palliative care should also explicitly include family members (next of kin), bringing their physical and psychological needs into the plan of care. Lower caregiver quality of life is associated with decreased patient survival (Pequeno et al., 2022). Factors, such as age, sex, and attitudes, shape multiple quality-of-life domains (Waghmare et al., 2023). EPC can strengthen coping in patients and caregivers (Greer et al., 2020), and caregivers' illness perceptions are linked to patient quality of life (Richardson et al., 2015).

However, studies show that hospitals often score better in medical treatment than in information provision and next of kin involvement (Bergerød et al., 2020). According to EORTC-QLQ-C15-PAL(Figure 5), which is the questionnaire sending to patients during palliative care, only two out of fifteen questions concerns about the mental well-beings of patients, while no question is being asked about the well-being of the family (next of kin). Moreover, the questionnaire is the only measurements for healthcare providers to understand the condition of the patient and family and offer help.

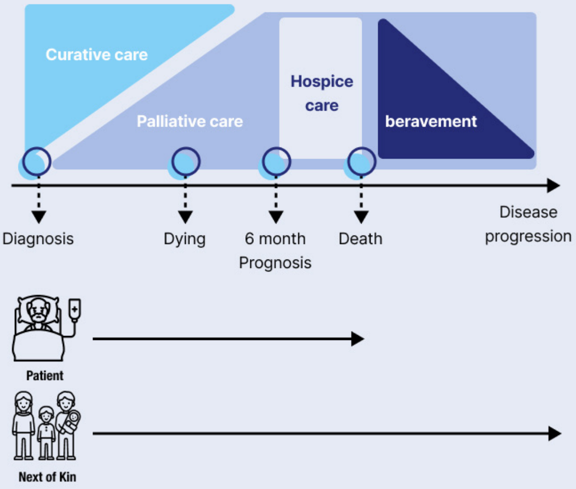
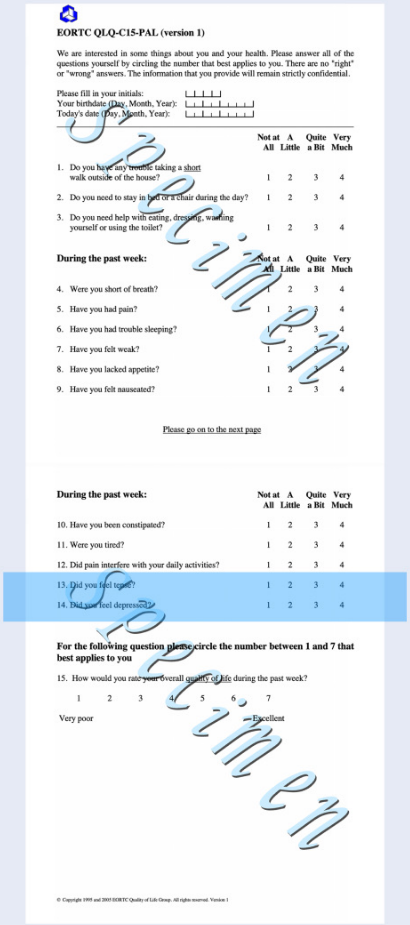


Figure 4. Refined model of palliative care stages



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

Please go on to the next page

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

2/15 questions:

whether the patient feel tense and depressed?

Figure 5. EORTC-QLQ-C15-PAL analysis, questionnaire given to the patients/families

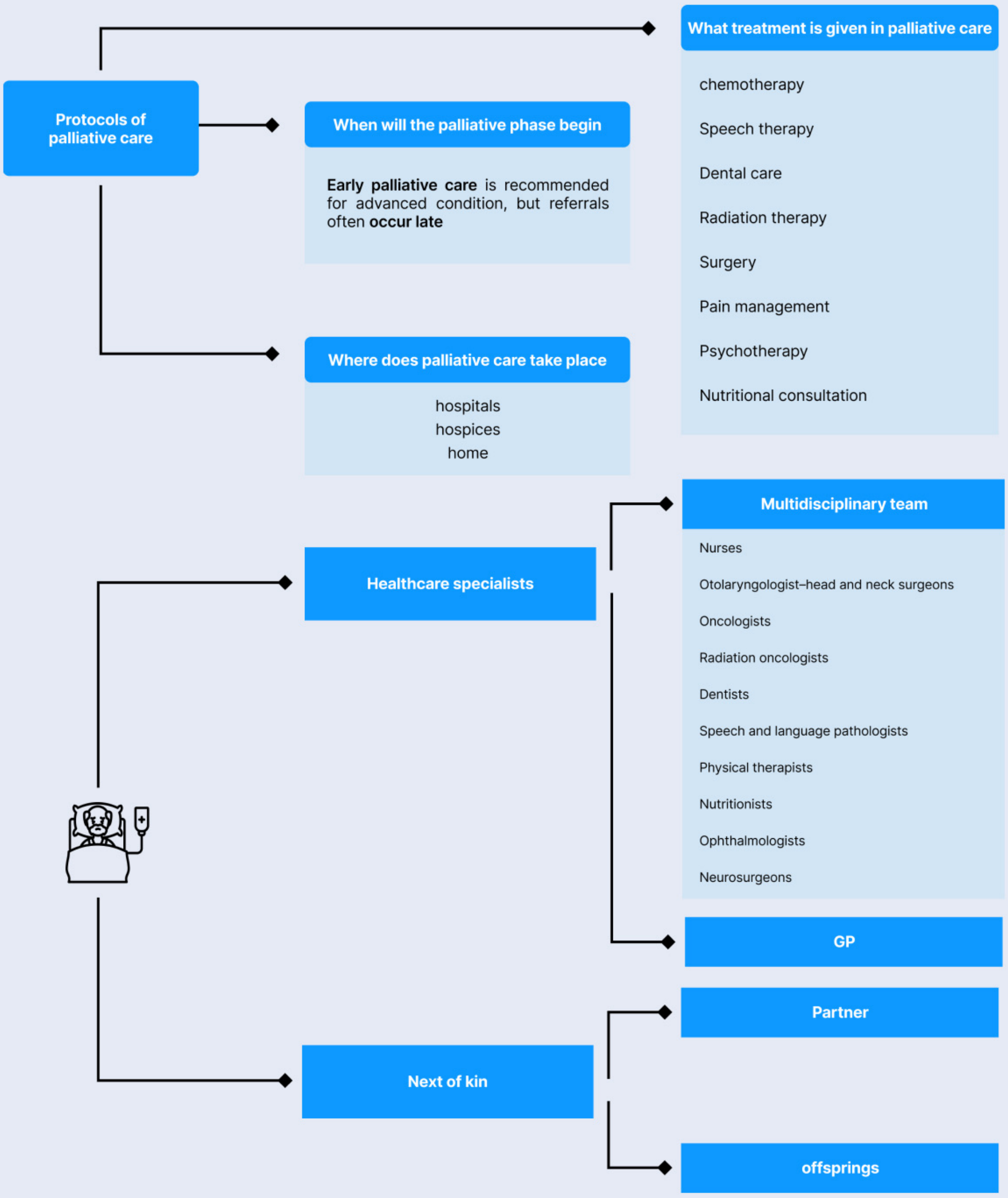
2.1.4 Protocols

Because palliative-care pathways and management protocols differ across countries and health systems, this review is organized in two parts: (1) a synthesis of broadly applicable, evidence-based core protocols, and (2) an examination of Netherlands-specific pathways, guidelines, and operational practices. This structure enables comparison of Dutch practice with internationally recognized standards. The review employs a Q&A format to address key questions concerning palliative care protocols.

1. Global perspective on palliative care

Palliative care for head and neck cancer patients requires a multidisciplinary approach to address complex symptoms and improve quality of life (Ratnasekera et al., 2023). Management strategies involve pain control using the WHO pain ladder, nutritional support, and addressing psychosocial needs (Cocks et al., 2016).

Figure 6.protocols of palliative care & stakeholder involved



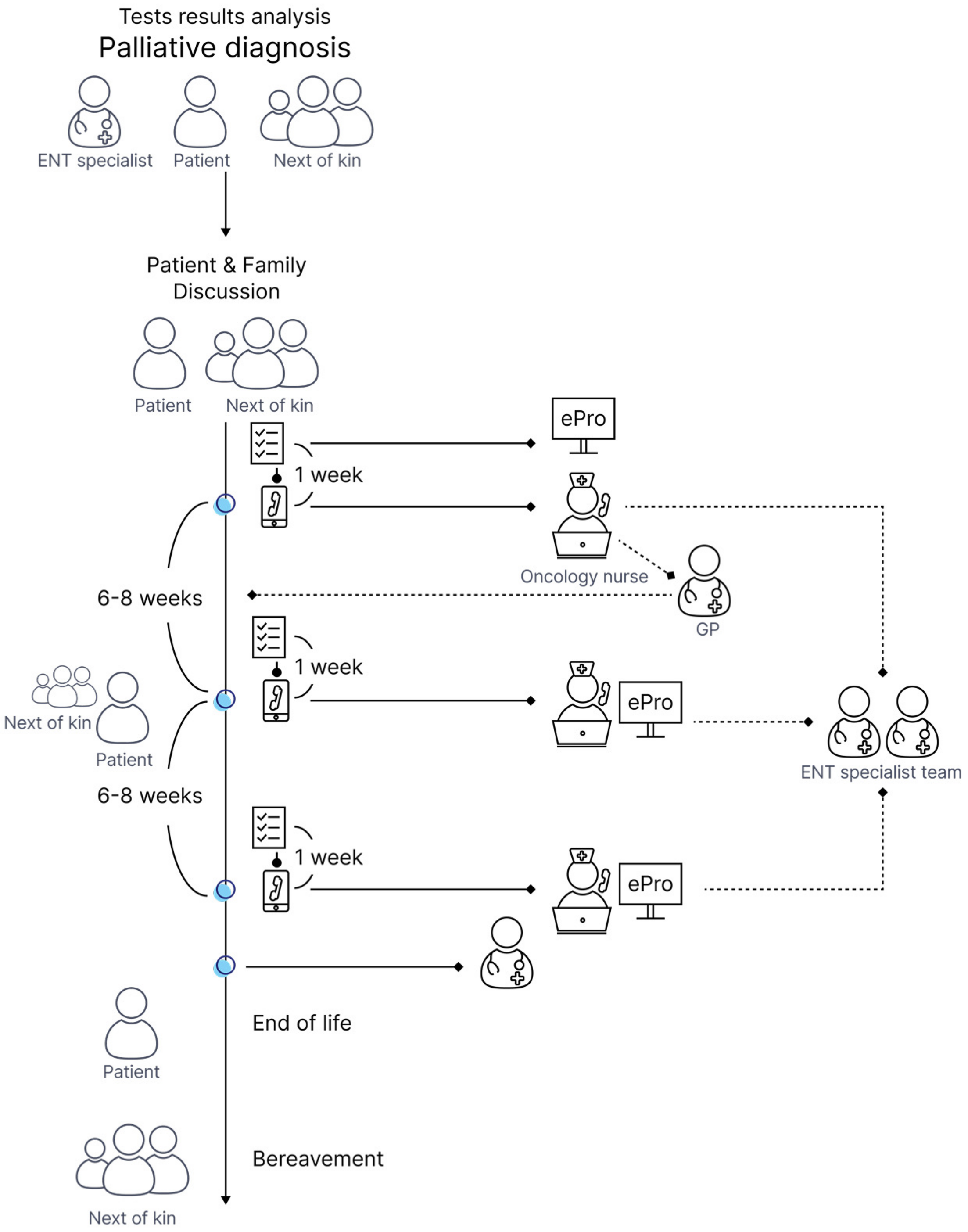


Figure 7. Patient pathway of palliative care at Erasmus Medical Center (Kim et al., 2025)

2. Current patients pathway in the Netherlands

While early palliative care may be effective for advanced cancer patients. According to Dorr et al. (2022), the current palliative phase only last for 5.1 months in medium. The question followed then is what is the palliative pathway for HNC patients? What roles different stakeholders play in phases of palliative care?

To understand this, the researcher mapped out a basic road map based on the treatment plan for patients in Erasmus Medical Center (EMC), stating the role and help patients and family receive during the time when palliative care taken place (Figure 7).

Conclusion & reflection

By analyzing the current palliative care pathway at Erasmus MC, we gain a more holistic understanding of the healthcare system in place for patients with head and neck cancer (HNC). One important observation is the presence of a gap between 6-8 week term of structured monitoring, which is conducted via phone call by EMC HCPs. While HCPs remain available for contact, communication during this period relies more on patients and family members, who often do not reach out proactively despite ongoing issues. Therefore, the Value-based health care (VBHC) team from EMC aims to provide more structured, proactive care during this period.

The next phase of this research will involve validating these contextual findings through further consultation with healthcare professionals at Erasmus MC. The aim is to gain deeper insight into the actual support mechanisms provided during palliative care and to create a clearer, more comprehensive map of the patient and next of kin journey. Understanding what palliative care truly means to families emotionally and physically, and identifying the struggles they face at different stages is critical. With the existing touch points as a foundation, more detailed mapping is necessary to uncover emotional, relational, and logistical challenges, ultimately guiding design interventions that are both meaningful and well-timed.

2.2 Experiences of patients and families

After understanding the context of palliative care for head and neck cancer patient, a deep dive into the patients and families' experience and what impact the disease have on their life is needed.

RQ2: What challenges are confronted by patients and families?

In this part, we separate the experience of the patients and their next of kin to understand the difference of their mindset and what are the factors that caused their symptoms.

2.2.1 Physical impact on patients

Head and neck cancer patients receiving palliative care experience a wide range of physical symptoms and quality of life impacts. Common physical symptoms include pain, dysphagia, weight loss, fatigue, dyspnea, and oral problems such as xerostomia and mucositis (Tinti et al., 2020). It is crucial to specify the daily impact each symptom has on the patient and the palliative treatment plan for each symptom because for most home-care patients, next of kin will be the caregiver in practice (Table 2). The symptoms and care plans show how sophisticated the life of family caregiver is and why they should be involve in the palliative care.

Table 2. Physical impact & treatment plan

Symptoms	Impact	Treatment
Weight loss	Weakness and decreased mobility	Careful monitoring & tube feeding
Inflammation pain Mucositis	Discomfort and distress, sleeping disorder	Allopurinol mouthwash Granulocyte-macrophage colony-stimulating factor Immunoglobulins Human placental extract
Cough	Disrupts sleep and daily activities	Opioids or other oral drugs, 2-4 times daily
Dysphagia	Malnutrition and dehydration	Consultation with speech and language pathologist Artificial hydration and nutrition
Eating & digest	malnutrition and dehydration	gastrostomy tube feeding/bolus feeding
Oral thrush	Discomfort, difficulty with eating and speaking	Frequent intake of water, ice chips18 Use of sugarless candy or gum18 Artificial saliva18 Pilocarpine (starting dose 2.5 mg enterally 3 times daily)

2.2.2 Emotional impact on patients

Patients experienced varied emotions due to knowledge of their illness, duration of untreated illness, and object of blame, indicating a high risk of emotional disturbances (Jagannathan & Juvva, 2016). The physical pain and discomfort of the patient will also impact their emotional status, including fear, worry, loneliness, and shock (Saghafi et al., 2023). Coping strategies involve maintaining a positive attitude, seeking support, and trusting healthcare providers (Saghafi et al., 2023).

Nonetheless, psychosocial support is often insufficient, with patients and caregivers reporting unmet needs (van den Besselaar et al., 2024).For the current pathology, while in most cases patients receive remote care, they still felt safe and grateful to have a conversation. Face-to-face consultation is also positively experienced.

There is also a shift of mindset during the time span of the treatment, Manuel et al., 1987) indicates that if the patient used approach or avoidant coping strategy in early stage, their emotional distress is lower. The peak of their anxiety is during the time of the confirmation of their diagnosis and recedes along the treatment.

2.2.3 Social life and daily communication

Numerous symptoms can affect their daily life in different aspects, include difficulties with speech, eating, and drinking, as well as facial disfigurement, which can lead to social isolation and relationship problems (Anderson & Franke, 2000; Argerakis, 1990; Semple et al., 2008). Patients often experience anxiety, depression, and loss of self-esteem (Pruyn et al., 1986). The severity of these issues tends to increase over time, potentially due to "patient burnout" (Rapoport et al., 1993).

Social eating and drinking become particularly challenging, affecting patients' psychological well-being and close relationships (Dornan et al., 2021). Patients with extensive disfigurement report more significant impacts on self-image, sexuality, and social isolation compared to those with minor disfigurement (Gamba et al., 1992).

The opinions on the physical conditions also varies between patients themselves and the families due to the communication barrier. Next of kin cares more about the prevalence and somatic symptoms in most cases. If the patient is receiving oncology treatment in palliative phase, then the family’s focus will shifts to the mental status of the patients.

In conclusion, the family’s concerns focus on where the healthcare is not fully covered and how severe the condition is.

2.2.4 Impact on family and relatives

Because of the sensitivity of the project, interviews with patient or patient family is limited, therefore, finding existing research done with patients and their next of kin to learn from their experience is crucial for this study.

This part of the literature review will combine quotations from patient/family interviews in the literature to build a comprehensive understanding of the experience of the next of kin and how the disease affect the life of the family. The themes are divided into three parts: the circumstance the next of kin is in, the attitudes towards palliative care, their coping strategies.

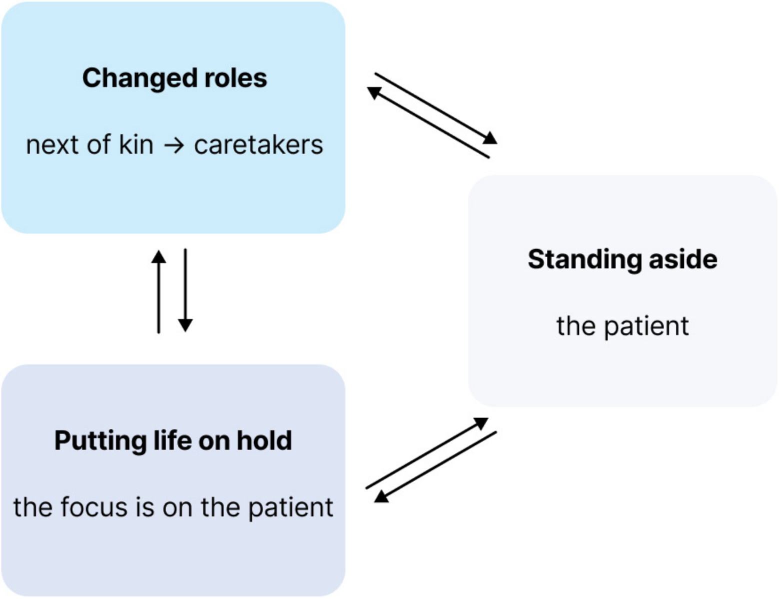


Figure 9. Three themes of the life of the next of kin

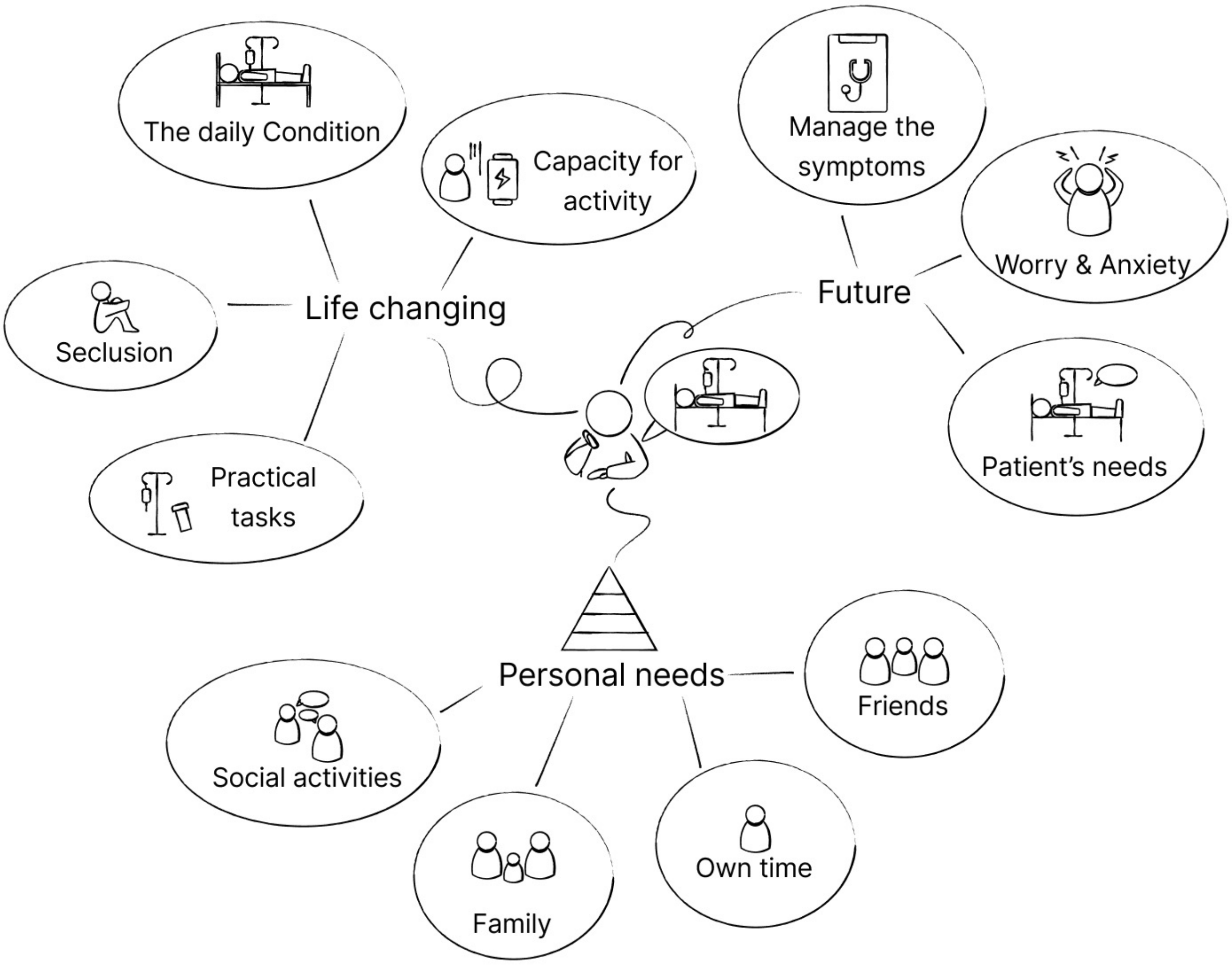


Figure 8. Mindset of the next of kin's life during palliative care phase

1. Main themes of the life of the next of kin

The following section introduces three central themes that characterize the lived experience of family members caring for head and neck cancer (HNC) patients during the palliative phase. These themes were identified in the research conducted by Johansson et al. (2023) and are further supported by quotations and insights drawn from both prior literature and interview studies.

The three themes are:

1. A Shift of Roles
2. Putting One's Own Life on Hold
3. Standing Beside the Patient

Quotations included in this section are extracted from Johansson et al. (2023) The quotations help establish the context in which this design project is situated, and inform the direction of the design intervention in addressing emotional and experiential needs of the next of kin.

a. Life Changing

The next of kin change their life in various ways according to the treatment plan for the patient. The treatment requires the next of kin to constantly checking the patient's condition and act quickly.

> *" I must check mom I check her several times a week I shop to her shower her ...just checking so she is doing as well as she can with her breathing or in her daily everyday life."*
>
> —— *Daughter 46* (Johansson et al. 2023)

> *" more and more that he needs help ... for example, showering, getting dressed, eh... yes, cooking and such, I do it, and chores, it's up to me."*
>
> —— *Partner 73* (Johansson et al. 2023)

Moreover, the next of kin felt unprepared and lack of information for taking care of the patient, leading to anxiety and panic attack.

> *"I didn't have that information then so maybe I had more anxiety that grew until I got the information."*
>
> —— *Partner 71* (Johansson et al. 2023)

b. Putting Life On Hold

The life of the next of kin also changes according to the emotions and symptoms of themselves appeared during palliative care.

For example, the next of kin were taking most of their time taking care of their loved one and they sometimes forget their own social needs, leading to loneliness and despression.

> *"... sometimes you don't feel so well yourself because you can feel lonely ... ... it can be several days that you don't meet other people I don't feel good about it."*
>
> —— *Partner 73* (Johansson et al. 2023)

Symptoms like loss of sleep also lead to low energy and forgetfulness, which will affect their own personal life.

> *" ... I notice that I sleep very poorly, I ... uh ... get sad easily... ... I think I'm kind of stressed mentally, so I forget things ... ... uh I focus so much on things being*
>
> (Johansson et al. 2023)

> *good at home and like uh ... ... yes I'm actually taking on a role that I shouldn't have to take on like how should I say almost become .... "*
>
> —— *Partner 53* (Johansson et al. 2023)

c. Standing Aside the Patient

Being physically present by the patient means that family members are not only closely involved in the patient's suffering, but also witness it directly and continuously.

The contact on a daily basis intensifies their emotional involvement and often deepens their sense of helplessness regarding recovery.

> *"Yes, because I can't help him ... ... what I think you feel so helpless or what to say it's...."*
>
> —— *Partner 68* (Johansson et al. 2023)

The next of kin will start to wonder if their life will ever be normal again because of the experience of losing someone slowly.

> *"A lot of thoughts about ...what will happen if XXXXX passes away, what will happen to me then, I would sit here alone ... "*
>
> —— *Partner 66* (Johansson et al. 2023)

In conclusion,

the next of kin are forced to shift form their original life to taking on the responsibility of informal caregiver. Therefore, they sometimes feel **unprepared and overwhelmed** by the life changing event. Without formal training and competence, the role of the caregiver is unclear and confusing.

More often, the next of kin who stay closely by the patient feel they have **put their own personal life on hold**. The next kin sometimes become **isolated and excluded** from social activities, hence, developing depression.

Standing aside the patient and watching the beloved one suffer from the disease can be traumatizing. The family could **easily gets affected** by the symptoms of the patient with **fears** of losing the one making them feel alone.

However, in the study, Milberg and Strang (2011) shows that the family gained **the sense of secure** through the knowledge about the diagnosis, disease progression, care strategies and taking care of themselves from healthcare providers.

While a clear pathway to create such design to help the patient and family is obscure, these research has shown great value and importance of patent-family-centered designs in palliative care for cancer patient.

2. Attitudes towards the disease

Through thematic interviews with the next of kin of patients diagnosed with cancer for more than half years, Thorsnes et al. (2014) concluded two themes that shows how the next of kin view and think of the cancer.

a. The devoting care

The next of kin of patients are engaged in improving **the living quality of their loved ones**. Along the way, they face numerous unforeseen challenges and uncertainties.

Yet, family members willingly devote themselves to learning new knowledge and staying by the patient's side at all costs. Through this shared struggle, the emotional bond between the patient and their loved ones often grows even stronger.

> *" We had to fight to get the help we felt she needed. We met many health organisation hindrances. We had to search for information, and I felt a great responsibility. I should have done more for her. Often, I had a guilty conscience. I felt alone while fighting to get her the right treatment. We became closer because of this situation."*
>
> (Thorsnes et al. 2014)

In addition to caring for the patient, next of kin must also face the challenge of **taking care of themselves**. Many experience profound fatigue and emotional distress, often forcing themselves to stay composed for the sake of the patient. The combined weight of financial strain and psychological suffering can feel suffocating. Therefore, in this difficult journey, they should not be left to navigate it alone. Instead, they need to be meaningfully supported by nurses, general practitioners, and other healthcare professionals.

> *" It is a struggle to be close to someone who is suffering. I feel like I almost cannot breathe. You must be the strong one ... but I have to fight in order to keep standing on my feet. I was in a "bubble" and felt I almost could not breathe. For the first time in life, I felt that I would not be able to cope."*
>
> (Thorsnes et al. 2014)

Family members are also challenged with **managing their own emotions in their interactions** with others. They often become more emotionally sensitive than usual and may feel irritated by seemingly minor issues.

As a result, it can be difficult for them to regulate their emotions and maintain a sense of dignity and rationality. Yet despite these internal struggles, they are still expected to show understanding and respect toward others—adding another layer of emotional complexity to their experience.

> *"You have to use all your strength for the loved one, even though you are very frightened and tired. I had no help in learning how to communicate and to be a good helper. I felt frustrated. We had a good time occasionally, but I was not always at the top of my form and not always as kind as I should have been."*
>
> (Thorsnes et al. 2014)

b. A Journey From Disorientation To Acceptance

Peer support groups can provide family caregivers with emotional relief and a sense of solidarity, helping them to process negative emotions in a more open but exclusive environment. However, participation in such groups often raises concerns regarding engagement and accessibility. Many family members prefer to devote all their available time to being with and caring for the patient, and are therefore reluctant to join support groups that require time and emotional investment.

This highlights the importance of raising awareness that taking care of one's own emotional well-being is not a distraction from caregiving, but rather an essential part of being able to support the patient effectively. Helping caregivers recognize that participation in such programs can ease their emotional burden is key to improving their willingness to engage.

" ... If you are stressed, you cannot learn. The mood of the group was nice, and we had the courage to ask, open up, narrate, and discuss...I went from feeling alone in the situation to being in a group of people who understood each other... It was important for my adaption and coping process. I have been so afraid of talking about her sickness and my sorrow, and now I have learnt how important it is to have someone to talk to. I have learnt to be more open, and that has been beneficial for relations among family and friends."

(Thorsnes et al. 2014)

When family members first accompany patients into palliative care, many lack the ability to effectively manage their own emotions or cope with unexpected situations.

As a result, they often seek external support to navigate this unfamiliar and emotionally challenging phase. Through this process, they begin to develop personal coping mechanisms and gradually equip themselves with tools to manage their own well-being more effectively.

" I had no personal life. I felt guilty if I thought of my hobbies. Through the course, I have learnt how important it is to take care of myself. I have also learnt how important it is to accept the situation and to share thoughts and feelings with others. I have learnt to sort out what thoughts, feelings, and worries are important for my ability to cope with daily life. We also learnt breathing exercises and relaxation techniques in order to cope with the stress and to accept myself within the situation: I'm doing the best I can, and that's good enough."

(Thorsnes et al. 2014)

In Conclusion,

The experiences and attitudes of the next of kin reflect the immense levels of stress and emotional pressure placed on their shoulders. Many report feelings of self-doubt and a perceived lack of self-worth, often believing they are not doing enough for the patient. These feelings are further intensified by the need for coping strategies and medical knowledge, which amplify their emotional responses to caregiving and the anticipation of loss.

Family caregivers that have gone through these symptoms, are particularly vulnerable as "invisible second patients" who experience chronic stress and social isolation (Sanders, 2016; Kovaleva et al., 2018).

As Lazarus and Folkman (1984) suggest, while people may adopt different coping strategies to deal with stress and depression, the process is inherently personal. There is no universal solution to managing emotional strain; individuals must make their own choices about what helps them feel better.

Given this, the design focus should be on raising **awareness of their own fundamental needs and restoring a sense of autonomy**, encouraging next of kin to also care for themselves while caring for others.

3. Coping strategy

Utilizing metasynthesis, Lien and Rohde (2022) proposed two directions for coping the need and emotions of the next of kin: creating a supporting system within the next of kin, restoring agency and embracing acceptance.

a. A Supporting System Within The Next Of Kin

A resilient and optimistic personality can have a positive emotional impact on others, including the patient.

Having a supportive system in place can ease the transition from being a family member to becoming a caregiver. Dialogues within support groups and with others in similar situations can be extremely valuable, not only by broadening caregivers' understanding of the illness and what to expect in the future, but also by strengthening emotional bonds among close family members.

> *"Just support from family and friends, that was important to me, and just knowing that I could call on them ..."*
>
> *"From time to time, I need to be able to talk to someone. Because when I lay down in the evening, then it starts to work in the inside."*
>
> (Thorsnes et al. 2014)

However, the feasibility of support group participation remains limited. On one hand, such groups are often perceived as emotionally demanding, as listening to other families' stories can be distressing. On the other hand, some caregivers see spending time with anyone other than their closest loved ones as a poor use of the limited time they have left together.

> *" You see a positive evolution, and everything that goes better is good for her. (...) Nobody can forbid us to have hope. And miracles happen. Whether we believe it or not, that's not the point, it is the only thing to focus on."*
>
> (Thorsnes et al. 2014)

b. Restoring Agency

During the palliative care process, family members often find themselves passively receiving information and seeking solutions reactively. If this passive search can be transformed into a more proactive approach—by equipping them with timely, transparent information based on the stage of the disease—they may be better prepared to respond constructively to challenges.

> *"So it's a, it's a roller coaster of emotion but for the most part I've been, 'What do we need to do? Where do we need to be?' And then just read, read, read whatever I can find out, whatever information because I feel like whatever I know, I can ask for."*
>
> (Thorsnes et al. 2014)

Empowering them with knowledge not only fosters emotional resilience but also enables them to take a more active role in caregiving with greater confidence and strength.

> *"People ask you how you cope. But what if you were to give up? You've got to cope—and we do have each other! (...)."*
>
> (Thorsnes et al. 2014)

c. Embracing acceptance

There is a transitional phase that the next of kin often go through as they begin to understand and accept the reality of palliative care. In early stages, many may experience resistance to the situation, holding on to hope that things could return to how they were. It's a way of mentally escaping the harshness of the present, as if imagining life in an alternate timeline where the illness doesn't exist. The response is a natural part of the process, but still require effort and courage to embrace it.

> "I've sort of stowed it all away, I suppose. It is as if I'd experienced it from the outside or seen it on TV. It's often that way with sorrowful things."
>
> (Thorsnes et al. 2014)

And sometimes, this is not easy because they would not allow themselves to be happy and obtain joy as they think this is not appropriate.

> "I had no personal life. I felt guilty if I thought of my hobbies. "
>
> (Thorsnes et al. 2014)

However, creating a safe and supportive environment can help the next of kin moving from resistance and isolation to openness and emotional acceptance. This is an important step in coping and building resilience.

> "At first, I was afraid to talk about the illness and my sorrow... ...But being in a safe space with others who understood helped me open up and accept the situation... ...It made a big difference in how I cope and connect with others."
>
> (Thorsnes et al. 2014)

In conclusion,

One of the most effective ways to help family caregivers cope with their emotional challenges is to support their sense of agency. By encouraging them to reflect on the root causes of their stress and equipping them with clear, accessible medical information, caregivers can be empowered to navigate the palliative care process more confidently.

Reducing unnecessary learning barriers and presenting knowledge in a user-friendly, understandable format is essential. At the same time, it is important to help caregivers recognize that their own physical and emotional well-being plays a vital role in the care process. They not only deserve care themselves—but must also be encouraged to prioritize their own needs.

To provide an overview of the circumstances faced by the target users and to highlight the broader challenges in their environment, a stakeholder map is used to illustrate the relationships surrounding the next of kin. It also helps identify how various stakeholders can be involved in offering support and contributing to their well-being (Figure 10).

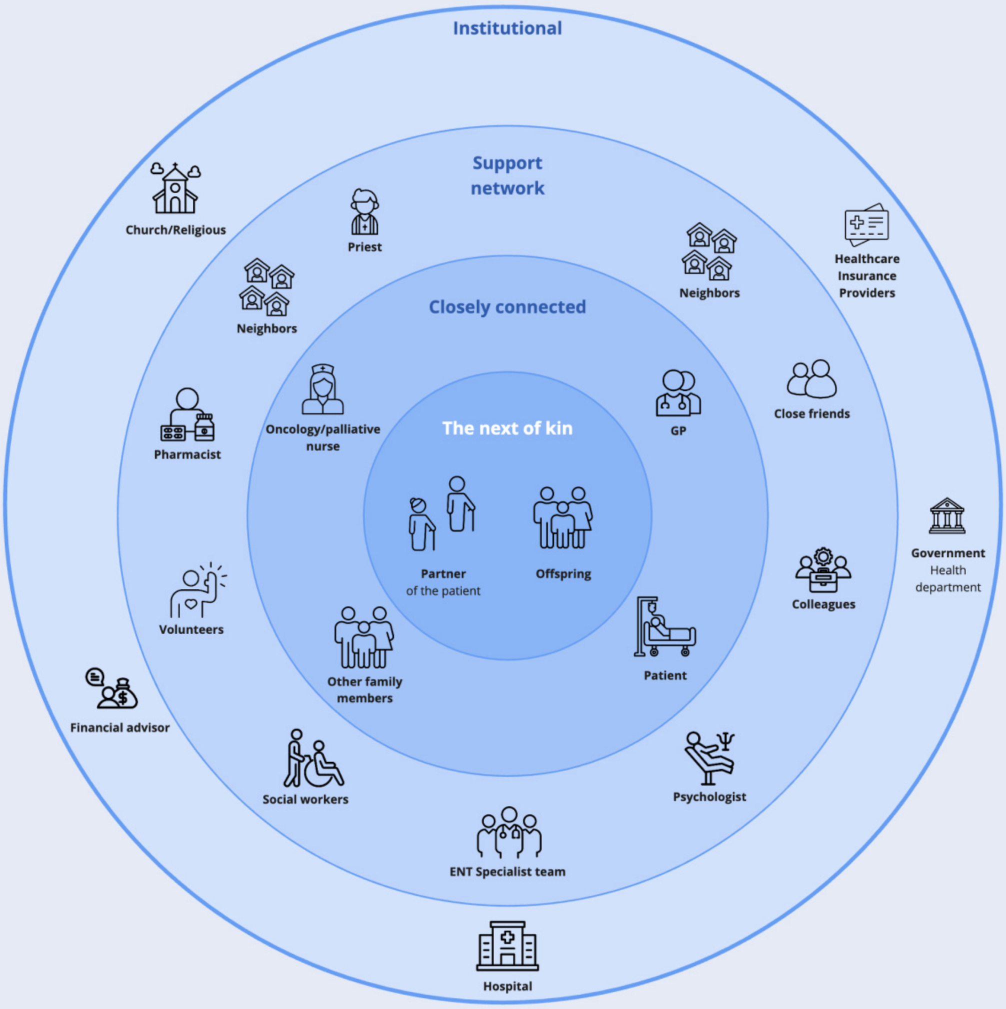


Figure 10. Stakeholder map for the next of kin during palliative care

2.4 Implication and future palliative care

In addition to understanding the situation faced by the next of kin, it is essential to examine existing applications and support solutions currently available to them. This allows us to identify the limitations and pain points within current services and explore opportunities for improvement and innovation.

RQ3: What support do the families need and how can we improve the service?

This section begins by exploring existing applications and tools currently available on the market, including the platform used by EMC. The goal is to understand how these tools provide support to family members of palliative care patients. The analysis will examine the strengths and limitations of each solution, assess the specific needs they aim to address, and evaluate how effectively these needs are being met.

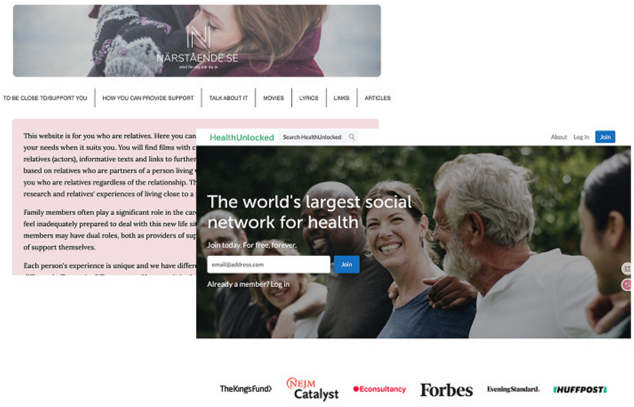
2.4.1 Current and emerging practices

a. Online platforms & communities (Figure 11)

Online communities offer a digital space where individuals can connect with others facing similar experiences.

Platforms like HealthUnlocked and Inspire enable users—both patients and their loved ones—to share stories, ask questions, and find comfort in shared community.

While they may lack professional guidance or structured support, peer group also creates an open-minded and related environment, fostering empathy, relatability, and belonging. They are particularly valuable during emotionally intense phases like diagnosis, treatment, or bereavement.



This website is for you who are relatives. Here you can
your needs when it suits you. You will find films with c
relatives (actors), informative texts and links to further
based on relatives who are partners of a person living
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research and relatives' experiences of living close to a

Family members often play a significant role in the car
feel inadequately prepared to deal with this new life si
members may have dual roles, both as providers of sup
of support themselves.

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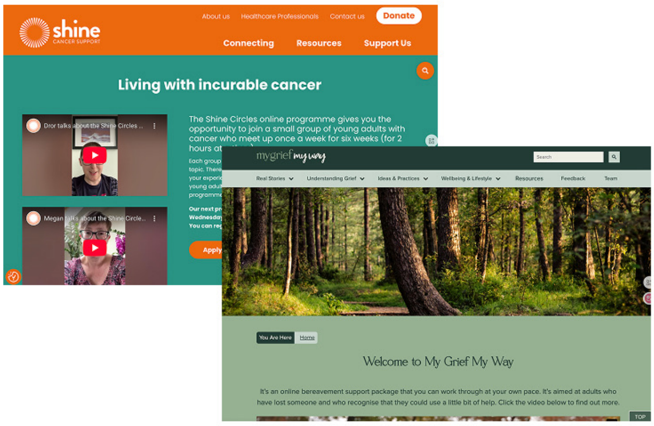


Living with incurable cancer

The Shine Circles online programme gives you the opportunity to join a small group of young adults with cancer who meet up once a week for six weeks (for 2 hours at

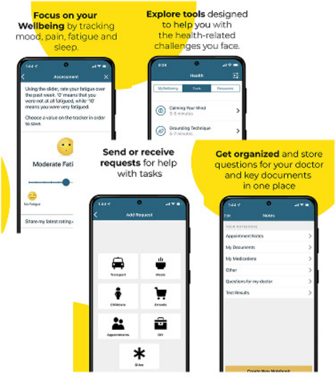
Welcome to My Grief My Way

It's an online bereavement support package that you can work through at your own pace. It's aimed at adults who have lost someone and who recognise that they could use a little bit of help. Click the video below to find out more.

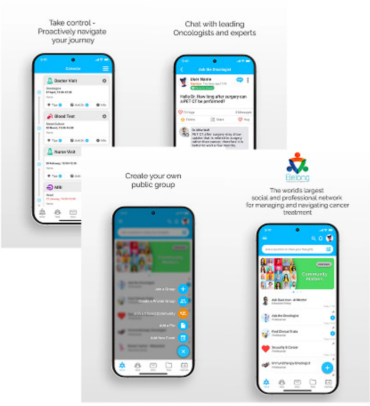
Shine Cancer Support & my grief my way

Figure 11. Website Application for Palliative care family & patient

ACS Care



Living With App



Belong Cancer App

Figure 12. Mobile Application for Palliative care family & patient

2. Mobile applications (Figure 12)

Mobile apps provide structured, accessible tools for managing the complex journey of cancer—from symptom tracking and emotional monitoring to logistical planning and content navigation.

Apps like LivingWith and ACS CARES empower users to regain a sense of control and autonomy, offering reminders, personalized content, and integrated tools to help manage daily challenges.

For caregivers and family members, these apps also provide clarity and coordination. However, while rich in functionality, they may feel impersonal or overly task-oriented, lacking the emotional depth.

To understand the emergence of applications designed for cancer patients and their next of kin, it is essential to first examine their underlying purposes and the human needs they aim to fulfill. This analysis explores the extent to which these digital platforms address emotional, practical, and social needs throughout the cancer journey. To guide this evaluation, the research applies **the framework of the 13 fundamental human needs (Figure 13) for human-centered design** (Desmet & Fokkinga, 2020). As illustrated in Figure #, the analysis reveals which needs are effectively supported across different application types, as well as which needs remain underrepresented or unmet.

Competence

Having control over your environment and being able to exercise your skills to master challenges

Autonomy

Being the cause of your actions and feeling that you can do things your own way

Purpose

Having a clear sense of what makes your life meaningful and valuable

Community

Being part of and accepted by a social group or entity that is important to you

Relatedness

Having warm, mutual, trusting relationships with people who you care about

Impact

Seeing that your actions or ideas have an impact on the world and contribute to something

Beauty

Feeling that the world is a place of elegance, coherence and harmony

Security

Feeling that your conditions and environment keep you safe from harm and threats

Comfort

Having an easy, simple, relaxing life

Stimulation

Being mentally and physically stimulated by novel, varied, and relevant impulses and stimuli

Fitness

Having and using a body that is strong, healthy, and full of energy

Morality

Feeling that the world is a moral place and being able to act in line with your personal values

Recognition

Getting appreciation for what do and respect for who you are

Fundamental Needs

Figure 13. 13 Fundamental needs by Desmet & Fokkinga, 2020

Building on Maslow's hierarchy of needs (Maslow, 1943) and Sheldon et al.'s basic psychological needs (Sheldon et al., 2001), Desmet and Fokkinga (2020) propose a comprehensive set of 13 fundamental human needs that collectively represent the full spectrum through which design can support well-being.

In the context of palliative care, these fundamental needs may not directly determine momentary happiness. However, they can serve as a lens for evaluating and improving existing products and services in a way that integrates humanistic values and promotes the well-being of the next of kin of seriously ill patients.

To conduct this analysis, I used three key **criteria** to determine the whether a feature aligns with and supports a specific fundamental need:

1. **Affordance** – What actions or possibilities does the application or service enable for the next of kin? (Massaro & Norman, 1990)
2. **Psychological Empowerment** – How does the application contribute to the sense of control, autonomy, or capability of the next of kin?
3. **Behavioral Engagement** – What actions or behaviors are encouraged, supported, or facilitated by the application?

To explore these questions, the researcher systematically reviewed selected applications and interpreted the intended affordances by analyzing the features and interaction modalities they present.

Additionally, an evaluative framework was introduced to quantify affordance levels, enabling comparison across applications and highlighting potential gaps in addressing fundamental needs. This scoring method was inspired by the Function-Task Design Matrix proposed by Galvão and Sato (2005), which assesses the degree of affordance offered by a product or service.

Each application was evaluated across all 13 fundamental needs, using a **three-dimensional interaction model:**

- **Perceptual Interaction** – Information delivery or awareness-raising
- **Physical Interaction** – In-person or tangible forms of help and assistance
- **Cognitive Interaction** – Educational content or reflective engagement that empowers the user cognitively

These interaction types formed the basis of a composite evaluation matrix (Table 3), mapping how each product fulfills the needs of the next of kin, and revealing areas for improvement or under-addressed needs in the current care ecosystem.

Degree of fulfillment: 1, 2, 3, 4

		Competence	Autonomy	Purpose	Community	Relatedness
Online Communities	Health unlocked	2	4	2	4	4
	My grief My way	2	4	4	2	2
	CancerCare	2	2	2	4	4
	Narstaende.se	1	2	1	2	2
Mobile apps	ACS Cares	2	4	2	2	2
	Living With	2	4	2	2	4
	Belong Cancer	2	4	2	4	4
Specialized Service	NCI Caregiver	2	2	2	1	1
	Wonder & Worries	2	1	2	2	4
	Dave (AI chatbot)	4	2	2	1	1
Creative/meditation tools	Breamy (AR)	2	2	1	1	1
	Create to heal(Meditation)	1	4	2	1	1

Table 3. Fundamental needs fulfillment by selected application & category

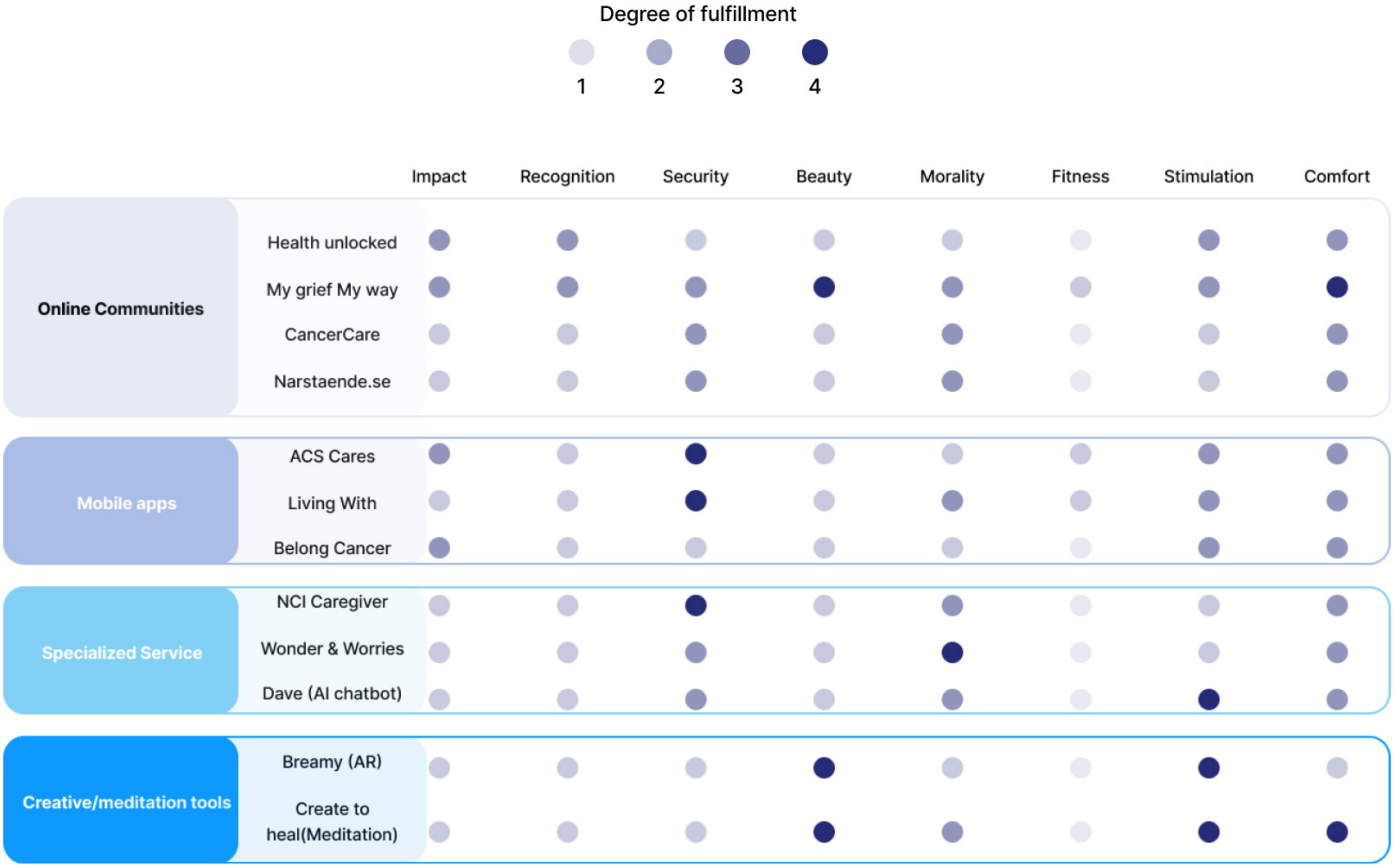
From the evaluation, almost every app scores 2–3 on autonomy and competence, reflecting the broad emphasis on self-directed learning, task control, and skill-building for the next of kin.

Mobile apps and specialized services, such as NCI Support, Wonders & Worries, consistently score 2–3 on Security and Comfort, showing that anticipation of the future condition and situation and emotional ease are core to healthcare design.

Across every category, recognition rarely exceeds 1–2. These mean that few platforms actively celebrate users' progress or acknowledge their efforts. Instructions on physical treatment and training are also limited.

Online platforms are particularly strong in fostering a sense of belonging and interpersonal connection. However, they depend heavily on users' own information-seeking skills, presenting content in a largely passive format. As a result, they score very highly on Community yet tend to fall short in delivering Impact and Stimulation.

Mobile Apps (ACS CARES, LivingWith, Belong Cancer) are highly effective at building users' competence and ensuring their sense of security. However, they tend to focus on practical features and give comparatively little attention to aesthetic qualities (Beauty) and ethical engagement (Morality).



Degree of fulfillment: 1 2 3 4

		Impact	Recognition	Security	Beauty	Morality	Fitness	Stimulation	Comfort
Online Communities	Health unlocked	3	3	2	2	2	1	3	3
	My grief My way	3	3	3	4	3	2	3	4
	CancerCare	2	2	3	2	3	1	2	3
	Narstaende.se	2	2	3	2	3	1	2	3
Mobile apps	ACS Cares	3	2	4	2	2	2	3	3
	Living With	2	2	4	2	3	2	3	3
	Belong Cancer	3	2	2	2	2	1	3	3
Specialized Service	NCI Caregiver	2	2	4	2	3	1	2	3
	Wonder & Worries	2	2	3	2	4	1	2	3
	Dave (AI chatbot)	2	2	3	2	3	1	4	3
Creative/meditation tools	Breamy (AR)	2	2	2	4	2	1	4	2
	Create to heal(Meditation)	2	2	2	4	3	1	4	4

Table 3. Fundamental needs fulfillment by selected application & category

In conclusion,

The evaluation shows that while existing applications partially support the fundamental needs of the next of kin, they often emphasize **perceptual interaction** (e.g., information delivery and symptom tracking) over cognitive and physical interaction.

Three needs—Impact, Recognition, and Fitness—were found to be the least addressed. While Fitness can be supported through other general wellness tools, Impact and Recognition are more emotionally complex and often overlooked in high-stress caregiving situations.

This gap highlights the opportunity for designs that affirm the caregiver's role, reminding them that their efforts matter and deserve recognition. Supporting these emotional needs can promote a clearer sense of purpose and well-being.

Therefore, future designs should include comforting and encouraging elements that help caregivers practice self-appreciation and self-care, enabling them to better care for their loved ones.

2.2.2 Research gap

Head and neck cancer (HNC), particularly head and neck squamous cell carcinoma (HNSCC), is associated with relatively poor long-term survival rates. Global five-year overall survival varies widely depending on tumor stage and location, ranging from approximately 35% to 70%, with an average of 50–60% in most populations (Heinolainen et al., 2025).

Once curative treatment is no longer viable, or is declined due to treatment-related suffering, patients transition to palliative care, where median survival often decreases to approximately five months, though variability can extend from several days to multiple years (Hoesseini et al., 2024).

Despite the substantial emotional and practical challenges faced by caregivers, limited research has specifically examined the palliative care experiences of family members of HNC patients.

A notable misconception among both patients and caregivers is the belief that curative treatment and palliative care are mutually exclusive, despite evidence and clinical guidelines supporting their concurrent use in many cases.

Care transitions into palliative care often occur rapidly, leaving families with little time to prepare emotionally or logistically. This abrupt shift, coupled with a lack of targeted caregiver education, often results in confusion, fragmented information access, and an increased emotional burden. At present, much of the information available is scattered, requiring caregivers to actively seek out resources on their own which can be overwhelming and inefficient during a highly stressful period.

There is a clear need for further investigation into the emotional pathway and support needed of caregivers of HNC patients during the palliative care phase. Mapping these needs across different stages of palliative care could inform the development of targeted interventions that improve both caregiver well-being and patient outcomes. Such research is critical to addressing the current gap in patient-family-focused palliative care strategies and to creating practical solutions.

Reflection

From the literature review, contextual information about palliative care and the lives of next of kin was obtained, but it lacked validation and direct contact with the target users. Due to the sensitivity of the project, addressing this limitation proved challenging without formal ethical approval.

Through this experience and interaction with the client, I learned that in certain cases, it is necessary to acknowledge and embrace such constraints, and to identify alternative ways of progressing with research and design. I also realised that design and prototyping do not necessarily have to follow research in a linear sequence; instead, they can be developed in parallel as tools for exploration.

Prototypes can serve as conversation starters, enabling participants to articulate needs, expectations, and concerns that might otherwise remain unexpressed. For example, presenting a prototype and asking why it might not work for a specific user group can reveal valuable insights into user expectations, perceived benefits, and unaddressed needs.

This experience broadened my understanding of design thinking by challenging the fixed sequence of traditional design processes. Moving forward, the next step will be to design specific tools that facilitate open conversations with nurses, and to create user personas and care pathways based on the insights gathered.

CONTEXT MAPPING

In this chapter, I aim to understand the current situation of palliative care patient and their family member during the transition and when the actual care phase starts. Because of the sensitivity of the research, at this early stage, it is challenging to involve actual patient in this research. Therefore, paramedical staff from Erasmus MC participated in the interviews and shared insights and knowledge about the palliative process to concrete the journey map.

Structure of research

3.1 Studying the context： What is offered to patient and the next of kin during palliative care ?

This chapter aims to build a deeper understanding of the care experience from both the patient's and the next of kin's perspectives during the palliative care journey in EMC. The core of the study is based on interviews conducted with a paramedical staff member from head and neck department of Erasmus Medical Center, whose direct involvement in palliative care provided valuable professional insights.

3.1.1 Interview Setup

The interview was conducted within the hospital environment to ensure contextual relevance and alignment with existing care protocols. The research questions were carefully crafted to explore how palliative care is currently practiced, how family members are involved and supported, and what challenges healthcare professionals encounter in this process. A particular emphasis was placed on understanding the emotional and psychological dimensions of care, not only for the patients, but also for their next of kin.

To support a more human-centered conversation, a visual brochure illustrating the 13 fundamental human needs (Desmet & Fokkinga, 2020) was used during the interview. This served as a reflective prompt to explore whether, and to what extent, current care practices acknowledge and address the emotional needs of the next of kin within routine procedures.

The aim of the interview was to map the experiences of both patients and their families from the perspective of a care provider, and to uncover the practical and emotional challenges faced by the next of kin throughout the palliative care journey. The discussion was structured around seven key themes:

1. the transition and mindset shift during the palliative phase;
2. the type and emotional tone of care provided during follow-up calls;
3. the role, involvement, and emotional state of family caregivers;
4. the training and informational support available to them;
5. communication and collaboration between medical staff, patients, and families;
6. reflections and recommendations from the nurse's experience; and
7. the current implementation of remote monitoring systems, including questionnaires and check-in calls.

The collected qualitative data was analyzed using thematic coding (Milena & Dainora, 2008). This method helped identify recurring patterns and reveal opportunities for potential design interventions.

Figure 14. Thematic coding of current palliative practice in EMC

3.1.2 Thematic coding

Thematic coding was used to identify and organize the main themes emerging from the interview with the nurse, following the approach described by Milena & Dainora (2008). This method enabled the categorization of textual data and the development of a structured conceptual framework, as outlined by Gibbs (2007). Figure 14 presents the results of thematic coding, highlighting key aspects of the current protocols and challenges in palliative care for head and neck cancer (HNC) patients at Erasmus Medical Center (EMC).

During the thematic analysis (Figure 14), several key themes emerged from the interview data. One notable finding was the that throughout the palliative journey. 6-8 weeks of “gap period” was recognised, during which both the patient and the next of kin might feel difficult to express their mental struggles. In contrast, the routine check-in calls from nurses highlighted how meaningful it is to feel seen and supported. As one quote noted, both patients and family members appreciated “simply being asked how they were doing.”

When the family are first confronted with the news, they might be unlikely to be equipped with sufficient knowledge of taking care of the patient. During home care, they would also like to have more proactive care and contact. This is addressed to what would happen if the family and patient are being treated in the hospital, where they could have more chance to ask about their situation and learn from the professionals.

Several challenges mentioned above contribute to the gradual and longer phase for the family to accept the palliative situation, and many family members struggle to adapt to the circumstance while learning the skills needed to support both the patient and themselves.

Despite these difficulties, families still manage to spare out small moments for their own needs. These moments present valuable opportunities for healthcare professionals or design interventions to offer support, whether by providing practical caregiving knowledge or by helping to ease emotional strain and create space for the family to care for their own well-being.

This initial thematic analysis represents the first step in interpreting insights gathered from the coding process. The emerging themes offer a preliminary understanding of the full experience of patients and their families as they navigate palliative care.

3.1.3 Insights interpretation

Additional insights emerged from the interview and were translated into design inspirations. Quotations are mentioned as “”, while other insights are based on the interpretation of the interview. These findings help further define the overall design direction and inform specific features or qualities that the final design should embody.

1. **Limited contacts:** After entering palliative care, head and neck cancer (HNC) patients have a median survival of approximately 5.1 months (Dorr et al., 2022). According to the staff interview, check-in calls are scheduled only every 6–8 weeks. The communication underscores a critical gap in emotional connection and continuity of care, particularly in addressing the needs for relatedness and recognition.

INSPIRATION

*Create a self-initiated but gentle touchpoint system to offer **frequent emotional check-ins or moments** of care in between nurse calls.*

↓

DESIGN

*should aim to **extend the sense of being cared for**, even without professional involvement—e.g., daily reflection tools, inspirational cards, or subtle emotional prompts.*

2. **Awareness and reflection:** Although nurses do inquire about patients’ mental well-being during these calls, asking question like “how are you doing recently?”, it might be still difficult for patient and family to come up with specific problems. This could be the case that the timing of the phone call may not be ideal and they may not have enough time to reflect before respond, therefore, neglecting their mental health struggles.

INSPIRATION

*Design for guided emotional exploration, using conversational tools, metaphors, or soft prompts that help users **reflect in a more personal and approachable way**.*

↓

DESIGN

*A tool that offers thematic cards, daily guided journaling, or metaphor-based storytelling could **invite meaningful emotional expression.***

3. **Gap period in active monitoring and proactive care:** During the interim 6–8 week period between calls, support from healthcare professionals depends on the patient or family initiating contact when issues arise. Even though the all kinds of support is provided by EMC, family members might be less mindful about their own mental well-being while more focus is on the patient’s physical conditions, therefore, less likely to ask for help.

INSPIRATION

*Develop **low-barrier, proactive** tools that provide the feeling of ongoing support without requiring high levels of user activation or nurse time.*

↓

DESIGN

*The design should be **encouraging reminders**, tips, or **light self-check** prompts could fill in the gaps.*

4. **Dual Burden of the Next of Kin:** Family caregivers, often the partner or adult children of the patient, are in constant contact with both the patient and healthcare staff. This positions them as critical intermediaries, responsible not only for interpreting and communicating medical updates but also for managing their own emotional well-being. The primary caregiver is typically the partner according to the interview, who is often elderly themselves, adding layers of physical and emotional vulnerability.

INSPIRATION
Design tools that recognize and validate their invisible labor—offering both ***functional support*** *(reminders, tips, resources) and* ***emotional validation*** *(affirmations, reflection prompts).*

↓

DESIGN
could include caregiver-specific reflection tools, simple logging of emotional/physical states, or ***ways to feel acknowledged****.*

5. **Emotional dependency on patient's condition:** The emotional state of the next of kin is closely tied to the fluctuations in the patient's health. They often experience an emotional roller coaster, with their mental well-being rising and falling in response to the patient's symptoms and prognosis. This dependency increases their stress and complicates their ability to engage in self-care.

INSPIRATION
Create tools that help ***stabilize their internal emotional rhythm.***

↓

DESIGN
include a physical or digital breathing aid, ***calming rituals, or a daily anchor moment*** *like lighting a candle or drawing a card.*

6. **Delayed Acceptance and Grief Processing:** Compared to patients, family members often take longer to accept the reality of the situation. They may hold on to hope or struggle with denial, especially early in the palliative phase. Their grief often begins before death occurs, but they may not be emotionally equipped or supported to process it.

INSPIRATION
Offer tools that ***gently introduce acceptance*** *over time, allowing the family to process grief in micro-moments and feel emotionally accompanied.*

↓

DESIGN
a progressive card set with ***emotional cues or stories of others*** *who have gone through similar experiences.*

7. **Fear of uncertainty:** The next of kin frequently express anxiety regarding progression of the illness. This uncertainty is often shared by HCPs, who themselves may be unable to offer definitive answers or timelines. This creates a space of shared ambiguity that amplifies emotional distress and underscores the need for guidance and reassurance.

INSPIRATION
Design tools that ***acknowledge uncertainty*** *while* ***reinforcing a sense of control*** *in the present moment.*

↓

DESIGN
Mindfulness prompts, small achievable actions, or tools that help users ***make peace with uncertainty****.*

In conclusion,

The seven identified themes shed light on the emotional, informational, and relational challenges faced by the next of kin during the palliative care journey. From the limited structured contact, the burden of dual roles and the fear of uncertainty, these insights highlight significant unmet needs.

Translating these findings into design directions has led to the identification of several key qualities the final intervention should embody: **continuity of care**, **emotional validation**, **gentle guidance**, and **support for self-reflection and acceptance**.

By addressing these areas, the design aims not only to provide proactive intervention during the gap period, but also to empower family members **restore their autonomy in life while taking good care of the patient**. These insights will serve as a foundation for developing a sensitive, human-centered design that offers both comfort and clarity in one of life's most vulnerable phases.

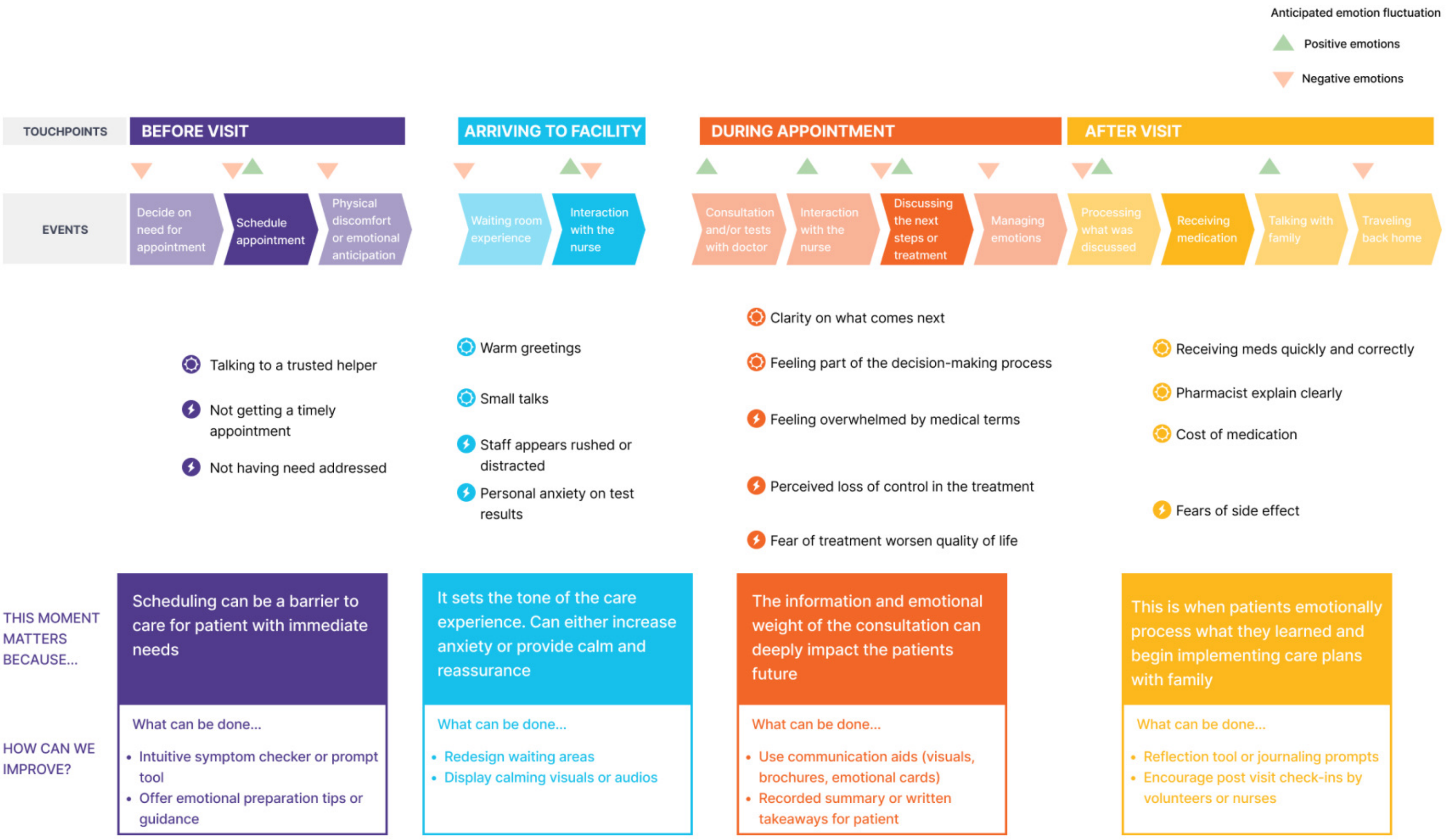


Figure 15. Palliative care journey map for HNC patient (See in Appendix)

3.2 Journey Mapping

3.2.1 The journey map of the patient

The patient journey map (Figure 15) was constructed to outline the emotional and practical experience of patients with head and neck cancer undergoing palliative care. This visual analyze the patient journey of each phase of the care process, starting from scheduling an appointment to the final stage of life.The map breaks down each of the seven major phases into smaller touch points.

The touch points outlined here do not represent fixed or universally experienced interactions; patients may encounter different experiences and emotions depending on individual circumstances. Nevertheless, anticipating potential experiences and identifying possible pain points can provide valuable insights into phases where patients may feel uncertain or require additional support. This analysis also offers design indications by highlighting phases where interventions could be most impactful. Each touchpoint is therefore accompanied by a discussion of why the moment matters and suggestions for how the patient experience might be improved.

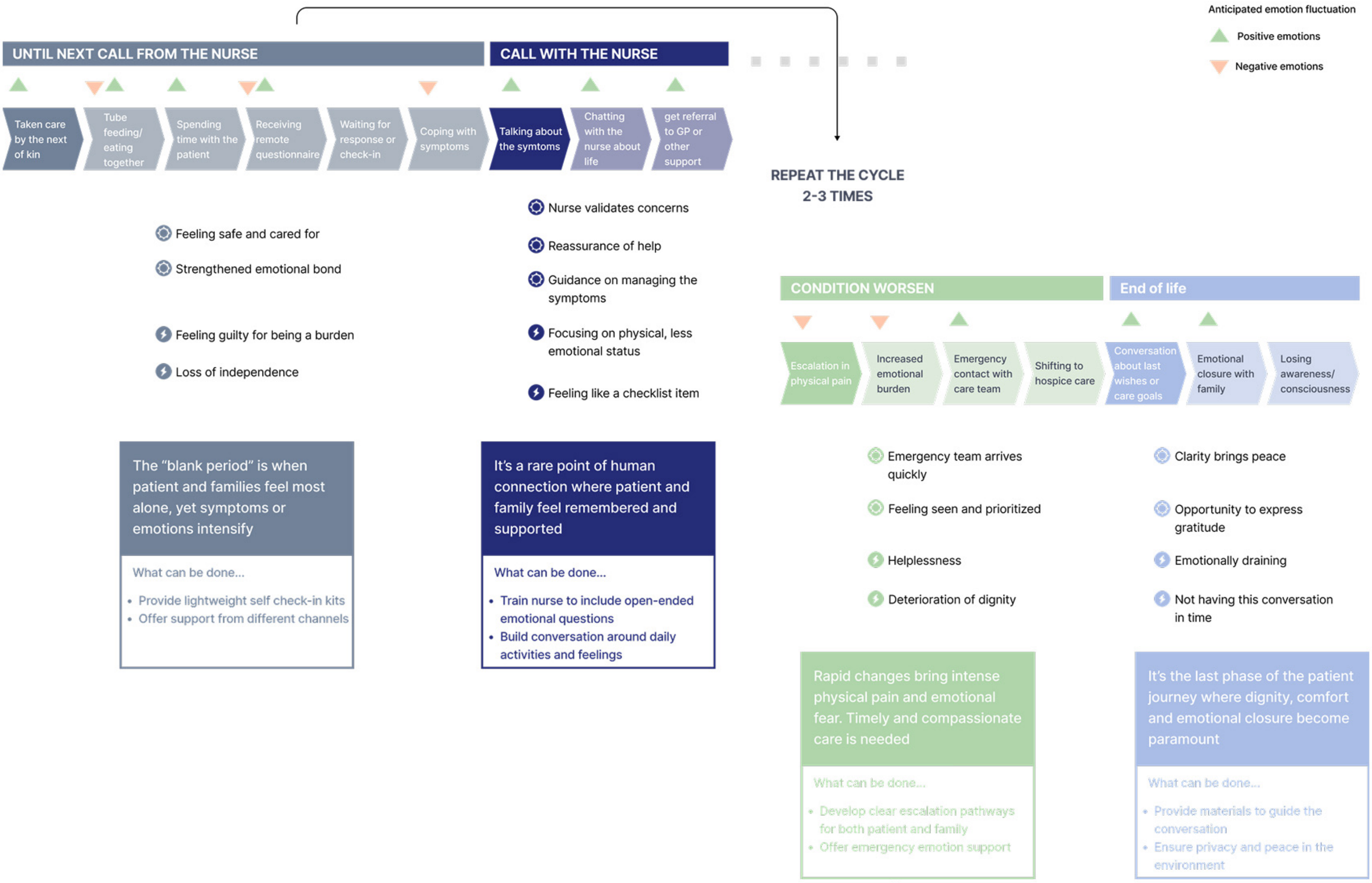


Figure 15. Palliative care journey map for HNC patient (See in Appendix)

The development of this journey map is extracted from the literature review and interview insights. Academic studies provided fundamental understanding of patient experiences in palliative care, while in-depth conversation with the paramedical staff at Erasmus MC offered real-life insights into how patients experience care transitions, symptoms management, emotional support and end-of-life decisions.

More importantly, the patient journey map is inextricably linked to the journey map of the next of kin. Many of the patient's experience, such as symptom management, emotional distress, or feeling supported, are directly impacted by the presence and role or the family caregiver. In turn, how the patient experiences care often reflect the effort of healthcare professionals and family caregivers. Thus, mapping the patient journey is critical not only to understand the patient's experience, but also to define moments where the next of kin's role becomes central.

Through this mapping process, several key insights emerged:

- Emotional vulnerability and uncertainty are high, particularly in the early stage of palliative care.
- Emotional comfort often depends on how well informed the care is
- Communication gaps between formal check-ins might cause distress or leave both patient and family feeling unsupported.
- Bright moments, like nurse check-ins or spending time with family often results in better compassionate care, providing strength and faith for patient.

These findings highlight the importance of addressing the "gap period" — the time when patients and their families are largely left to manage on their own between clinical check-ins. While hospitals and nurses remain available for support if needed, this approach tends to be reactive rather than proactive. As a result, potential issues may go unnoticed or unaddressed until they escalate, underscoring the need for more anticipatory and continuous forms of support throughout the palliative care journey.

In conclusion,

the patient journey map provides valuable insights into the structure and emotional flow of palliative care from the patient's perspective. Since the experiences of the next of kin are deeply intertwined with those of the patient, analyzing the patient's touch points allows us to identify critical phases where family caregivers assume greater responsibility. In particular, the period of **home care between clinical appointments and nurse check-in calls** emerges as a phase where the next of kin are most actively involved and require additional support and attention.

3.2.2 The journey map of the next of kin

The journey map of the next of kin was developed (Figure 16) to explore the palliative care experience from the perspective of family caregivers—those who often take on the role of informal support systems for patients with life-limiting illnesses. While the patient remains the primary focus of clinical treatment, the experience of caregiving is deeply intertwined with that of the patient, and understanding this interconnection is essential to identifying moments where additional emotional or practical support may be most needed.

1. **Structure and touch points**

The journey map is structured around nine core phases that align with the trajectory of a typical palliative care process:

1. Before Visit
2. Arriving to the Facility
3. During the Appointment
4. After the Visit
5. Until the Next Call from the Nurse
6. Call with the Nurse
7. Condition Worsens
8. End of Life
9. Aftercare

Each of these phases includes touch points that could possibly encountered by the next of kin and their emotional engagements. For example:

- In the “Before Visit” phase, touch points include discussing symptoms with the patient, booking the appointment, and coordinating logistics (transportation, time off work), which often involve anticipated stress and a need for clarity or reassurance.
- In “During the Appointment,” the next of kin may listen to medical updates, ask questions, and participate in care planning. These moments are marked by vulnerability, uncertainty, and a strong need for understanding and recognition.
- During “Aftercare,” the caregiver is tasked with emotionally processing the loss and adjusting to a new reality—often without structured support, which may lead to prolonged emotional burden.

The journey map anticipates emotional variation across all these stages, recognizing that the emotional state of the next of kin is closely tied to that of the patient, yet often more complex due to dual roles as both caregiver and grieving family member. Emotions such as anxiety, helplessness, responsibility, guilt, and grief emerge repeatedly throughout the map, particularly when care shifts back into the home environment.

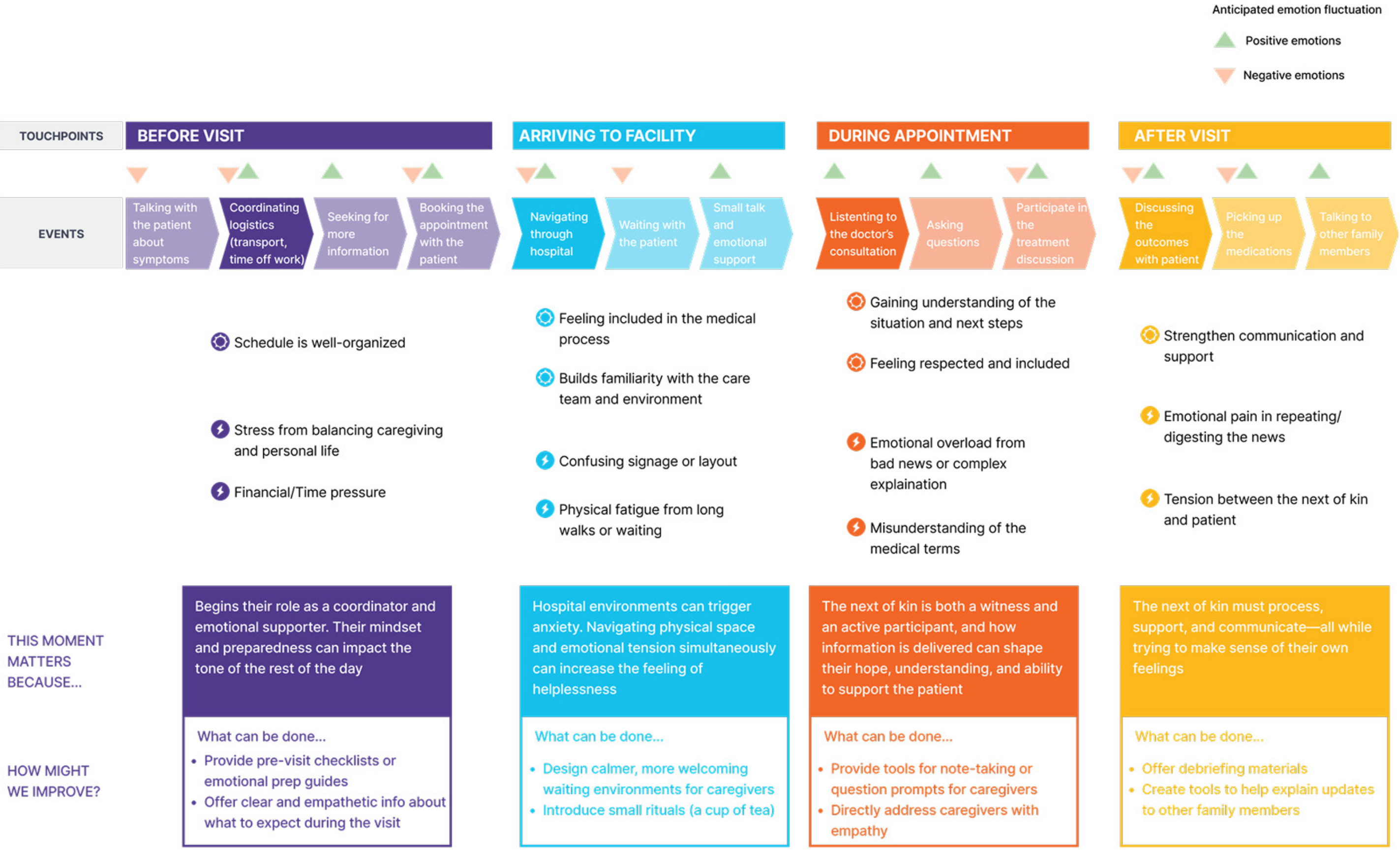
2. Why This Journey Was Mapped

Mapping out the journey helps identify where support from Erasmus MC could be strengthened for families of HNC patient, who are, or will soon be, provided with care at home. The map is structured to anticipate the emotional and practical transitions families may face across different phases of treatment and care. It also emphasis on care that can be provided by the hospital at home which could be overlooked or not directly addressed when mentioning typical scope of medical care.

3. Context during the “Gap period”

While the focus on the blank period is needed, more information is needed to understand how can help be present in what form and at what time during this period.

To understand the context here, the families mobility is largely restricted depending on the condition of the patient. Their attention is focused on taking care of the patient and satisfying their needs, leaving little space for their own activities or emotional processing. The suppression of the emotions could be the reason leading to further emotional break out after the patient passes away. To avoid or even mitigate this burnout, design interventions should be placed during this period, prompting the family members to take care of their own well-being as well.



BEFORE VISIT

Events: Talking with the patient about symptoms; Coordinating logistics (transport, time off work); Seeking for more information; Booking the appointment with the patient

- Schedule is well-organized
- Stress from balancing caregiving and personal life
- Financial/Time pressure

Begins their role as a coordinator and emotional supporter. Their mindset and preparedness can impact the tone of the rest of the day

What can be done...
- Provide pre-visit checklists or emotional prep guides
- Offer clear and empathetic info about what to expect during the visit

ARRIVING TO FACILITY

Events: Navigating through hospital; Waiting with the patient; Small talk and emotional support

- Feeling included in the medical process
- Builds familiarity with the care team and environment
- Confusing signage or layout
- Physical fatigue from long walks or waiting

Hospital environments can trigger anxiety. Navigating physical space and emotional tension simultaneously can increase the feeling of helplessness

What can be done...
- Design calmer, more welcoming waiting environments for caregivers
- Introduce small rituals (a cup of tea)

DURING APPOINTMENT

Events: Listenting to the doctor's consultation; Asking questions; Participate in the treatment discussion

- Gaining understanding of the situation and next steps
- Feeling respected and included
- Emotional overload from bad news or complex explaination
- Misunderstanding of the medical terms

The next of kin is both a witness and an active participant, and how information is delivered can shape their hope, understanding, and ability to support the patient

What can be done...
- Provide tools for note-taking or question prompts for caregivers
- Directly address caregivers with empathy

AFTER VISIT

Events: Discussing the outcomes with patient; Picking up the medications; Talking to other family members

- Strengthen communication and support
- Emotional pain in repeating/ digesting the news
- Tension between the next of kin and patient

The next of kin must process, support, and communicate—all while trying to make sense of their own feelings

What can be done...
- Offer debriefing materials
- Create tools to help explain updates to other family members

Figure 16. Palliative care journey map for the family of HNC patient (See in Appendix)

To be more specific on why this period is chosen for the further design exploration:

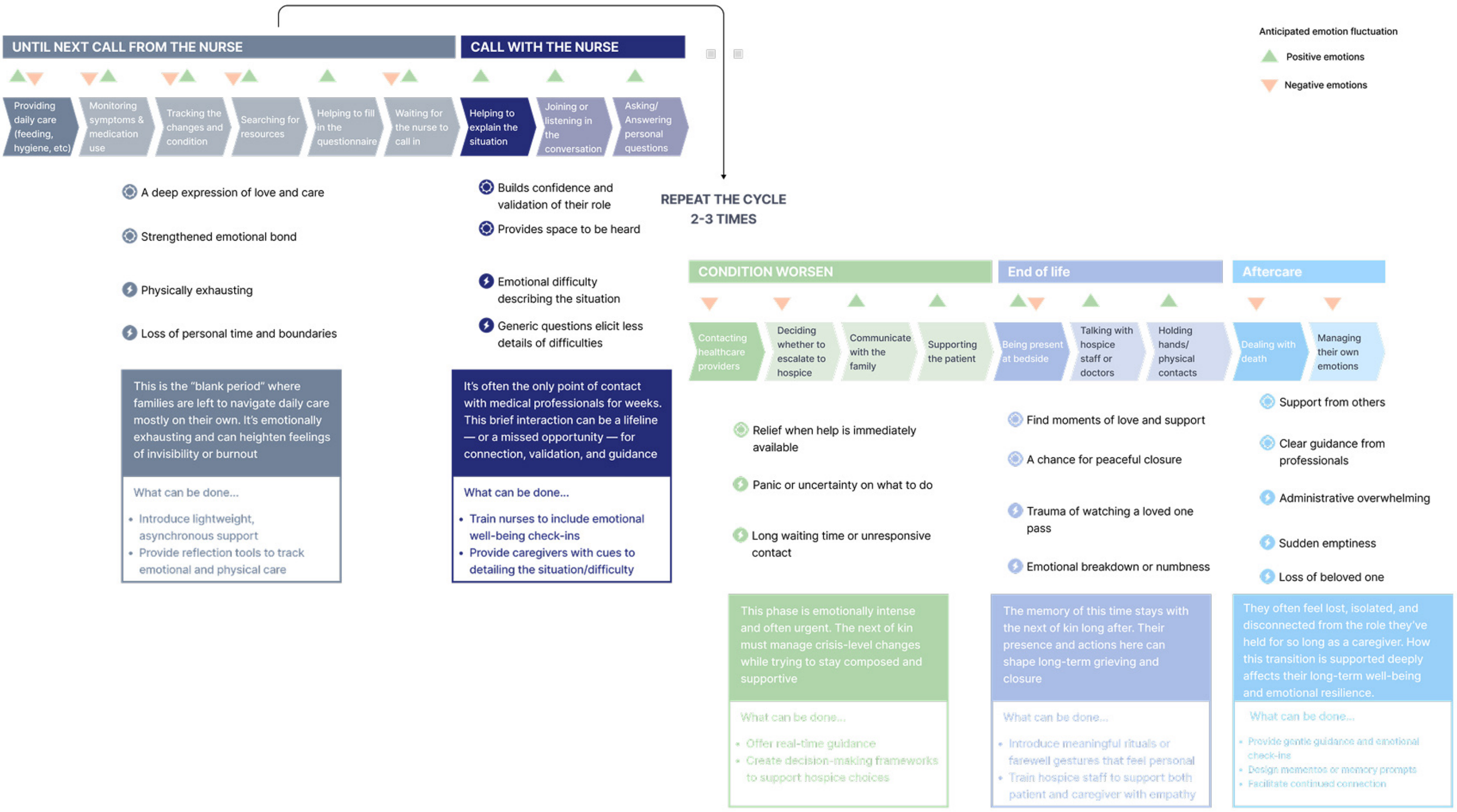
- There is formal emotional check-in with the caregiver during this time, but their well-being is largely self-managed.
- It is during this time that caregiver burnout and emotional overload are most likely to develop, exacerbated by isolation, uncertainty, and lack of time for self-care.
- The emotional state of the next of kin directly impacts the patient’s quality of life, making this phase crucial for both parties’ well-being.

4. Rationale for Design Focus

Based on the journey map and its emotional landscape, this “blank period” between clinical touch points has been selected as the focus for further research and design development. It represents a low-visibility, high-impact phase, in which the emotional burden on caregivers is both intense and could be addressed more by existing services.

A design intervention targeting this phase could:

- Proactively offer emotional and cognitive support to caregivers;
- Enhance the perceived continuity of care;
- Reinforce caregivers’ sense of recognition, capability, and emotional stability;
- Foster a more sustainable caregiving environment by helping next of kin meet their own fundamental needs alongside those of the patient.



This is the “blank period” where families are left to navigate daily care mostly on their own. It’s emotionally exhausting and can heighten feelings of invisibility or burnout

What can be done...

- Introduce lightweight, asynchronous support
- Provide reflection tools to track emotional and physical care

It’s often the only point of contact with medical professionals for weeks. This brief interaction can be a lifeline — or a missed opportunity — for connection, validation, and guidance

What can be done...

- Train nurses to include emotional well-being check-ins
- Provide caregivers with cues to detailing the situation/difficulty

This phase is emotionally intense and often urgent. The next of kin must manage crisis-level changes while trying to stay composed and supportive

What can be done...

- Offer real-time guidance
- Create decision-making frameworks to support hospice choices

The memory of this time stays with the next of kin long after. Their presence and actions here can shape long-term grieving and closure

What can be done...

- Introduce meaningful rituals or farewell gestures that feel personal
- Train hospice staff to support both patient and caregiver with empathy

They often feel lost, isolated, and disconnected from the role they’ve held for so long as a caregiver. How this transition is supported deeply affects their long-term well-being and emotional resilience.

What can be done...

- Provide gentle guidance and emotional check-ins
- Design mementos or memory prompts
- Facilitate continued connection

Figure 16. Palliative care journey map for the family of HNC patient (See in Appendix)

In conclusion,

the next of kin journey map serves as a foundation for user-centered design, helping to visualize and validate caregiver experiences while highlighting the phase where the family caregiver might be under great pressure and in the need of support.

The journey map show similar “gap period” for 6-8 weeks when they are presented with support from hospital, but seems to be unprepared and overwhelmed to spend enough time to reflect on their personal well-being and ask for help.

Moreover, this is also the period when most of the activities and interaction between the family and patient happen, representing the three themes of the family caregiver in palliative care.

Therefore, understand and explore the possible design intervention that support family caregiver during this period shows great potential of helping them rebalance their life and restore autonomy.

3.2.3 Persona of family caregivers

Now that a specific touchpoint has been identified for the design intervention, it is important to further define the user profile in order to better understand the target users, their interests, and their struggles. To this end, two personas were developed to represent the main types of potential family caregivers.

The personas are based on insights from a nurse, who noted that most patients are male and that their primary caregivers are usually their partners, often in the same age group (60–70 years old). In addition, adult children may also take on a caregiving role. Accordingly, two personas were articulated:

1. The elderly partner – in her 60s, someone who has lived with the patient for over 30 years and now carries the full responsibility of caregiving.

2. The adult daughter – in her 30s, balancing a professional career while still managing to provide daily care for her father.

These two characters were intentionally chosen from different age groups, as their mindsets, daily needs, and coping strategies may differ significantly. Such differences can greatly influence how each caregiver restores their own pace of life and maintains a sense of autonomy (see Figure #).

Elsa

Phase: Taking care of the patient everyday

Age: 67

Relationship: Partner of the patient

Living Situation: Living with the patient

Occupation: Retired to provide care

Description of Elsa:

Elsa is a 67-year-old retired woman who has spent the last two years caring for her husband, who is in the palliative phase of head and neck cancer.

Before her husband's illness, Elsa loved spending peaceful mornings in the garden with him, reading on the porch, and cooking slow meals together while listening to the radio. They used to take weekend walks in the nearby woods and enjoy visiting their grandchildren. Her husband's illness gradually took these shared moments away, and caregiving became her full-time role.

Quotes:

> *"When I got the news, I lost my purpose. Taking care of his life is now the only thing that keeps me going."*

Current State:

- Struggles with sadness, loneliness, and regret
- Misses the patient and the structure caregiving brought
- Feels forgotten—no follow-up from care team
- Knows therapy might help but has no energy to search

Sofia

Phase: Transitioning from curative care to palliative care

Age: 34

Relationship: Daughter of the patient (68, recently stopped curative treatments)

Living Situation: Lives 30 mins away, now visiting daily

Occupation: Full-time teacher (on leave)

Description of Elsa:

Ever since her father agreed on palliative care, Sofia has taken leave from work so she can be with him more — she now visits every day or every other day, even though she lives 30 minutes away.

She feels like everything in her life is on hold — she's stopped seeing friends, spending time alone, or doing things she enjoys. Most of her energy goes into being present for her father, which is both emotionally and financially draining.

She finds the word "palliative" really heavy — it made her feel like nothing more could be done, and it's hard not to see it as the beginning of the end. Even though she wants to be strong, she often feels stuck.

Quotes:

> *"When they said it was time for palliative care, it felt like the end had already started. I just want to be there for him — but I don't know how to be there for myself anymore."*

Current State:

- Struggles with daily care errands
- Loneliness and start to isolate herself from others
- Loss of sleep and anxiety evey time thinking of her dad

The two personas, an elderly partner and a younger daughter, highlight different yet overlapping needs in the caregiving experience. While their circumstances vary, but they both face emotional, physical, and psychological challenges that call for tailored while inclusive design solutions.

The elderly persona represents someone who has been providing care for an extended period. Over time, the emotional and physical demands of caregiving have gradually drained her energy. As part of a more vulnerable population, she requires extra support but often struggles to articulate what kind of help she needs or where to begin looking for it. Although she wants to stay strong for the patient, deep down, she is emotionally unprepared to confront the reality of the situation. Where there once was joy in shared daily activities, her life has now become constrained and solitary.

The younger daughter persona reflects the experience of working adults trying to balance professional responsibilities with caregiving. Having taken a leave from her full-time job to support her father through palliative care, she now finds herself overwhelmed. The burden of moral responsibility leads her to deny herself small pleasures or moments of relief. Her social life almost disappeared, and she feels depleted, both emotionally and physically, with no space left for personal recovery.

Both personas share a deep emotional burden and a misperception of self-care. In such emotionally heavy times, happiness or joy may seem inappropriate or even selfish. However, this does not mean that individuals should neglect their own needs. In fact, taking care of oneself is a necessary condition for being able to care for others effectively (Vrettos et al., 2009).

In conclusion,

This project acknowledges that moments of sadness and emotional struggle are entirely natural in palliative caregiving contexts. However, as supported by Lazarus and Folkman (1984), individuals can regain emotional balance through two primary coping strategies: emotional regulation and cognitive reframing. Helping caregivers find and practice their own coping strategies is crucial to maintaining their well-being.

Rather than offering a one-size-fits-all solution, **the design aims to raise awareness about personal well-being and create opportunities for small, meaningful acts of self-care.** The goal is not to impose a fixed path to happiness, but to remind caregivers that even amidst emotional hardship, it is feasible and necessary to make time for themselves.

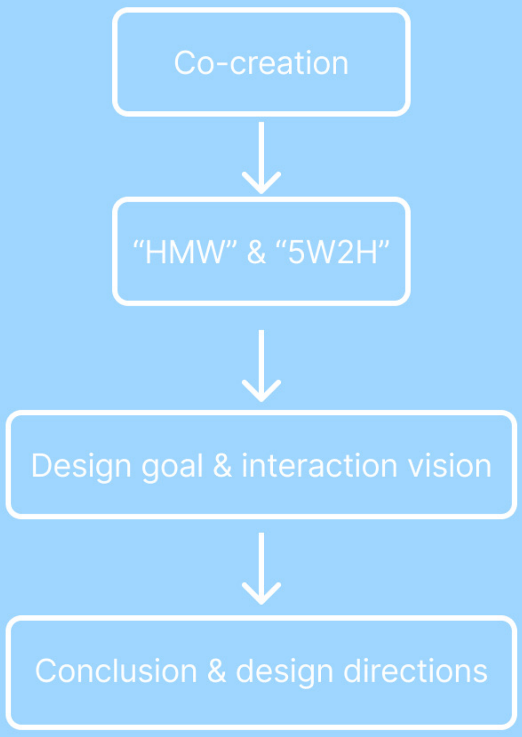
By supporting both personas in recognizing and reclaiming small moments of balance, the design promotes sustainable practices that can be integrated into everyday life. This shared space between the two user groups becomes the central design opportunity: gently guiding caregivers to care for themselves so they can continue caring for others—without losing their own sense of self in the process.

DEFINE

After exploring the context through literature, interviews, and journey mapping, this chapter aims to translate the insights into a clear design direction. The Define phase focuses on identifying the core challenges and opportunities within the experiences of the next of kin of palliative care patients.

To support and validate this process, I organized a mini co-creation workshop with two fellow students from TU Delft. Together, we discussed possible directions based on the research findings and formulated three “How Might We” (HMW) questions and utilize “5W2H” to define different usage scenarios. These HMWs became valuable prompts for generating a meaningful design goal and understand what type of interaction is intended for the target user.

Structure of research



4.1 Design scope

Based on the analysis of both the patient and next-of-kin journey map, the design scope for this project (Figure 17) will be focusing on two under-addressed but emotionally intensive phases:

- The transitional phase - the shift from curative care to palliative care, which is often filled with emotional turbulence, uncertainty, and a need for mental preparation and mindset adjustment by both patient and their family.

- The "blank period" - a period after the initial palliative diagnosis to the next check-in call with the nurse. During this period of time, the patient and the family will have limited contact with HCPs, leaving the next of kin in a space where they carry much of the caregiving responsibility alone. During this period, emotional needs are often neglected and a sense of helplessness can grow.

Rather than aiming for a solution that exclusively addresses one persona or use case, the project takes a different perspective of the measurements that can be done to improve their well-beings. The goal is to explore how design can gently raise awareness of one's own fundamental needs (based on Desmet & Fokkinga's 13 needs), and encourage micro-moments of joy/calm, reflection, and emotional resilience.

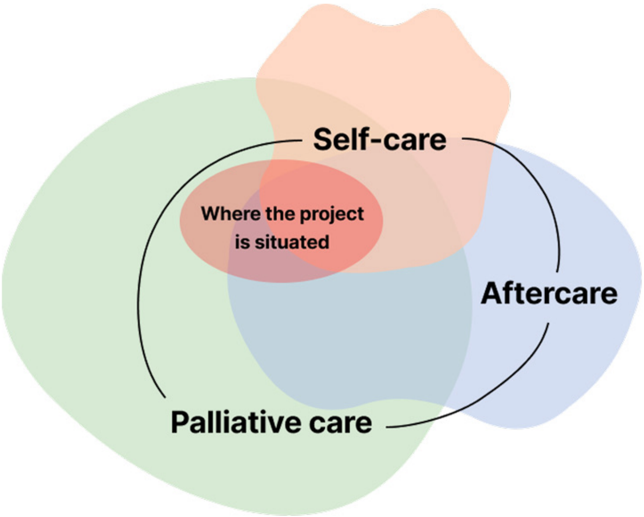


Figure 17. Diagram of the relationship of different care and where this project is situated

The diagram above shows the intersection of three domains:

- **Palliative care:** focuses on medical and emotional support during the final phase of life of HNC patients and can be extended to aftercare and also was advocated to include the next of kin into this care to ensure they will not become the “invisible patient”.

- **Aftercare:** includes grieving and emotional recovery after the patient has passed away and support for the family to processing the death of the beloved one.
- **Self-care:** spans both before and after the patient passed away, and addresses the caregiver’s own emotional and physical well-being.

The project is situated at the intersection of all three, where palliative care, aftercare, and self-care overlap. This highlights that while palliative care systems primarily serve the patient, it is also crucial yet still under supported area where family caregivers must be empowered to take care of themselves — both during the caregiving journey and after loss.

The project seeks to extend the emotional support that typically ends with the clinical care timeline, and instead **make well-being a continuous thread**, **stretching from the palliative phase into the early stages of grief**. The design intends to provide a self-guided space where hints or guidance can be given to the family, and the family can act upon their own needs and regain their balance in life.

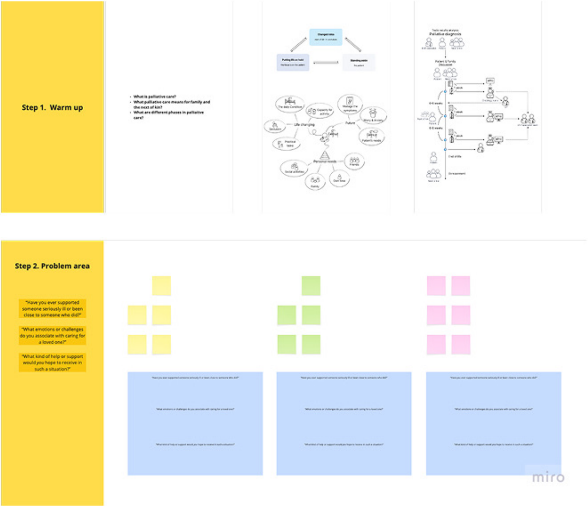
4.2 Creative session

4.2.1 Creative session setup

To further define the design directions and explore areas where meaningful interventions can be introduced, a creative session was organized with two fellow master’s students from TU Delft. Before the define phase, we have already discussed the transitional and “blank period” phase where we deemed design intervention could be implemented to improve the well-being of the next of kin.

This session aimed to collaboratively reflect on the experiences of next of kin in the context of palliative care, and identify potential entry points where design can offer emotional, practical or reflective support in these two phases (Figure 18). The main goals of this creative session were to:

- Identify “How Might We” (HMW) questions that uncover design opportunities for supporting the next of kin.



Step 1. Warm up

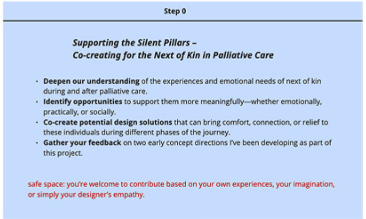
- What is palliative care?
- What palliative care means for family and the next of kin?
- What are different phases in palliative care?

Step 2. Problem area

“Have you ever supported someone seriously ill or been close to someone who did?”

“What emotions or challenges do you associate with caring for a loved one?”

“What kind of help or support would you hope to receive in such a situation?”



Step 0

Supporting the Silent Pillars –
Co-creating for the Next of Kin in Palliative Care

- **Deepen our understanding** of the experiences and emotional needs of next of kin during and after palliative care.
- **Identify opportunities** to support them more meaningfully—whether emotionally, practically, or socially.
- **Co-create potential design solutions** that can bring comfort, connection, or relief to these individuals during different phases of the journey.
- **Gather your feedback** on two early concept directions I’ve been developing as part of this project.

safe space: you’re welcome to contribute based on your own experiences, your imagination, or simply your designer’s empathy.

- Gain personal and empathetic insights into the emotional and behavioral
- patterns of family caregivers in palliative contexts.
- Evaluate ideas based on impact and feasibility, helping to prioritize directions for future concept development.

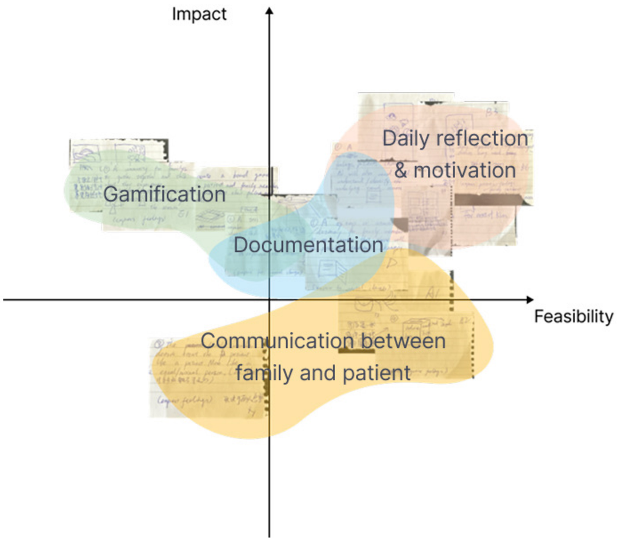


Figure 19. Evaluation of concepts based on feasibility and impact.

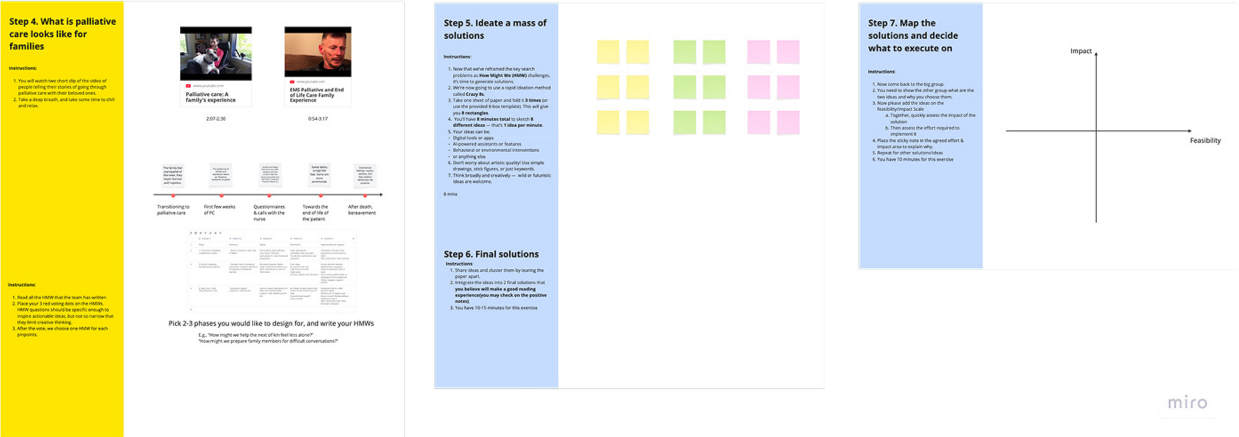
4.2.2 Results of the creative session

Two “HMW” questions wer brought up:

1. How might we let the family member know that their feelings also mater?
2. How to help the patient express their negative feelings to the family member?

The participants were asked to ideate based on these two questions and use crazy 8 minutes. The goal of crazy 8s is to push beyond your first idea, frequently the least innovative, and to generate a wide variety of solutions to your challenge(S, 2024). See in Figure 19, the concepts are categorized into four parts based on their similarity and the purpose of the concepts.

The matrix reveals that the most feasible and impactful concepts lie in the red quadrant, particularly the idea of a daily reflection tool. This concept stands out for its potential to integrate seamlessly into everyday life, increasing the likelihood that users will engage regularly and take small, meaningful actions to support their own well-being.



Step 4. What is palliative care looks like for families

Instructions:

1. You will watch two short clip of the video of people telling their stories of going through palliative care with their beloved ones.
2. Take a deep breath, and take some time to chill and relax.

www.youtube.com
Palliative care: A family's experience
2:07-2:30

www.youtube.com
EMS Palliative and End of Life Care Family Experience
0:54-3:17

Transitioning to palliative care
First few weeks of PC
Questionnaires & calls with the nurse
Towards the end of life of the patient
After death, bereavement

Pick 2-3 phases you would like to design for, and write your HMWs

E.g., "How might we help the next of kin feel less alone?"
"How might we prepare family members for difficult conversations?"

Instructions:

1. Read all the HMW that the team has written
2. Place your 3 red voting dots on the HMWs. HMW questions should be specific enough to inspire actionable ideas, but not so narrow that they limit creative thinking.
3. After the vote, we choose one HMW for each pinpoints.

Step 5. Ideate a mass of solutions

Instructions:

1. Now that we've reframed the key search problems as **How Might We (HMW)** challenges, it's time to generate solutions.
2. We're now going to use a rapid ideation method called **Crazy 8s**.
3. Take one sheet of paper and fold it **3 times** (or use the provided 8-box template). This will give you **8 rectangles**.
4. You'll have **8 minutes total** to sketch **8 different ideas** — that's **1 idea per minute**.
5. Your ideas can be:
   - Digital tools or apps
   - AI-powered assistants or features
   - Behavioral or environmental interventions
   - or anything else
6. Don't worry about artistic quality! Use simple drawings, stick figures, or just keywords.
7. Think broadly and creatively — wild or futuristic ideas are welcome.

8 mins

Step 6. Final solutions

Instructions:

1. Share ideas and cluster them by tearing the paper apart.
2. Integrate the ideas into 2 final solutions that **you believe will make a good reading experience(you may check on the positive notes).**
3. You have 10-15 minutes for this exercise

Step 7. Map the solutions and decide what to execute on

Instructions:

1. Now come back to the big group.
2. You need to show the other group what are the two ideas and why you choose them.
3. Now please add the ideas on the feasibility/Impact Scale
   a. Together, quickly assess the impact of the solution
   b. Then assess the effort required to implement it
4. Place the sticky note in the agreed effort & impact area to explain why.
5. Repeat for other solutions/ideas
6. You have 10 minutes for this exercise

Figure 18. The structure of the co-creation session

In contrast, concepts in the green quadrant, such as gamification and joyful event prompts, while potentially high in emotional impact, were considered less feasible. Participants expressed concerns that these ideas might unintentionally add pressure or guilt, especially if users felt they weren't "doing enough" to enjoy life during a difficult period.

The blue quadrant included ideas around sharing notes or leaving messages for the patient. These were seen as emotionally valuable and feasible but less suitable for daily integration. Their occasional or symbolic nature may limit their long-term engagement or impact, as they lack the momentum to become part of a sustainable daily practice.

Based on the concepts generated and the initial "HMW" question : "How might we let the family member know that their feelings also matter?", a new, more focused "HMW" question was articulated:

How might we promote healthy well-being during the intense emotional stages of palliative care?

Addressing this question, I linked the question with the theory of fundamental needs: by supporting family members in meeting their own fundamental needs, they can begin to restore their autonomy, resilience, and balance in life. Building on this connection, a clear design goal has been formulated to guide the next phase of development.

4.3 Design goal & interaction vision

4.3.1 Design goal

Based on the interpretation of the journey maps, two key phases were identified where palliative care at Erasmus MC could benefit from more focused support and improved care delivery: the transitional phase between curative and palliative care, and the so-called "blank period" when families are left largely on their own between check-ins. These moments were seen as critical in shaping the emotional well-being of both patients and their families.

Through the co-creation session with fellow students, a central "How might we" question emerged:

How might we promote healthy well-being during the intense emotional stages of palliative care?

To answer this question, the theory of the 13 fundamental human needs (Desmet & Fokkinga, 2020) was used as a guiding framework. The theory emphasizes that by fulfilling these basic psychological and emotional needs, individuals can begin to restore their autonomy, self-worth, and emotional resilience — even under highly stressful conditions.

Therefore, the design goal of this project is to:

> *Design a **daily ritual** for **the family** of head and neck cancer patients to **make space and time for actions to meet their own fundamental needs** during the emotionally intense **palliative care** journey.*

A daily ritual refers to a small, repeated activity that becomes part of someone's routine. In this context, it is something simple and calming, that can serve as a consistent moment of personal time.

The family of palliative care HNC patient is the target user of the design, the group is rather vulnerable of worrying about losing their beloved ones. They are taking on responsibilities of both taking care of the patient and balancing their own needs and own life.

Make space and time for themselves highlights the need to create space mentally, emotionally, and physically for oneself. For family caregivers, time often divided into two: one taking care of the patient and one to meet the basic living demands. The design aims to offer moments of intentional pause to help them care for themselves without or with less guilt.

Actions to meet their own fundamental needs refers to translating abstract fundamental needs into small actions or activities that could be done in the daily life of the family caregivers. These activities may not guarantee the restore of their well-being, but could be the first step towards regaining a sense of control of their life and be mindful about their own needs.

During Palliative care refers the the specific time either when the family just entered palliative care phase or they have been in palliative care for some time and feel drained physically and emotionally The design intervention will be placed starting from the transitional phase till the end of palliative care, in between the nurses calls where the next of kin becomes the main caregiver.

Figure 20. AI generated image for reference of the intended interaction vision

4.3.2 Interaction vision

“Crossing a river, step by step, together.”

My interaction vision is like *“**crossing a shallow river with stepping stones.** A friend walks before you, **pointing out the next stone**, reminding you to balance, and **waiting as you find your footing**. **Each step is yours to take**, but you know you won’t fall because they keep pace with you. ”*

In this time of emotional overwhelm and life-altering transitions, support should not overpower, but gently accompany with the user. To depict a scene with a moment of vulnerability, guidance, and courage, this interaction vision draws from the image of a child is accompanied by an adult crossing a shallow river using stepping stones.

The adult character represents the product itself, embodying both experience and gentleness. The young child symbolizes the user, someone entering the palliative care journey for the first time with limited knowledge and understanding of the care pathway. The adult’s act of pointing out the next stepping stone illustrates the product’s role in offering gentle reminders, guiding the user and helping them anticipate upcoming challenges. This gesture also reflects the product’s intention to empower the user, encouraging them to make their own choices and become more aware of their actions. With the support of the product, the child feels secure and confident in taking the next steps, moving forward with greater clarity and reassurance.

4.3.3 Interaction qualities

Crossing a shallow river with stepping stones/ Paying attention to ones's balance/Hearing the sound of the water streaming down

Stimulating

New and exciting experiences or interactions. The user can be motivated for continuous use of the product to form a ritual/routine

Pointing out the next stone

Guiding

Guiding the user through the journey, while provide them with the necessity. Even a clear overview of what could happen could help the user to find coping strategies

Waiting as you find your footing/And holding hand

Comforting

The interaction should be gentle, not to elicit intense emotional feelings, but to create a safe and comfortable environment

Each step is yours to take

Empowering

Providing the user with relevant knowledge and skills to accomplish something by themselves.

4.3.4 Design criteria

Based on the interaction qualities, the design criteria is the extension of the qualities divided into more understandable and measurable aspects. By interpreting the intended interaction qualities, the criteria help guide and evaluate the design and prototypes in ways to ensure the envisioned user experience is consistently reflected in tangible design decisions:

- **Interesting:** Whether the product is interesting enough and provides user new experience. This is important for the purpose of forming a daily reflection ritual/ habit. The stimulating character will promote the usage of the product.

- **Calming:** The product should provide a sense of peace and emotional grounding in this period of uncertainty. It should not elicit too radical feelings or emotions which may worsen the situation.

- **Supportive:** The product should offer quiet and peaceful encouragement, helping users feel accompanied and understood.

- **Flexible:** The project should allow for personalization and adapt to varying emotional states or routines. Users should be able to interact, and reflect in their own way and on their own terms.

- **Rewarding:** The mechanism of the formation of a habit is providing a rewarding system and motivate people to keep using the product or doing something. The rewarding can also be utilized in this design project, prompting the user to continue the usage of the product.

After explaining why these five pillars were selected, it is important to emphasize that the purpose of establishing design criteria at this stage is to provide a clear foundation for evaluating ideas in the later design phase.

In conclusion,

In this chapter, the focus was placed on defining the scope and direction of this design project. Drawing from a comprehensive analysis of the patient and next of kin journeys, the design scope was clarified to address the “blank period” during palliative care. This is the time when the next of kin often take on increasing responsibilities with limited proactive support. Rather than aiming to “solve” grief or create joy, the design goal is to prompt self-care and emotional resilience by raising awareness of one’s own fundamental needs

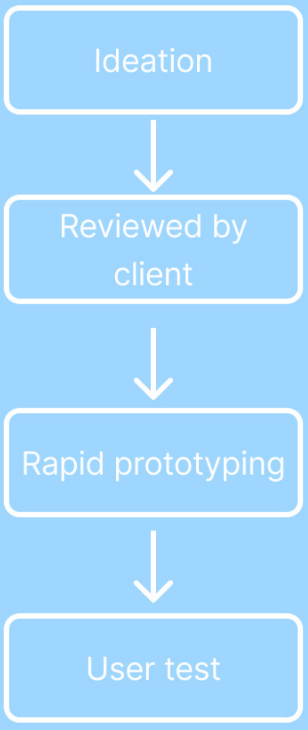
This chapter also introduced an interaction vision that captured the intended design interactions: a product that offers quiet guidance, emotional grounding, empowerment, while respects personal pace and autonomy.

The next step after settled with the design goal and interaction vision is to understand what interaction could provide the targeted feelings and how do people interpret the interactions in return.

DESIGN

In this session, the first goal is to find design directions that align with the design goal and interaction vision as the first-round iteration on design solutions. Once the design direction is confirmed, I used fast prototyping to design multiple interactions and test with fellow students about what brings them joy/calm in daily life, how the emotions are linked with daily activities and finally access the prototypes and interactions. The second round of design iteration will be access with Harris Profile with the design criteria mentions in the last chapter. Then, the final design concept will be build on the selected concept.

Structure of design



5.1 Design opportunities

Having drawn conclusions from the exploration of palliative care pathways and the emotional challenges faced by the next of kin, potential ideas were generated to support their well-being during the most demanding phases of caregiving. After identifying promising directions, sketches, scenarios, and early concepts were developed as low-fidelity prototypes to explore how these ideas might fit into the daily lives of family caregivers.

These initial designs were shared with peers and informed by feedback from healthcare professionals and academic experts, which helped refine the understanding of what could make supportive strategies both meaningful and actionable. This process laid the foundation for defining the key design objectives and opportunities presented in this chapter.

5.1.1 Initial ideas

As described in previous chapters, one of the core challenges faced by the next of kin in palliative care is the emotional burden of anticipatory grief, uncertainty, and the long periods of caregiving without consistent professional support.

These experiences often lead to emotional fatigue, self-doubt, and a diminished sense of self-worth, as caregivers may question whether they are doing enough, or feel guilt for even considering their own needs.

To address these emotional needs, it becomes essential to promote awareness and fulfillment of the caregiver's fundamental human needs, such as autonomy, recognition, and emotional balance (Desmet & Fokkinga, 2020). Literature on stress and coping (Lazarus & Folkman, 1984) highlights that people under chronic stress benefit most from strategies that both acknowledge emotional complexity and restore a sense of control in everyday life. This includes creating small moments of self-care, and developing sustainable coping strategies that fit naturally into daily routines.

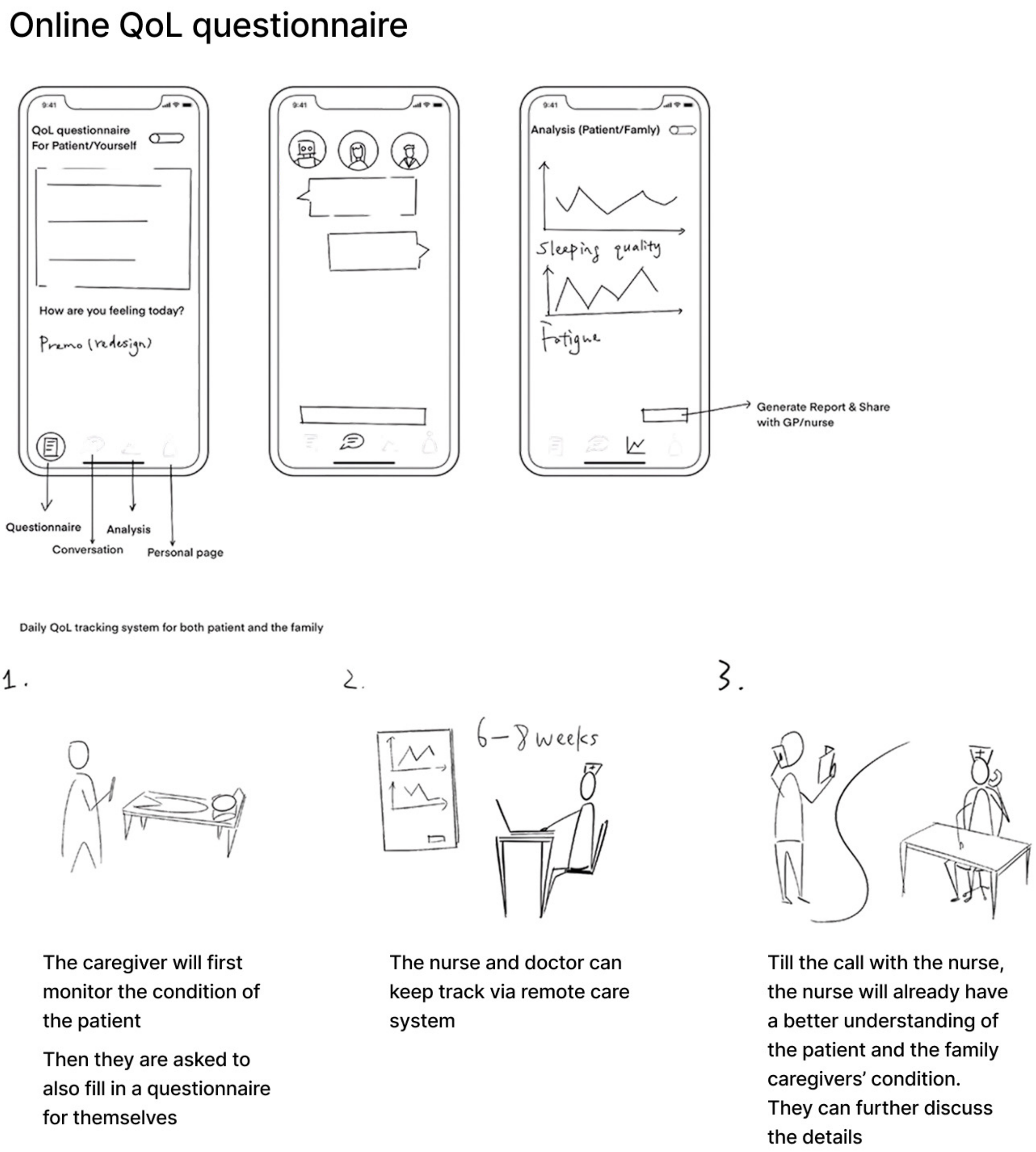
These strategies can be divided into two key directions, which were used to frame the initial design ideation:

Raise awareness of personal needs and emotional well-being, e.g.:

- Encouraging self-reflection
- Identifying and celebrating small accomplishments
- Supporting autonomy through open-ended prompts and rituals
- Reframing difficult emotions (e.g., guilt, helplessness) as part of a normal caregiving experience

2. **Support gentle emotional regulation and connection, e.g.:**
    - Offering subtle reminders of existing support systems (e.g., family, friends, care teams)
    - Facilitating moments of emotional connection with the patient or others
    - Creating space for quiet routines that allow for emotional recovery
    - Helping users pace themselves and build sustainable rhythms of care and self-care

These directions formed the basis for developing and evaluating ideas that aim to offer not just tools, but companionship, guidance, and emotional grounding during one of the most complex and vulnerable times in life.



Daily QoL tracking system for both patient and the family

1. The caregiver will first monitor the condition of the patient

Then they are asked to also fill in a questionnaire for themselves

2. The nurse and doctor can keep track via remote care system

3. Till the call with the nurse, the nurse will already have a better understanding of the patient and the family caregivers’ condition. They can further discuss the details

Figure 21. Concept 1: Online QoL questionnaire

Concept description:

This concept (Figure 21) envisions a remote care interaction system designed to support both palliative care patients and their family caregivers during the time between clinical check-ins. The system integrates daily questionnaires, emotional and physical monitoring, and reflection prompts to help caregivers manage care responsibilities while enabling healthcare professionals (nurses and doctors) to stay informed and engaged remotely.

Usage:

The mobile interface allows caregivers (often partners or children of the patient) to:

1. Answer daily check-ins
    - Simple questionnaires about the patient’s condition and their own well-being.
    - Prompts related to emotional and physical states.
2. Track and analyze patterns
    - View trends in symptoms, sleeping patterns, or emotional changes over time.
    - Use visual indicators (graphs or emojis) to help caregivers reflect on the current situation.
3. Facilitate remote communication
    - Prepare for the nurse’s check-in call with a record of symptoms, behaviors, and concerns.
    - Share emotional or logistical updates directly with healthcare staff.
4. Access gentle reminders and Support
    - Internal pages include suggestions, reminders, or coping strategies for caregivers.
    - Gentle nudges (e.g., “Have you taken a moment for yourself today?”) can promote emotional self-care.

Context:

This product is designed for use in home care environments during the palliative phase of illness. It empowers caregivers to monitor and manage care at home while preparing for more informed and efficient nurse-patient-family communication.

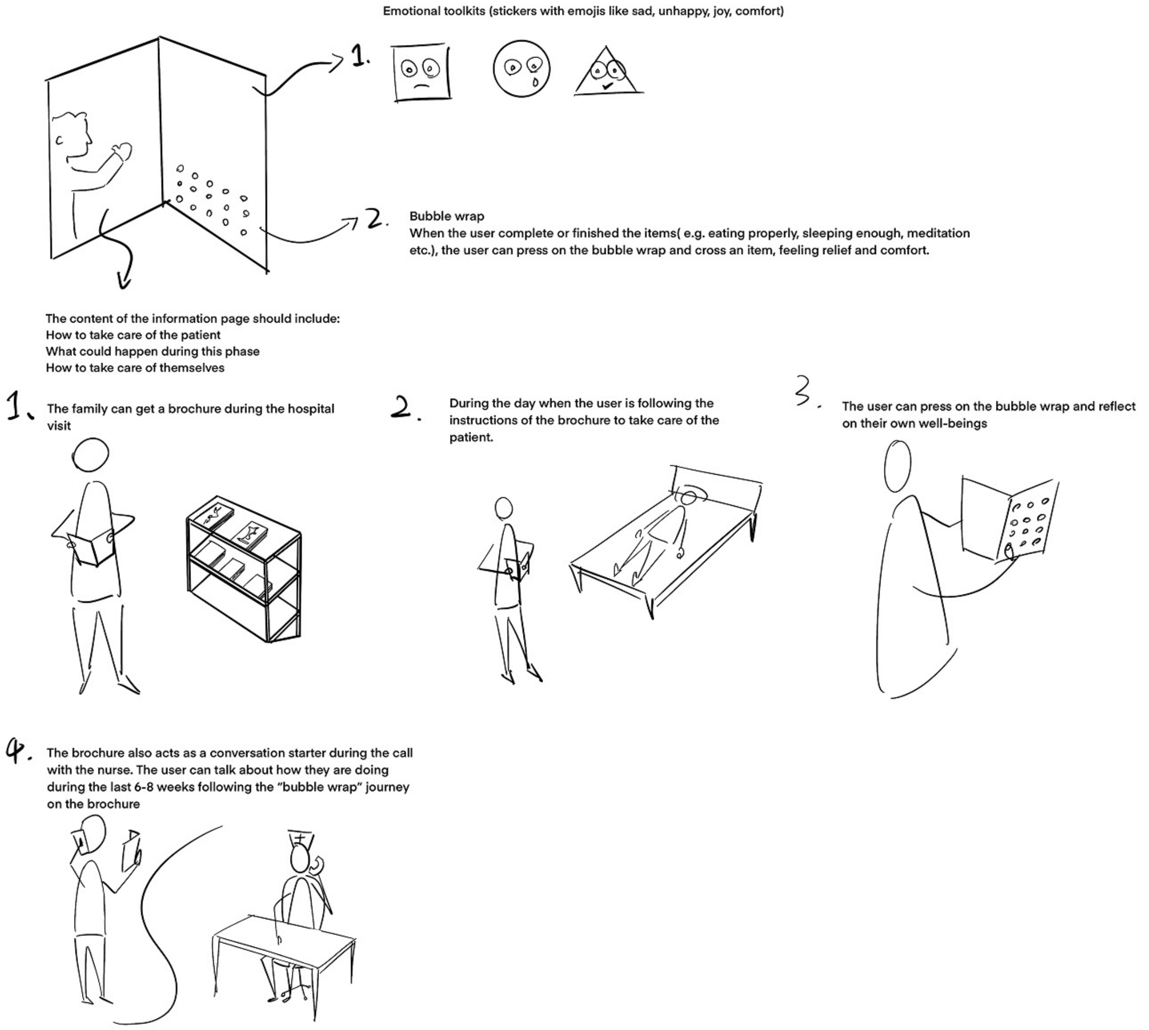
Involvers & connections:

The patient, the next of kin caregiver, and the healthcare team are involved and facilitated by the product for more efficient communication.

Sub-concepts:

1. **Shared Emotional Diary:** A space where both patient and caregiver can reflect individually, with optional sharing.
2. **Emotional Safety Prompts:** Based on the 13 fundamental needs, prompts encourage reflection on needs like recognition, meaning, and care.

Bubble relief



Emotional toolkits (stickers with emojis like sad, unhappy, joy, comfort)

1.

2. Bubble wrap
When the user complete or finished the items(e.g. eating properly, sleeping enough, meditation etc.), the user can press on the bubble wrap and cross an item, feeling relief and comfort.

The content of the information page should include:
How to take care of the patient
What could happen during this phase
How to take care of themselves

1. The family can get a brochure during the hospital visit

2. During the day when the user is following the instructions of the brochure to take care of the patient.

3. The user can press on the bubble wrap and reflect on their own well-beings

4. The brochure also acts as a conversation starter during the call with the nurse. The user can talk about how they are doing during the last 6-8 weeks following the "bubble wrap" journey on the brochure

Figure 22. Concept 2: Bubble relief

Concept description:

The concept (Figure 22)centers around a supportive, reflective digital product designed for the next of kin of palliative care patients. Its core function is to **facilitate emotional reflection**, **prompting small actions or activities for one's well-being**, and **creates opportunity for communication** between family caregivers and healthcare professionals. The tool aims to creates meaningful conversation starter with patient or the HCPs and motivate the user to talk about their struggles and well-being.

Usage:

The user first encounters the brochure during their initial visit to the hospital with the patient. After the patient is diagnosed and transitions into palliative care, doctors encourage the family member to take the brochure home. The brochure provides accessible information about what palliative care entails, what emotional or physical responses are considered normal, and what kinds of feelings or symptoms family members might experience throughout the process.

By reading the brochure, the family caregiver gains a clearer understanding of what to expect during this phase of care. They are then guided to engage with the interactive element of the brochure—a bubble wrap sheet. Each day, they are invited to pop one bubble. Underneath each popped bubble is a background color that corresponds to one of the fundamental emotional or psychological needs. They will look for the reference for the color on the back of the brochure.

Along with this revealed need, a few small, gentle actions are suggested as inspiration. However, the reader is encouraged to reflect on the need and take action in a way that feels personally meaningful. The goal is to support emotional awareness and promote self-care through small, mindful steps that build resilience over time.

Context:

The product is designed for use during the “blank period” in palliative care—typically the 6 to 8 weeks between scheduled medical contacts or nurse check-ins. It supports:

- Family members who are suddenly taking on a large caregiving role with limited formal support.
- Remote palliative care settings, where in-person visits from healthcare professionals are infrequent or not always possible.
- Emotionally intense moments, where the caregiver feels alone, uncertain, or overwhelmed.

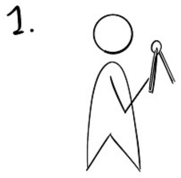
Involvers & connections:

Next of Kin (Primary User) will gain insights and knowledge from the brochure. The patient is involved because the next of kin is expected to have a shared conversation regarding the activity he/she did. The nurse will have gain more insight into how did the patient and the next of kin feel for the last 6-8 weeks with more details.

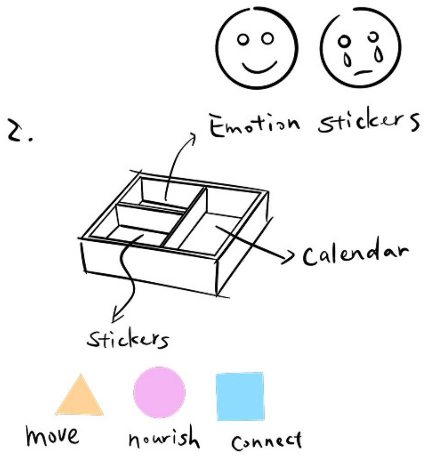
Sub-concepts:

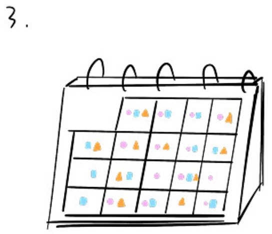
1. **Shared Journal or Voice Notes:** An optional feature to leave messages for the patient, themselves, or the nurse.
2. **Conversation Starters for Nurse Check-Ins:** provides topics and previous activities for the next of kin to discuss with the nurse during the call.

Emotion calendar



The next kin will receive a calendar with toolkits





Based on their understanding and interpretation, they put emotion stickers and need stickers on the calendar each day

They can reflect and check on the calendar to form a better conversation with the nurse regarding their needs.

Concept description:

The concept (Figure 23) focuses on the documentation of the emotions and what needs are fulfilled and unmet for the next of kin. The next of kin is also welcomed to put pictures or record a memo to share the story with the patient each day.

Usage:

The user will receive a package from Erasmus MC. The box contains three parts: the emotion stickers, needs stickers, and the calendar. Different color and shape of the needs sticker represents different categories of the needs. Based on their interpretation of the needs, They can document what needs they think were fulfilled today. Then they can rate the day with the emotion sticker.

Later on, when they receive the call with the nurse, they could reflect on the calendar checking how he/she has been doing for the last 6-8 weeks.

Context:

The product is designed for use during the whole period of palliative phase, and encouraged to do so even for the aftercare.

Involvers & connections:

The family caregiver and nurse are highly involved in this product, the calendar is for documenting the mental status of the family caregiver and later on act as a conversation starter for discussion with the nurse.

5.1.2 Feedback from peer students and clients

Four discussion session has been done with peer student in TU Delft to understand the whether the proposed concept can achieve the target goal and vision. Then a follow up meeting with clients from Erasmus MC was held to gain insights and feedback from the client's side as they are also researcher relative field.

Based on all the feedback gathered, the main insights are:

- The patients have a specific portal for filling out the questionnaire, and the questionnaire is tested and evaluated based on larger scope of validation. To design a questionnaire for the family caregiver is possible, but need more research data and input from different perspectives.

- Any application that will be published by Erasmus MC will be compliant to the regulations and the HNC patients in Erasmus MC are mostly digitally disabled. Therefore, the feasibility to build an application for the family caregiver and patient is relatively low.

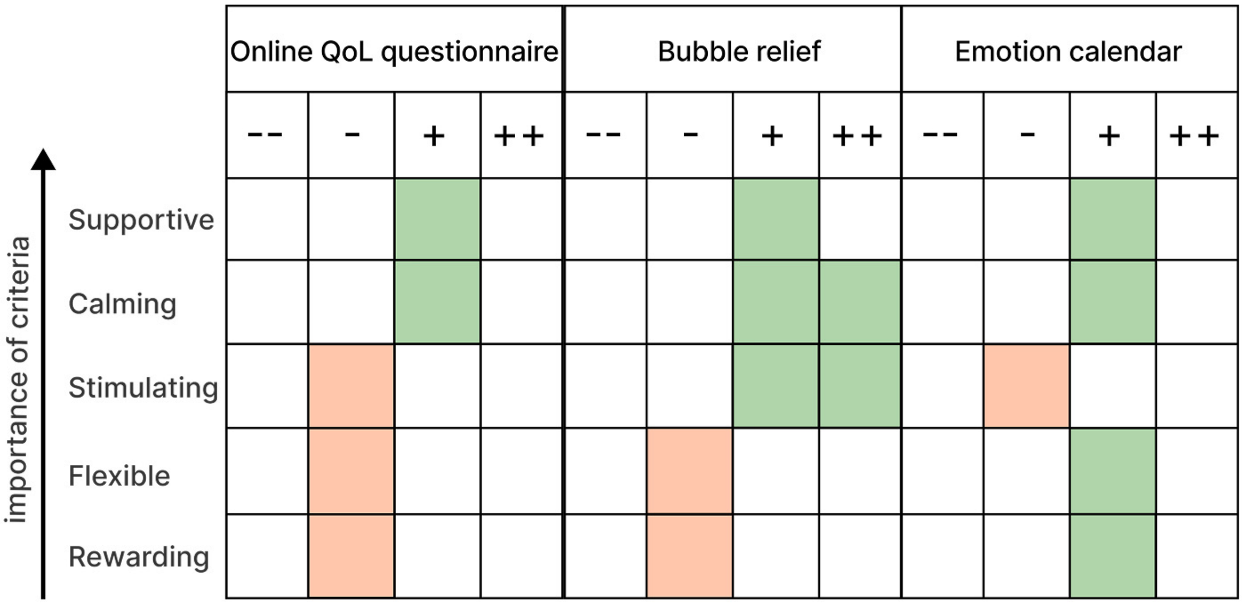
- Providing something physically interesting and stimulating is not only more feasible from the hospital's side, but also build a bridge between the hospital and remote home care. A few consideration needs to be thought through, for example, the cost of the physical product, whether the interaction is physcially and emotionally safe.

5.1.3 Harris profile analysis

The Harris Profile (Leven, 2006) is a design evaluation framework used to assess concepts across multiple dimensions of user experience and design effectiveness. It offers a structured way to evaluate ideas beyond functionality, focusing also on emotional and contextual relevance.

In this project, the Harris Profile was employed as a tool to assess the initial concepts generated from co-creation sessions and contextual research. Each concept was mapped against the five design criteria of the profile to evaluate its potential to support the next of kin emotionally, practically, and contextually during palliative care. This helped to identify which ideas aligned most strongly with the design criteria, including being stimulating, calming, and supportive, and which ones required refinement or reconsideration.

By using the Harris Profile, the evaluation process remained user-centered, ensuring that the final direction was not only feasible but also meaningful and emotionally resonant for the intended users.



importance of criteria	Online QoL questionnaire				Bubble relief				Emotion calendar			
	--	-	+	++	--	-	+	++	--	-	+	++
Supportive			🟩				🟩				🟩	
Calming			🟩				🟩	🟩			🟩	
Stimulating		🟧					🟩	🟩		🟧		
Flexible		🟧				🟧					🟩	
Rewarding		🟧				🟧					🟩	

Table 4. Harris profile evaluation of the initial four concepts

After evaluating the Harris Profile (Table 4), the next step is identifying better ideas based on the results. Three ideas have shown better performance than others, based on their position on the Harris Profile curve and cumulative points. The concept is “Bubble relief”, which creates a nice stimulating interaction but also is calming and relieving .

Online QoL questionnaire: This concept offers practical emotional support and documentation tracking system. It eases communication between caregiver and nurse, making it ideal for enhancing remote care and relieving pressure during consultations. However, the interaction is more functional than emotionally engaging, and may feel repetitive over time. Meanwhile, the application does not provide any rewarding system or stimulation to promote the usage of the product.

Bubble Relief: The concept successfully combines gentle daily reflection with physical interaction. It is ideal for a low cost product but create interesting interactions. The bubble wrap itself can already create a calming effect and many of the test users will the interaction of popping up a bubble relieving.

Emotional Calendar: The Emotion Calendar encourages self-awareness and emotional tracking, offering a visual and expressive outlet. It allows for flexible interpretation, but may require consistent engagement, which might be difficult for caregivers in high-stress phases. One of the participants also mention that she feel like the calendar is like a countdown of the life of patient, which make her feel uncomfortable. However, the flipping interaction and documentation is showing that the design could providing a sense of accomplishment when finishing the task everyday. This product creates more a sense of ritual that could be integrated into the family’s daily life.

In conclusion,

Based on the Harris Profile evaluation and the feedback from the client (Erasmus MC), the most well-balanced concept is “Bubble Relief.” It successfully combines calming, supportive, and rewarding qualities while promoting action in a gentle and approachable manner. The interaction with bubble wrap already introduces an interesting and tactile experience, encouraging users to reflect daily in a causal yet meaningful way.

However, some challenges exist within the current concept. First, bubble wrap is a fragile material and not ideal for integration within a brochure format. Second, the brochure content itself lacks consistency, with part of it focusing on explaining the definition of palliative care and what to expect during this phase, while another part introduces actions related to fulfilling one’s fundamental needs. This can be mitigated with the “Emotional calendar” concept, which create a daily ritual that integrated into the daily life.

To address these issues, the next section of this chapter explores alternative interactions inspired by the bubble wrap experience. But also attempts to find or create a ritual that is suitable for the elderly people. The goal is to retain the engaging quality of the concepts while improving its sense of ritual. Several rapid prototypes will be developed representing different rituals that could be in one’s daily life and tested to evaluate how users respond emotionally and physically to different forms of interaction.

5.2 Second-round design iteration

5.2.1 Renewal of the reference of 13 fundamental needs

Before beginning the exploration phase, the reference images for the 13 fundamental needs were renewed (Figure 24) to ensure they align with the current context and user group. This insight emerged from an alignment meeting with the client, where it became clear that most family caregivers are partners of the patient and belong to the same age group. The previous set of reference images did not adequately represent how elderly caregivers might experience or relate to these needs. In some cases, the visuals could even cause discomfort; for example, showing a person running in a field might unintentionally trigger negative emotions for someone with limited mobility.

To address this, the reference images for the 13 fundamental needs were reselected to ensure they resonate with the target users. The selection was guided by the following criteria:

- **Representation:** As most family caregivers are women aged 60–70, the main characters depicted in the images should predominantly be elderly people. A

Competence

Having control over your environment and being able to exercise your skills to master challenges

Autonomy

Being the cause of your actions and feeling that you can do things your own way

Purpose

Having a clear sense of what makes your life meaningful and valuable

Community

Being part of and accepted by a social group or entity that is important to you

Relatedness

Having warm, mutual, trusting relationships with people who you care about

Impact

Seeing that your actions or ideas have an impact on the world and contribute to something

Beauty

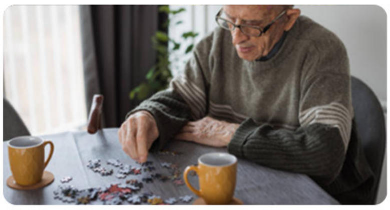
Feeling that the world is a place of elegance, coherence and harmony

Security

Feeling that your conditions and environment keep you safe from harm and threats

Comfort

Having an easy, simple, relaxing life

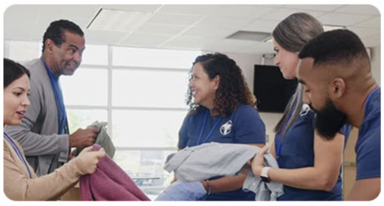


Stimulation

Being mentally and physically stimulated by novel, varied, and relevant impulses and stimuli

Fitness

Having and using a body that is strong, healthy, and full of energy



Morality

Feeling that the world is a moral place and being able to act in line with your personal values

Recognition

Getting appreciation for what do and respect for who you are

Renewed 13 Fundamental Needs

Figure 24. Renewed 13 fundamental needs

small number of images can still feature younger individuals to represent offspring.

- **Clarity:** The images should have a clear and unambiguous meaning to avoid multiple or conflicting interpretations.

- **Sensitivity:** Activities or visuals that could trigger vulnerable or sensitive topics should be avoided, ensuring that the images remain respectful and empathetic to the users' situation.

This approach ensures that the visuals not only communicate the fundamental needs more effectively but also foster empathy and connection with the target audience

5.2.2 Semi-structured Interviews

Interview setup

A total of eight participants were recruited for the study.

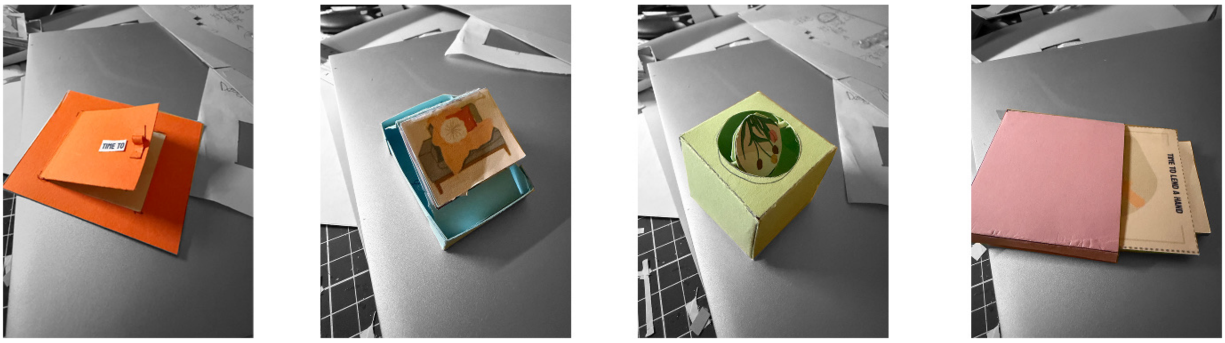
- Five interviews were conducted in person, allowing participants to directly engage with physical prototypes.
- Three interviews were conducted online, where prototypes were presented via video walkthroughs and guided explanations.

The use of a semi-structured format allowed flexibility in probing participant reflections while ensuring consistency across sessions. The combination of reflective tasks, interactive mapping, and prototype testing provided valuable insight into how different interaction styles resonate emotionally, and how they might contribute to promoting calmness, stimulation, or support which is key criteria for the final design

Interview structure

To support the second round of design iteration, a series of semi-structured interviews were conducted with the aim of gathering user feedback on early-stage concepts and exploring the emotional responses elicited by different types of interactions. Given that the participants were students rather than actual next-of-kin in palliative care, the interview was carefully designed to sensitize them to the context and reduce potential confusion about the subject matter. Therefore, participants were introduced to the interview as one focusing on their daily activities and mental well-being to keep the framing familiar and relatable.

A Miro template was developed to facilitate the interviews, consisting of three structured parts (see in Figure #):



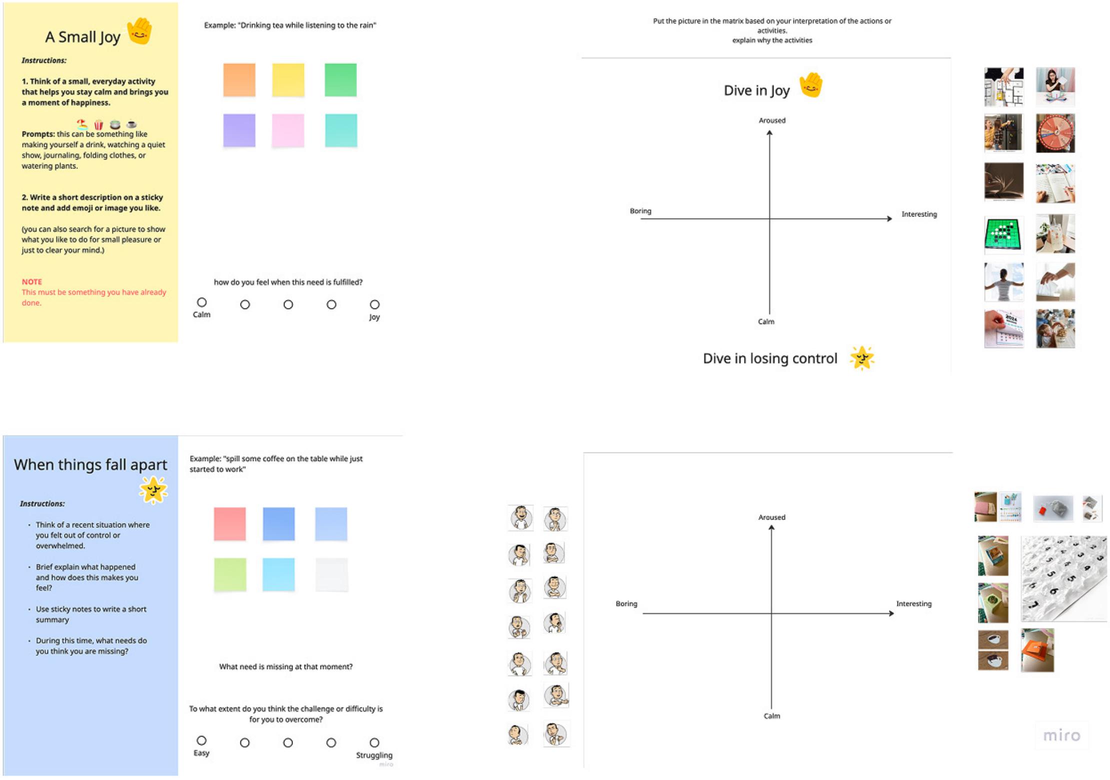
Opening book *Calendar Flipping* *Coin Rotating* *Draw a magnetic card*

Coaster *Tea bags*

Figure 25. Rapid prototype tested in the interview

1. Context Sensitization through Personal Reflection

In the first part, participants were asked to reflect on activities or moments from today or yesterday that brought them positive emotions or feelings. Follow-up questions were used to help identify which fundamental needs were being fulfilled through these experiences. Additionally, participants rated their emotional responses using a calm–joy scale, representing two contrasting dimensions of positive affect: relaxed contentment versus active happiness.



A Small Joy

Instructions:

1. Think of a small, everyday activity that helps you stay calm and brings you a moment of happiness.

Prompts: this can be something like making yourself a drink, watching a quiet show, journaling, folding clothes, or watering plants.

2. Write a short description on a sticky note and add emoji or image you like.

(you can also search for a picture to show what you like to do for small pleasure or just to clear your mind.)

NOTE
This must be something you have already done.

Example: "Drinking tea while listening to the rain"

how do you feel when this need is fulfilled?

○ Calm ○ ○ ○ ○ Joy

Put the picture in the matrix based on your interpretation of the actions or activities.
explain why the activities

When things fall apart

Instructions:

- Think of a recent situation where you felt out of control or overwhelmed.
- Brief explain what happened and how does this makes you feel?
- Use sticky notes to write a short summary
- During this time, what needs do you think you are missing?

Example: "spill some coffee on the table while just started to work"

What need is missing at that moment?

To what extent do you think the challenge or difficulty is for you to overcome?

○ Easy ○ ○ ○ ○ Struggling

Figure 26. Structure of the semi-interview in Miro

2. Interaction Exploration through Image-Based Sorting

Next, participants were presented with 12 images, each depicting a different interaction style or concept. They were asked to drag and place these images onto a 2×2 matrix with axes labeled Joy–Calm and Interesting–Boring. This exercise helped surface which types of interactions participants found emotionally engaging, stimulating, or soothing, and why.

3. Prototype Testing and Feedback

In the final phase, participants were introduced to a set of rapid prototypes developed based on earlier concepts. Depending on the setting, this was either through demonstration videos (for online interviews) or hands-on interaction (for in-person interviews). Participants were then invited to place the prototypes on the same Joy–Calm / Interesting–Boring matrix as before. This helped contextualize how the designed interactions were perceived relative to their earlier impressions and emotional expectations.

Results analysis

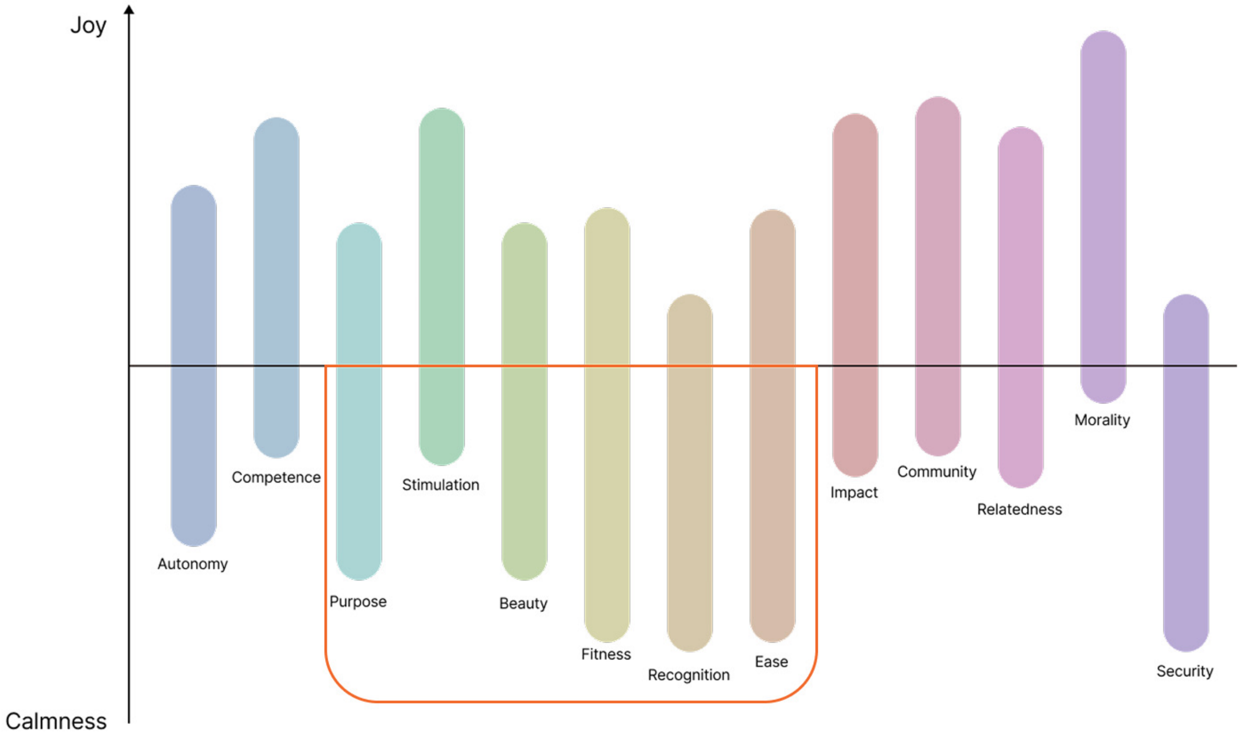


Figure 27. Fundamental needs met by daily activities and the difficulty level of fulfill the needs

Figure 27 shows different needs fulfilled by people and their effect on their emotional well-being. The effects were categorized into mainly two parts: Joy, which represents the happiness and positive feelings that are usually shared with others; And calmness, representing the inner comfort and peace of mind which are usually positive feelings that are kept to oneself.

Note that calm and joy are not counterparties that is the opposite meaning against each other. The Red rectangles highlight the needs that provides feelings of calmness, which is the targeted effect that the design intervention aims to achieve.

To further understanding which needs are most challenging to fulfill, thematic coding to a scaling were created to understand the difficulty of fulfilling certain needs (Figure 28):

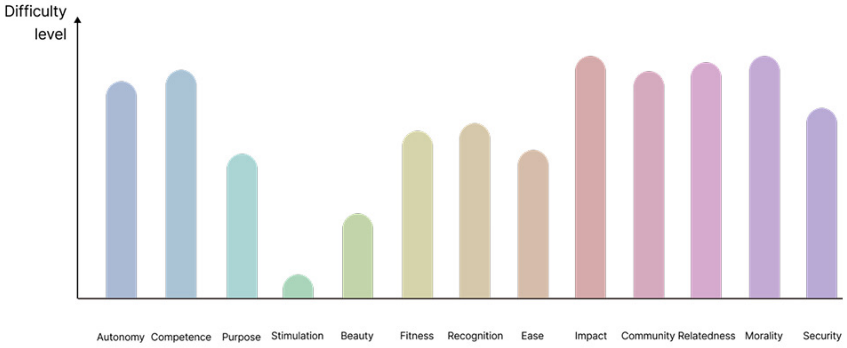


Figure 28. difficulty level of fulfilling the needs

In this figure, we can see that stimulation is the easiest to achieve, for example, with an interesting interaction, and will bring more joy rather than calmness.While for “impact”, “community”, “relatedness”, and ”Morality”, people are more struggling to achieve certain level, but once achieved, the joy it bring is much more than beauty, stimulation etc. The autonomy is well balanced in calm-joy matrix meaning that this need could swift to either side depending on the activities.

Concluded from the graphic, it becomes evident that for families in palliative care, experiencing moments of joy or happiness through fulfilling their fundamental needs can be challenging. However, small, manageable daily activities that offer a sense of calm and peace of mind already hold significant value in their emotional well-being.

Among the 13 fundamental needs, those that appear more likely to evoke positive emotions and are easier to access in the context of palliative care include: stimulation, beauty, fitness, ease, impact, recognition. These needs not only support emotional well-being but are also more feasible to integrate into everyday routines. Note that the 6 needs concluded here does not mean that activities to meet the other needs require higher thresholds. Activities in daily life may meet 2-3 needs at the same time. It is important to understand that the needs themselves do not stand alone, but more intertwined when they are actually being met in real life.

In conclusion, in shaping the content and focus of the design, the 6 needs selected to be easier to achieve present a meaningful direction for the development of design content. Prioritizing them ensures the design remains sensitive to the users’ circumstances while still offering opportunities for emotional restoration and a sense of balance in life.

5.2.3 Harris profile analysis

importance of criteria																								
	--	-	+	++	--	-	+	++	--	-	+	++	--	-	+	++	--	-	+	++	--	-	+	++
Supportive			🟩				🟩	🟩			🟩				🟩			🟧					🟩	
Calming			🟩				🟩				🟩				🟩				🟩				🟩	🟩
Stimulating			🟩				🟩				🟩	🟩		🟧				🟧				🟧		
Flexible		🟧				🟧				🟧				🟧					🟩				🟩	
Rewarding	🟧	🟧					🟩			🟧			🟧	🟧				🟧				🟧		

Table 5. Harris profile for prototypes and interactions

Based on the insights gained from the semi-interview, the prototypes were analyze by harris profile with the prioritized design criteria. Here, the tea bag concept has the highest score, because it not only integrated into a daily activity that elderly people in the Netherlands would do, but also brings new value to the original product. Drinking tea is already a calming and soothing activity, while during this time, now the family caregiver can take this small moment of daily life to reflect on their mental status and how well they are doing for themselves.

Each prototype includes an element of surprise to gently stimulate and engage the next of kin. This subtle revelation encourages continued use and supports the formation of a personal daily ritual.

The “Opening Book” evokes a supportive and calming experience, mimicking the act of reading. However, participants noted that its appeal depends heavily on the content revealed.

The “Calendar” aligns well with the idea of a morning routine, a key goal of the design. Still, its limited number of pages may restrict long-term engagement.

The “Flipping Coin” and “Fridge Magnet” introduce gamified elements that can boost interest. These could be further developed with components that link specific needs to corresponding activities or visual cues.

The “Tea Bag” prototype offers a familiar ritual for the target group. The tea tag presents a strong touchpoint for reflection, but the rationale for focusing on this moment requires clarification. Moreover, the connection between fundamental needs and visual prompts was unclear to users. Since tea tags are often overlooked, enhancing this interaction to create a more engaging and meaningful experience would strengthen the concept.

5.2.4 Conclusion & limitation

Limitation

While the interviews provided valuable insights into emotional responses and interaction preferences, a key limitation lies in the participant demographic. The intended target group for the design—family caregivers aged between 60 and 70—was not accessible within the scope and time constraints of this project. As a result, the interviews were conducted with students aged 20 to 30. Although their feedback helped evaluate the emotional and experiential aspects of the prototypes, it may not fully reflect the lived experiences, cognitive frames, or physical realities of the actual user group. Therefore, the findings from this round should be interpreted as preliminary insights, requiring further validation through future testing with the appropriate age group to ensure the design is truly aligned with their needs and context.

In conclusion,

This chapter translated research insights into design directions, following the understanding of the emotional and practical challenges faced by family caregivers during palliative care. Through iterative ideation, co-creation, and user feedback, several concepts were explored, evaluated, and refined using criteria rooted in the emotional needs of the target group.

The tea collection concept emerged as the most promising direction—balancing calming, supportive, and rewarding qualities. It gently integrates emotional reflection into daily routines, offering caregivers a low-effort yet meaningful interaction that promotes self-care and awareness of fundamental needs. “Flipping book” and “Magnets on the fridge” are some nice example of how to create an interesting interaction. These could inspire the further development of the tea collection concept.

By focusing on subtle emotional engagement and small daily rituals, the final concept aims to empower caregivers to regain a sense of balance, autonomy, and connection with the patient and HPCs, without overwhelming them during this vulnerable period. The next chapter will detail the final design and how it addresses the goals and values identified throughout this process.

Reflection

The concept chosen is for final concept is the tea collection for several reasons:

1. Calming and Supportive Nature
    - Tea drinking is a familiar, soothing ritual that fits naturally into the daily routines of many caregivers.
    - It encourages slowing down, taking a break, and creating moments of calm amidst emotional stress.
2. Emotionally Engaging
    - The tea notes offer subtle, non-intrusive prompts related to self-care and emotional awareness, aligning with the need for soft advocacy rather than direct confrontation during palliative care.
3. Balance of Stimulation and Reflection
    - Each tea bag includes a meaningful note or suggestion tied to fundamental needs, prompting gentle reflection or small self-directed actions.
    - This stimulates emotional engagement without being overwhelming or demanding.

4. Variations and Low-Effort Integration
    - The concept fits seamlessly into existing routines. Caregivers do not need to set aside extra time or learn new behaviors to use it.
    - Its flexibility makes it more likely to be accepted and sustained.

FINAL DESIGN & SHOWCASE

Based on the harris profile and the second-round iteration on the interactions, I choose to design a tea collection.

12 CUPS OF CARE is designed to support older adults in taking small, intentional moments for themselves each day. Each tea bag is wrapped in a folded illustrated card — creating a mini booklet — that pairs a specific type of tea with a short reflective prompt and a warm, relatable scene.

A Cup of Care

Each tea bag is paired with small activities connected to your fundamental needs.

The teas and prompts are chosen to reflect moments of calm, connection, movement, or rest.

Take this tea time to care for yourself.
Sip slowly, pause gently,
and let this be your moment.

Green Tea

Fold laundry, water some plants, or dust off the bookshelf

Let your hands tend with care

12 Cups of Care

Tea for your well-being

Green Tea	Ginger Tea
Lemon Balm	Earl Grey
Black Tea	Chamomile Tea
Hibiscus	Lavender Tea
Peppermint Tea	Rosehip Tea
Turmeric Herbal	Rooibos

12 TEA BAGS

12 Cups of Care

6.1 Design description

6.1.1 12 Cups of Care

12 Cups of Care is a tea experience designed to support the emotional well-being of family members in a palliative care context. The concept attempts to integrate personal fundamental needs into a familiar and calming tea drinking ritual for them to create small moments of care for oneself. It transforms everyday small events and actions into a soft prompt for reflection and cues, helping individuals connect with their own fundamental needs during the care for the loved ones.

This concept is based on the understanding that family caregivers sometimes forget or feel guilty about their own needs being fulfilled and having positive emotions during the palliative care phase. Despite ongoing emotional strain and responsibility, the concept aims to offer a low-threshold, accessible way to bring attention back to oneself. The design tends to support the family with their own well-being through not complex interventions, but simple, resonant moments of care.

6.1.2 Features

The Introduction (Figure 29) is divided into three sections regarding the context:

1. **Acknowledgment on the family caregiver's emotional struggles**: expressing empathy for common emotions during the palliative journey.
2. **Gentle reminder**: explaining why taking care of oneself is also important in this palliative care phase, and what can be done.
3. **Guidance on the intended use**: introducing the linkage between the visual and text cues to one's fundamental needs.

All elements are printed on 300g/m² paper to make sure a firm and comfortable sensation when flipping through the pages.

During palliative care, your loved one's needs will grow — but so might your own struggles.

It's normal to feel tired, overwhelmed, or unsure. You may forget to eat, to sleep, to rest well.

Try to care for yourself, too. Only by keeping yourself well can you stay strong for the one you care about.

Take small steps.
Let small moments be enough.
You don't have to do everything —
just what you can
when you can.

A Cup of Care

Each tea bag is paired with small activities connected to your fundamental needs.

The teas and prompts are chosen to reflect moments of calm, connection, movement, or rest.

Take this tea time to care for yourself.
Sip slowly, pause gently,
and let this be your moment.

Figure 29. Three sections of introduction: explaining the future, empathy on their struggles, and connection of fundamental needs with drinking tea

A Cup of Care

Each tea bag is paired with small activities connected to your fundamental needs.

The teas and prompts are chosen to reflect moments of calm, connection, movement, or rest.

Take this tea time to care for yourself.
Sip slowly, pause gently,
and let this be your moment.

Green Tea
Fold laundry, water some plants, or dust off the bookshelf
Let your hands tend with care

Lemon Balm
Take a hot shower, let fresh air in, or write a small grocery list
Let the day begin with calm

Black Tea
Light a candle, use your favorite fragrance or let in some fresh air
Let a soft scent fill the room

Hibiscus
Old favorites or soft tunes. Let sound carry you for a while
Let a melody fill the room

Peppermint Tea
Go for a walk, strech your back, or lie down and take a deep breath
Let a stretch wake you up

Turmeric Herbal
Warm your hands on your cup, turn on the radio, or read a page
Let a warm meal start your day

Ginger Tea
Joy, longing, or gratitude all are welcomed
Let photos guide your thoughts

Earl Grey
Share a thought, a memory, or simply how today feels
Let your feelings be heard

Chamomile Tea
in a soft chair, on the sofa, or wrapped in a warm blanket
Find your peace

Lavender Tea
Enjoy the sunset, write down a thought or a memory
Let the golden hour comfort you

Rosehip Tea
The flowers, the breeze, the bird. Even small moments hold life
Let the city move around you

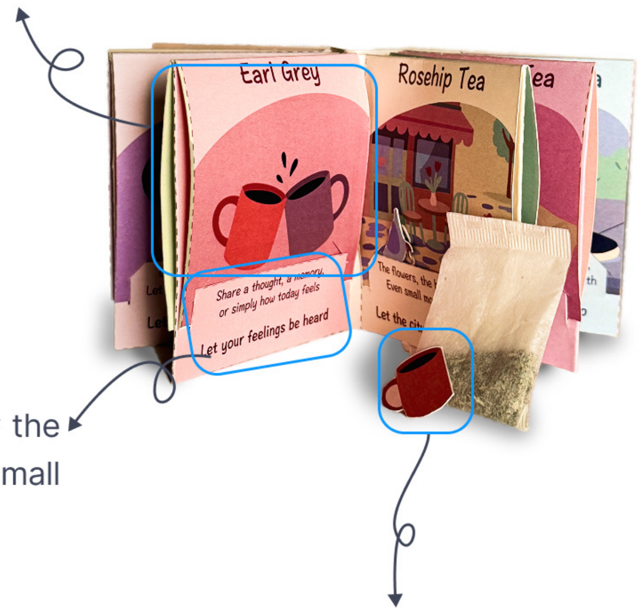
Rooibos
Pause by a tree, listen to the birds, feel the sun or wind
Let the nature come in

Try to care for yourself, too. Only by keeping yourself well can you stay strong for the one you care about.

Take small steps.
Let small moments be enough.
You don't have to do everything —
just what you can
when you can.

Figure 30. Overview of the 12 cups of care(folded)

A graphic illustration portraying a scene of gentle, everyday care (e.g., a refreshing shower, a walk outdoors, a shared moment)



A brief written prompt inspired by the scene, suggesting a specific small action to support well-being

A tea tag, embedded as a key object in the illustration, acting as a symbolic or playful trigger for action cue

Figure 31. Description of designed components

The inner packaging (Figure 30, 31) of the tea bags takes the form of small envelopes, each carrying a gentle reflective prompt (e.g., "Let your feelings be heard," "Let the morning greet you slowly"). Inside each envelope is a different type of tea, thoughtfully paired with the suggested moment or activity. The design draws on six fundamental needs identified in earlier research as being the most accessible for elderly users to fulfill in daily life. However, the suggestions are not limited to a single need; rather, they reflect an integration of several, acknowledging the interconnected nature of well-being. By encouraging users to act on these simple, low-effort prompts, the product aims to gradually restore emotional balance and

The flowers, the breeze, the bird.
Even small moments hold life

Let the city move around you

Function
Rich in vitamin C, immune-boosting, has a gentle fruity sweetness

Needs related
Beauty, Comfort, Stimulation

Pause by a tree, listen to the birds,
feel the sun or wind

Let the nature come in

Function
Caffeine-free, rich in antioxidants, supports heart health

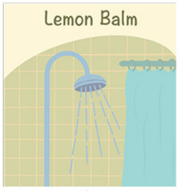
Needs related
Beauty, Fitness, Stimulation

in a soft chair, on the sofa,
or wrapped in a warm blanket

Let yourself find peace

Function
Calming, aids sleep, soothes anxiety and digestion

Needs related
Ease, Stimulation



Fold laundry, water some plants,
or dust off the bookshelf

Let your hands tend with care

Function
Uplifting, reduces stress, supports cognitive function

Needs related
Purpose, Fitness, Autonomy

Take a hot shower, let fresh air in,
or write a small grocery list

Let the day begin with calm

Function
Energizing, boosts brain function, supports metabolism

Needs related
Purpose, Impact, Morality

Light a candle, use your favorite
fragrance or let in some fresh air

Let a soft scent fill the room

Function
Comforting, improves alertness, has a grounding effect

Needs related
Stimulation, Ease, Security

Enjoy the sunset,
write down a thought or a memory

Let the golden hour comfort you

Function
Calming, lowers heart rate, good for rest and emotional release

Needs related
Ease, Beauty, Security

Go for a walk, strech your back,
or lie down and take a deep breat

Let a stretch wake you up

Function
Anti-inflammatory, grounding, supports immune system

Needs related
Fitness, Stimulation, Competence

Warm your hands on your cup,
turn on the radio, or read a page

Let a warm meal start your day

Function
Refreshing, helps with focus, relieves headaches and bloating

Needs related
Fitness, Stimulation, Purpose

Old favorites or soft tunes.
Let sound carry you for a while

Let a melody fill the room

Function
Tart and refreshing, lowers blood pressure, boosts energy

Needs related
Stimulation, Ease, Purpose

Joy, longing, or gratitude
all are welcomed

Let photos guide your thoughts

Function
Warming, helps digestion, reduces nausea and fatigue

Needs related
Recognition, Impact, Security

Share a thought, a memory,
or simply how today feels

Let your feelings be heard

Function
Uplifting and comforting, reduces anxiety

Needs related
Recognition, Relatedness, Security

create small moments of meaning and self-value within their everyday routines.

The 12 tea bags are designed around 6 key fundamental needs that emerged as most prominent and accessible in this context: Beauty, Ease, Fitness, Purpose, Stimulation, and Recognition.

For each need, two tea bags were selected—one offering a refreshing, energizing effect, and the other promoting calmness and restful support. This approach ensures that whenever the user feels the urge to drink tea, they are gently motivated to engage in a meaningful activity, regardless of their energy level or emotional state. The activities also follow two distinct tempos: one mild and soothing, encouraging relaxation and ease, and the other more alert and mindful, supporting moments of clarity and activation.

The tag attached to each tea bag is derived from the key visual element within its corresponding illustration. For instance, in the envelope labeled “Let a soft scent fill the room,” the drawing depicts a hand lighting a fragrance candle, and the tea tag takes the form of a small flame.

The choice of the tea tag as a touchpoint was informed by insights from the second-round iteration interviews, where participants mentioned that they often subconsciously pull the tea tag in and out of the cup while steeping the tea, which is an automatic gesture that enhances the release of scent and flavor. Building on this habitual action, the design intentionally links the visual cue (the illustration) with the tactile experience of using the tea bag. This connection transforms the action into a reflective moment of understanding the needs and integrating the suggestions into something that could be accessible for them to do within their surroundings.

6.1.3 Design Rationale

The rationale behind the design is illustrated through a mind map that draws directly from the findings of prior research. **The literature review** provided theoretical grounding and directions for the development of content. **Insights from the design iterations** and user interviews further informed key design decisions, guiding the concept toward focusing on small, everyday rituals that can be naturally integrated into daily life. The research also revealed what forms of interaction and experience were most appreciated by users: those that offered gentle stimulation without evoking overly intense emotions. Additionally, the findings deepened the understanding of which fundamental needs are most accessible to fulfill in everyday contexts, and which types of activities evoke a sense of accomplishment or satisfaction. Together, these insights shaped the reflective prompts featured on the tea envelopes (Figure 32).

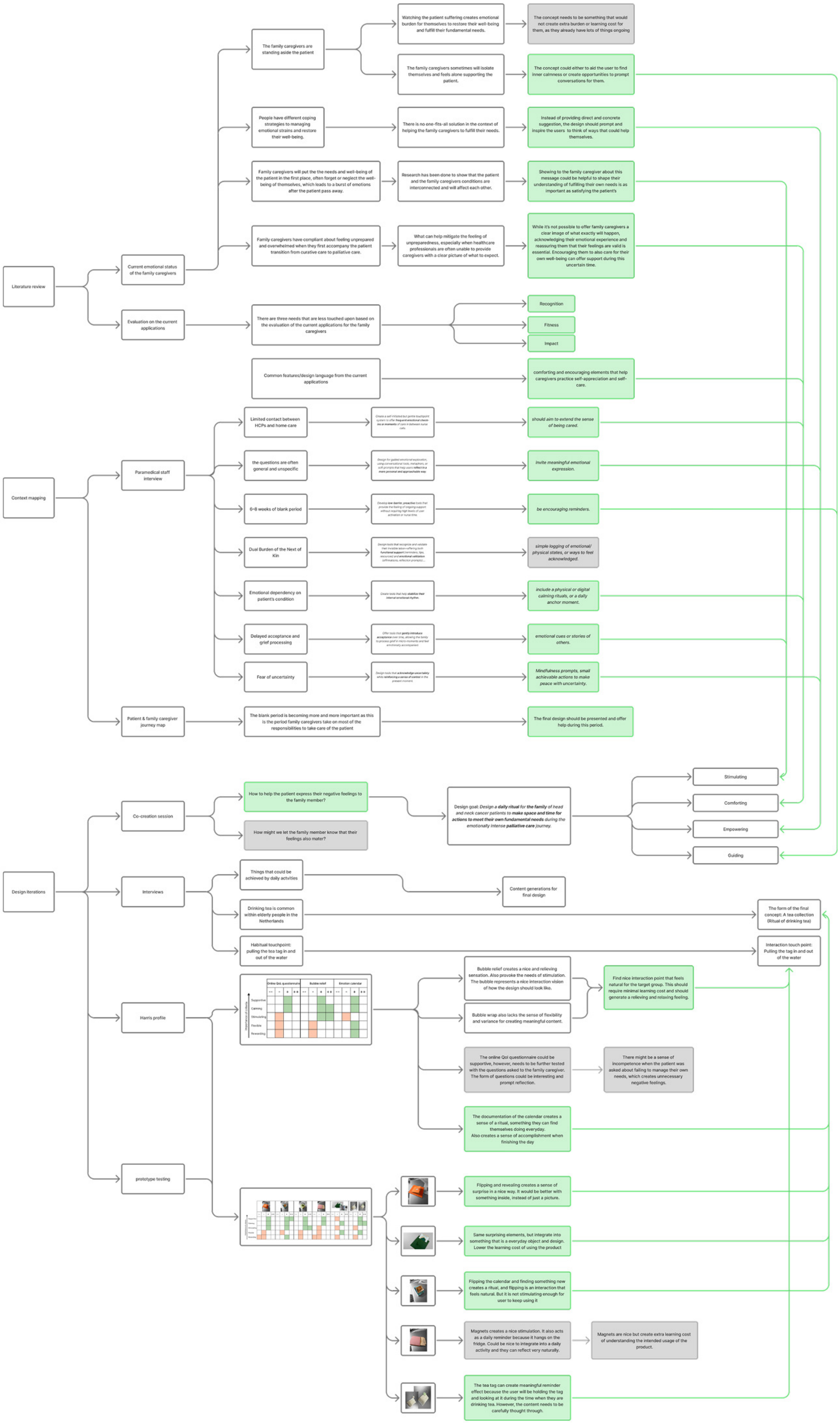


Figure 32. Insights touched upon during previous research and how they are translated into design decisions

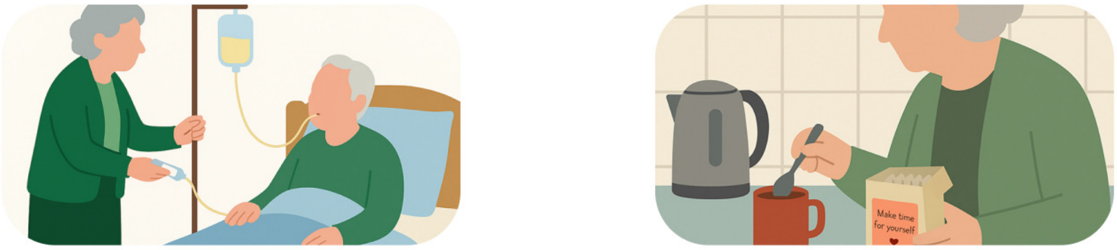
6.2 Story board

6.2.1 Story board of 12 Cups of Care

The storyboard (Figure 33) illustrates how the Tea Collection concept integrates seamlessly into the daily life of a family caregiver during the palliative phase. The small interactions serve as gentle prompts for reflection and emotional awareness, offering moments of calm and encouraging caregivers to care for themselves during a period that is both emotionally challenging and deeply connected to the patient.

1
The family received a palliative care package

2
They will receive a box of tea

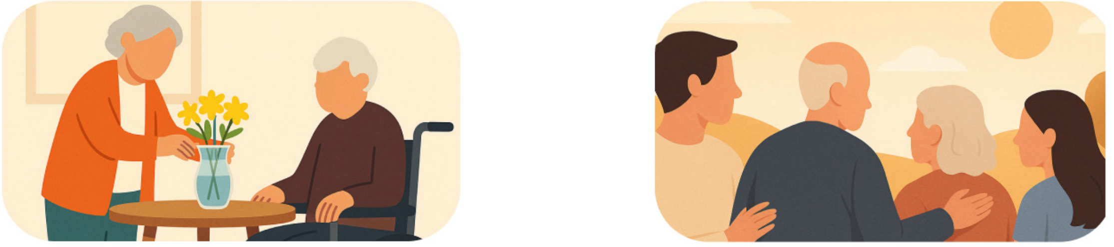


3
After a long day taking care of the patient

4
His partner would like to have some tea

5
Watching TV together with the patient, she notice the tag attached “Enjoy something beautiful”

6
In the evening when she goes to the grocery store, she remembers the tag and decides to buy some flowers



6
The family caregiver can also share the experience with the patient, even share the tea.

6
Family caregivers can together enjoy the tea with the patient, understanding each other’s needs.

Figure 33. Story board of the final design (generated by DALLE-3)

6.2.2 Intended Usage in sequence of pictures

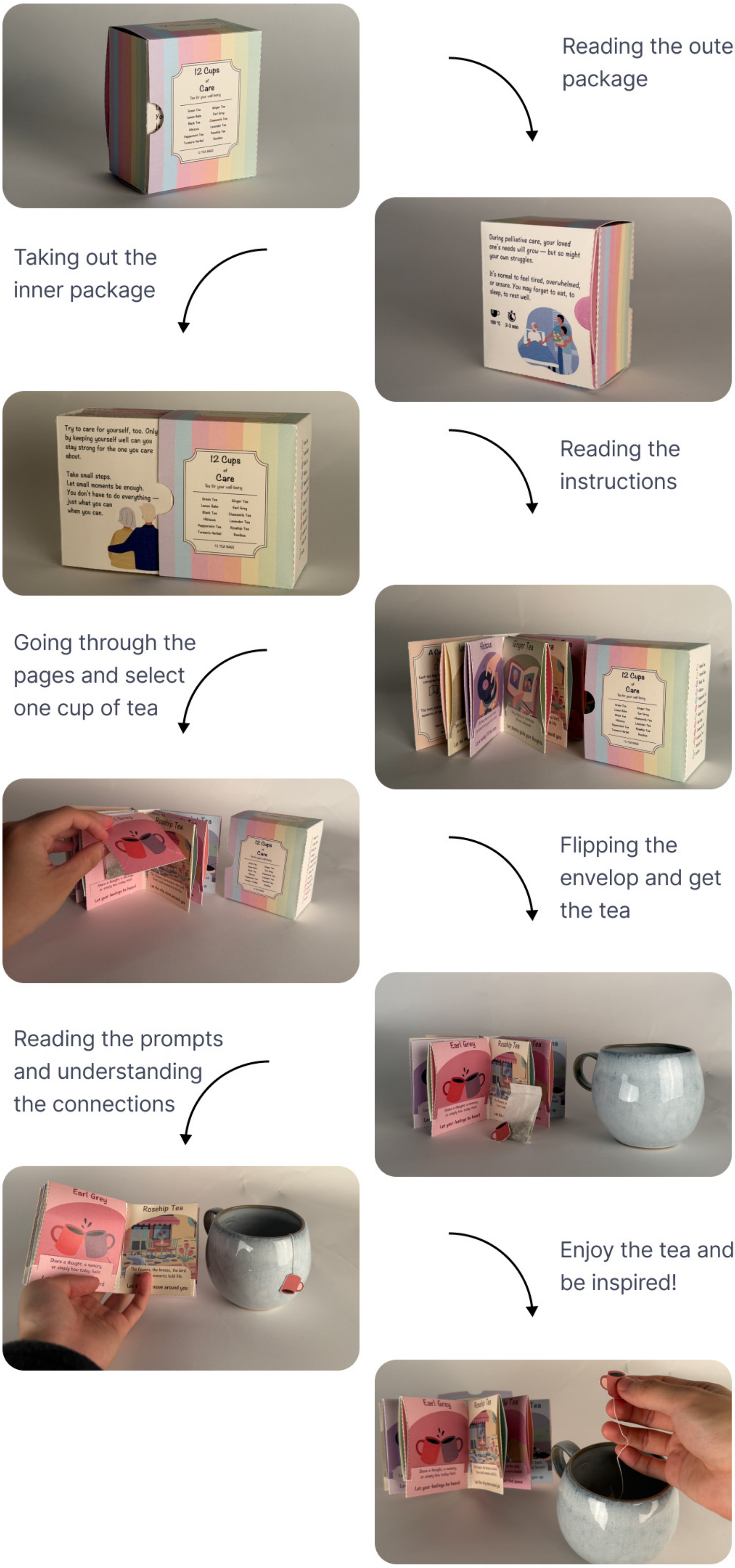


Figure 34. Step-by-step usage of the product

The product comes with a 8.5×5.5×10cm box with a inner package with a 0.5cm shrinkage. The shrinkage allows for a smooth take out of the inner package.

The envelops inside are made as a whole to ensure the integrity of the product. The first page is to empathy with the user and explaining the idea of only by taking good care of your own well-being, can you support the patient in a better way.

The inner page explains the relation of visuals with the fundamental needs and prompt the user to follow the suggestions.

Minimal font size is 14 px to ensure the readability for elderly group.

6.2.3 Positioning of the concept

While the prototype is tested with elderly users outside the direct palliative context, the final concept is envisioned to be introduced (Figure 35):

- By care professionals or support services early in the palliative caregiving journey
- In community centers, support group spaces, or via care packages
- As a passive support tool, requiring no external facilitation. Days after the consultation of changing of the treatment plan, the family caregiver will receive the package from the hospital

It is easily accessible and allows for broad distribution without additional learning cost for usage, making it suitable for informal integration within home care infrastructures.

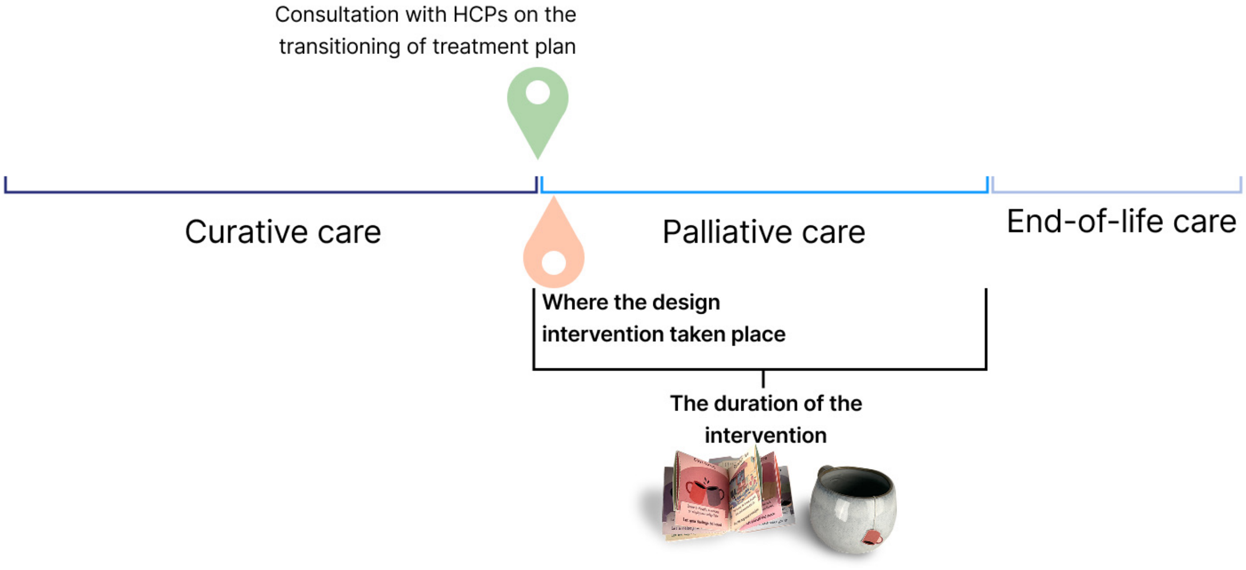


Figure 35. Positioning of the design intervention in the care pathway


Earl Grey
Share a thought, a memory,
or simply how today feels
Let your feelings be heard
The flowers, the breeze, the bird.
Even small moments hold life
Let the city move around you
chair, on the sofa,
or wrapped in a warm blanket
Let yourself find peace
Tea
your back,
a deep breath
Let a stretch wake you up
Let a melody fill the
Let the day begin

EVALUATION & VALIDATION

After the final prototype was made, follow-up tests and evaluation were planned to understand how the users perceive the design and whether the design is effective to achieve its intended purpose. More insights and improvements were gathered regarding the previous criteria of design.

7.1 Evaluation test

7.1.1 Testing setup

The final evaluation was set up with 3 participants in the form of interview. The participants were first sensitized with several questions regarding their previous care taking experiences. This was to understand their what the home caregivers situation really are. Even thought the participants were not caregivers for HNC patients, they indicated their previous experience of taking care of someone who is seriously ill. The conversation was structure mainly to get an overview of how clear the product deliver the message and whether the product could in any way provide support or motivations for the family caregivers to be mindful about their action and own mental well-being.

The interviews were 45- 60 mins long with the main research questions focusing on three aspects:

1. Emotional engagement: whether the product evoke comfort, reflection, or sense of care.
2. Clarity and usability: whether the prompts and hints are clear and people feel like the suggestions are feasible for them to achieve in daily life.
3. Perceived values: whether the product fits the intended use to provide user with support and whether the user would like to use the product alone or share it with others.

Two participants in the 60-70 age group were recruited and one in his 30s to ensure the evaluation covers the target age group. All the participants were first asked whether they have experience with palliative or end-of-life care. The three participants all indicated their experience of taking care of someone in their end-of-life stage.
To avoid sensitivity of the topics, the participants were informed with care to show that the topic may be a bit heavy in the sense that they will tell stories about their passed beloved ones. The discussions were reached to an agreement to not reporting the stories in any kind for the research but merely involve them in the context and think through a caregiver's perspective.

7.1.2 Methodology

The semi-interview includes two parts: first the user will be sensitized with some question regarding their experience of palliative care or end-of-life care. Then the users were asked to think out aloud while interacting with the product to see which parts caught their attention and which part did not.

Then, the data were analyzed through thematic analysis based on the conversation with reference user group. Key insights were gathered and categorized into main themes and recommendations for refinement.

7.1.3 Results

Overall, participants responded positively to the concept and design of the product. The interaction model and supportive intention were clearly understood as intended. Instructions and text were found to be readable and accessible for the target age group. The key insights are summarized below:

Visuals and Tone:
Participants appreciated the visual presentation and color palette, describing it as “innocent” , which is a quality they often associate with children. This conveyed a gentle, harmless presence that felt appropriate for emotionally vulnerable people.

Accessibility:
The product was perceived as highly accessible, with a low learning curve. Text size was suitable even for users aged 60–70, allowing for easy reading without glasses.

Relevance of Suggestions:
The activities described in the small envelopes were seen as small, manageable suggestions that align well with users’ daily routines. Participants noted that the tasks felt achievable without requiring much effort.

Experience for Tea Drinkers:
Regular tea drinkers felt the product aligned well with their existing routines and could enhance moments of calm. They noted that tea itself already holds relaxing value, and the addition of prompts added a new dimension to the ritual.

Experience for Non-Tea Drinkers:
Those who do not regularly drink tea still found value in the product. They mentioned that if the package were placed somewhere visible, it could function more like a booklet, something they would enjoy browsing through even without drinking the tea.

Flexible Use:
Across both groups, users expressed that reading the pages alone was already meaningful. The prompts were viewed as reflective and supportive, even if not directly linked to the act of drinking tea. The product was valued as a gentle source of inspiration in everyday life.

Role of Visuals and Action Cues:
Users recognized that the colors and visuals subtly indicate different fundamental needs. However, they felt it was not always necessary to make these needs explicit, as the activities themselves already conveyed the intent.

Positioning of Message:
Some participants felt that direct references to palliative care could evoke negative associations. They suggested a more indirect or empathetic way of addressing this context to avoid creating discomfort or resistance.

7.2 Recommendation & Limitation

7.2.1 Recommendation

1. Maintain a Gentle and Innocent Visual Tone
Continue using soft colors and child-like, “innocent” illustrations. These visuals were seen as emotionally safe and comforting, especially valuable in moments of vulnerability. Avoid overly clinical or somber aesthetics to keep the tone approachable and reassuring.

2. Preserve High Accessibility
Keep the current text size and clear layout, as it was readable even for participants aged 60–70 without glasses. Ensure consistent visual hierarchy and contrast for optimal legibility.

3. Keep Suggestions Simple and Achievable
Maintain the current format of short, manageable activities. Users valued that the actions were light and easy to do without requiring much effort. Consider keeping a mix of calming and activating prompts to match different energy levels or moods.

4. Embrace the Flexibility of Use
Recognize that the concept functions beyond tea drinking. Allow users to engage with it however feels right, as a booklet, a visual journey, or a reflective object. Highlight this open use of the product based on the users’ own habits and preference.

5. Tea drinking as a calming and relaxing ritual
Tea drinking is something that the user group has been already doing. This activity can be a medium to support the family caregivers’ well-being and provide more value for them during palliative care. Even little things and gentle words can already give them a feeling that they are being cared and supported by someone.

6. Continue Using Visuals to Suggest Needs, But Keep It Subtle
Keep embedding fundamental needs into the design through visuals and cues. Avoid overtly labeling the needs; participants felt the intent was already clear through the activities themselves.

7. Soften the Framing of Palliative Care
Consider repositioning the palliative care message with empathy. Instead of naming it directly on the front or at first glance, provide context gently through storytelling or inner messages, e.g., “For moments when care feels heavy” or “For those supporting a loved one.”

7.2.2 Limitations

While the final evaluation of the design concept gathered valuable insights from participants with caregiving experience, it is important to acknowledge key limitations.

The participants were not necessarily next of kin who had cared for someone during the final stages of life, and some had not experienced the death of the person they supported. This may influence the depth of emotional responses and the urgency of needs expressed. Additionally, younger participants may not have carried the full caregiving responsibility, especially in end-of-life scenarios, which could lead to different perceptions of stress, guilt, or support needs. As a result, the emotional impact and relevance of the concept may differ from those of family caregivers currently navigating the palliative phase of care.

However, it is important to understand that the people that is or has been going through palliative care are also just normal people, and they are just going through some difficult times. Their needs, habits, preferences may not be that different from other people in their age. Therefore, the design and intervention can still be viewed an indication of how Erasmus MC could provide more value and gentle care through this process despite all the effort they have already put for the family of head and neck cancer.

7.3 Personal reflection

Looking back on this graduation journey, I realize how much I have grown, not only as a designer but also as a person. This project has taught me that design is not only about creating solutions, but also about listening, understanding, and translating complex human experiences into something meaningful and supportive.

Working with **Erasmus MC** and receiving help and feedback from the medical staff I felt was one of the most grateful parts of this process. It allowed me to see firsthand how dedicated healthcare professionals are in their continuous effort to improve patients' well-being and support people in need. Observing their empathy, professionalism, and persistence deeply inspired me and made me appreciate the hospital's mission to always strive for better care. Their perspective helped me stay grounded, reminding me that design in healthcare is not about perfection, but about making even small, meaningful differences in people's lives.

Throughout this project, I also learned the value of clarity, both in communication and in process. Early on, I often found myself trying to explore too many directions at once. But through research, feedback, and reflection, I learned how to define priorities, make decisions with confidence, and communicate my intentions more effectively. This process taught me that being decisive does not limit creativity; rather, it allows ideas to take shape and move forward.

Collaborating with people from different disciplines, designers, researchers, and healthcare professionals, has helped me understand how crucial empathy and collaboration are in creating sustainable impact. The conversations and feedback I received from the medical staff often went beyond my initial design perspective and reminded me of the emotional and ethical dimensions of working within a healthcare context.

Personally, this project also challenged my patience and resilience. There were moments of uncertainty and self-doubt, but those experiences pushed me to find strength in persistence and to value learning over immediate results. Seeing the final concept take shape, and realizing how it could contribute to the experience of patients and their families, made the journey deeply fulfilling.

In the end, I graduate not only with a design project but with a clearer sense of purpose. I have learned how to combine empathy with structure, research with intuition, and theory with practice. Most importantly, I have developed a greater respect for the people working in healthcare and the quiet, ongoing efforts they make to improve the lives of others.

This project has reaffirmed my belief that design can play a meaningful role in supporting care, connection, and well-being, and I hope to continue exploring that path in my future work.

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