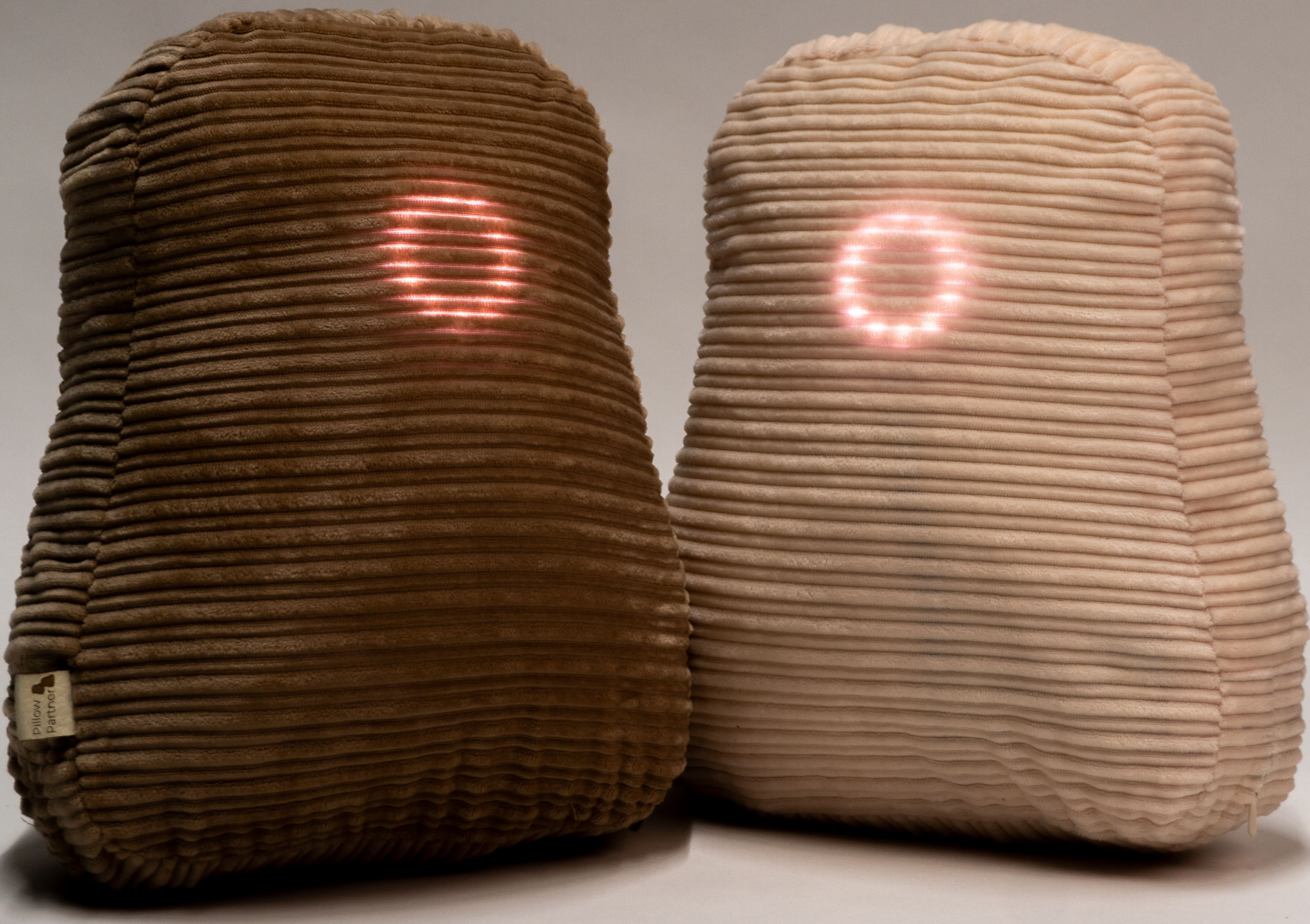
CAUGHT BETWEEN TWO SILENCES

Exploring Support for Sexual Well-being in Relationships Affected by Incurable Cancer



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MSc Strategic Product Design

COLOPHON

Caught Between Two Silences

Exploring Support for Sexual Well-being in
Relationships Affected by Incurable Cancer

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PREFACE

“Eroticism is assenting to life up to the point of death.”

— Georges Bataille

Serious illness often changes how people relate to their bodies, their partners, and themselves. In the context of incurable cancer, attention is understandably directed toward treatment, symptoms, and survival. Yet alongside these concerns, the need for closeness, touch, desire, and emotional connection does not disappear. Instead, it often becomes more complex, fragile, and harder to express.

This project starts from the assumption that sexuality and intimacy are not separate from life when illness is present, but remain part of it until the end. They are shaped by vulnerability, uncertainty, and shifting roles, but also by care, connection, and meaning. Addressing these themes requires sensitivity, openness, and an approach that goes beyond purely medical solutions.

As a design research project situated between healthcare and industrial design, this work seeks to explore how design can contribute to this sensitive domain. Rather than aiming to solve or standardize intimate experiences, the project takes an exploratory stance toward how sexuality and intimacy are experienced and expressed in the context of incurable illness. It is guided by respect for personal boundaries and by awareness of the emotional and ethical complexity that characterizes palliative care.

This thesis does not claim to offer final answers. Instead, it presents a careful exploration of how design might support people in staying connected to themselves and to each other, even when life is marked by illness and uncertainty.

EXECUTIVE SUMMARY

Sexuality and intimacy remain important aspects of quality of life in the context of incurable cancer and palliative care, yet they are often difficult to address within healthcare practice and intimate relationships. People with incurable cancer and their partners experience changes in intimacy, communication, and relational balance, while support for these experiences is often limited or primarily medically oriented. This graduation project explores how design can sensitively support sexual well-being in palliative care.

The project was conducted as part of a broader research initiative at Erasmus Medical Center and focused on translating qualitative research insights into a concrete design concept. A combination of design research methods and qualitative healthcare research approaches, including literature review and in-depth interviews, was used to explore the problem space.

The research identified two central relational mechanisms: autonomy and communication. Partners often struggle to express personal needs without guilt, while communication about intimacy becomes challenging due to emotional burden and shifting relational roles. These insights informed the formulation of design opportunities and guided a broad exploration of possible design directions.

Through a structured selection process, one concept direction was chosen for further development: the Pillow Partner. This concept consists of a pair of connected pillows that allow partners to record and listen to intimate voice messages. It aims to support autonomy by enabling control over timing and emotional exposure, and to support communication by offering an indirect and less confrontational medium for sharing sensitive thoughts.

The concept was refined through expert interviews and exploratory user interviews, which provided insights into emotional impact, usability, and contextual sensitivity. Key findings emphasized the importance of a warm, non-medical and gender-neutral design, physical comfort, and a sense of connection, while also revealing tensions between autonomy, simplicity, and relational responsibility.

Finally, implementation considerations were explored, focusing on low-threshold introduction, discretion, privacy, and the supportive role of healthcare professionals. Rather than presenting a final solution, this project offers a grounded design concept and strategic directions for further development. It demonstrates how design can meaningfully contribute to supporting communication and autonomy in intimate relationships affected by incurable illness, while acknowledging the ethical and emotional complexity of this domain.

TERMINOLOGY

To support clarity and accessibility, this section explains key terms and abbreviations used throughout this thesis.

Sexuality
In this thesis, sexuality is used in line with the World Health Organization (WHO) definition. It refers to a broad and multifaceted concept that includes physical, emotional, relational, and expressive aspects of human experience. Sexuality is not limited to sexual acts, but also includes feelings of closeness, identity, desire, communication, and meaning.

Intimacy
Intimacy is treated as a component of sexuality and refers specifically to emotional closeness, affectionate interaction, physical proximity, and relational connection between people. In palliative care contexts, intimacy is often used as a less explicit or more accessible term when discussing sexual matters. For this reason, the terms sexuality and intimacy sometimes appear together in interviews and materials. In the analysis, they are treated as related but not identical concepts.

Contextmapping
Contextmapping is a design research method used to explore people's experiences, emotions, and needs through reflective and often creative tools. In this project, contextmapping supports the exploration of sensitive topics that may be difficult to articulate directly.

Palliative care
Palliative care refers to care aimed at improving quality of life for people with life-limiting or incurable illness and their loved ones. It addresses physical, psychological, social, and existential dimensions of well-being, rather than focusing solely on curative treatment.

Autonomy
Autonomy refers to the experience of acting in line with one's own values, needs, and motivations, while remaining connected to others.

Within intimate relationships, autonomy does not mean independence, but rather having a sense of choice and self-direction in how needs and feelings are expressed.

Communication
Communication is used to describe both verbal and non-verbal ways in which partners share emotions, needs, boundaries, and experiences. In this project, communication is understood as a relational process that can be emotionally sensitive and influenced by context, illness, and power dynamics.

ROLES AND EXPERTISE

Sexologist
In this thesis, the term sexologist refers to professionals with medical, psychological, or therapeutic expertise related to sexuality, intimacy, and sexual well-being.

Healthcare professional
Healthcare professional is used as an umbrella term for medical specialists, nurses, psychologists, and other care providers involved in palliative care.

ABBREVIATIONS

- WHO – World Health Organization
- SDT – Self-Determination Theory
- EMC – Erasmus Medical Center
- IDE – Industrial Design Engineering

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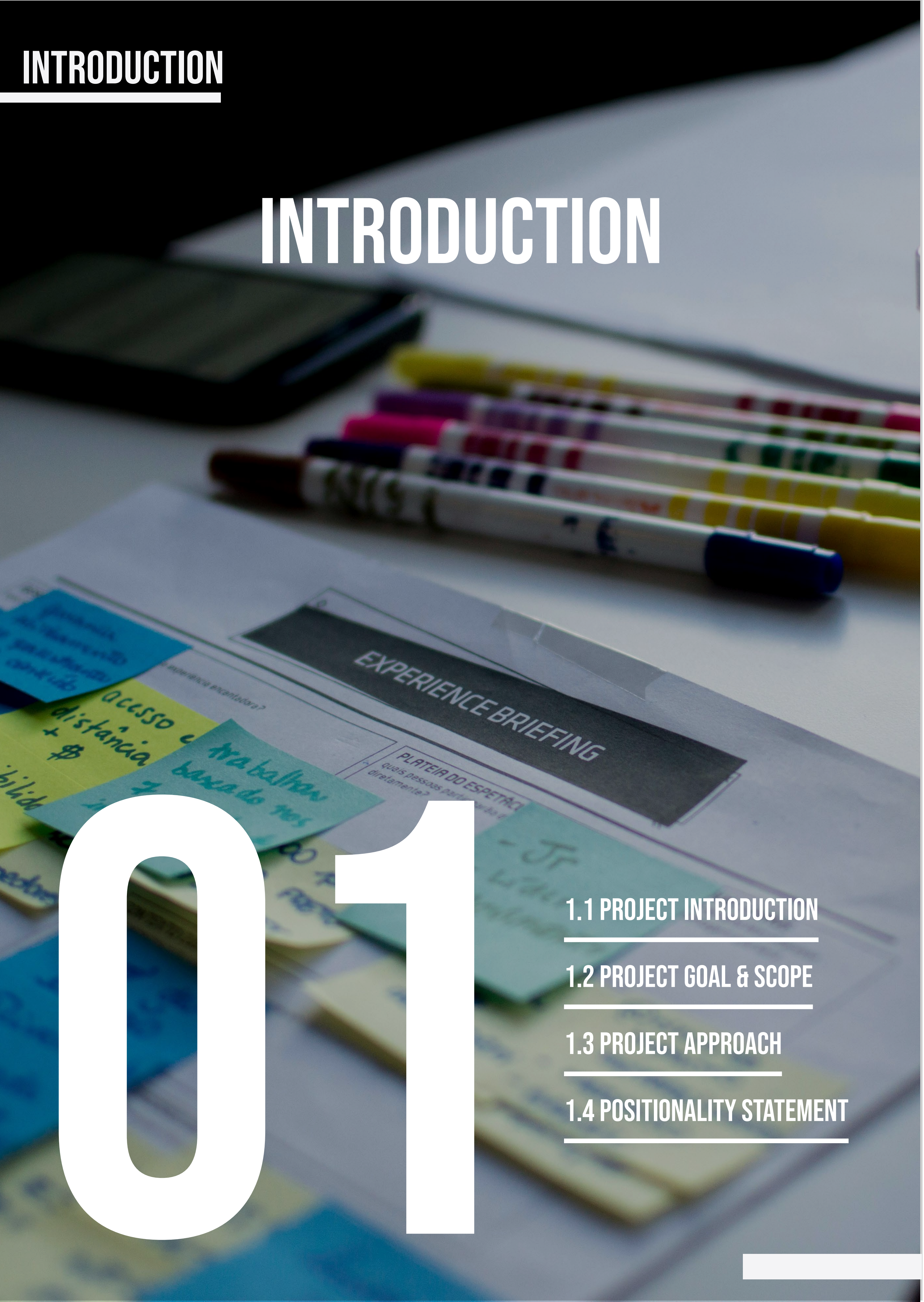


INTRODUCTION

01

1.1 PROJECT INTRODUCTION

Sexuality is known to be an important contributor to general well-being and quality of life (Robinson & Molzahn, 2007; World Health Organization: WHO, 2019). Although literature about the needs for sexual wellbeing of people with incurable cancer is limited (Hjalmarsson & Lindroth, 2020), it is clear that many people within this group experience problems related to their sexuality (Higgins & Hynes, 2018). In general 11-15% of the Dutch population is dissatisfied with their sex life (Seksuele Gezondheid in Nederland, 2017). Yet, a large European study conducted across six countries, including the Netherlands, shows that 42% of people with advanced cancer and 33% of their partners report dissatisfaction with their sex life (Matthys et al., 2024). Even after receiving a diagnosis of incurable cancer, many individuals and their partners continue to value sexuality as important aspects of their lives, regardless of health challenges (Wang et al., 2018). The need for sexuality in this special phase does actually not decrease, however it does often change (Kelemen et al., 2019).

Against this background, palliative care is increasingly framed in a holistic manner, in which care is not only aimed at physical symptoms but also addresses psychological, social, and existential domains (Over leven tot het laatst, 2025). Recent initiatives in palliative care specifically emphasize the recognition of sexual well-being as a topic of importance (Pal voor U, 2024). This increased attention represents an important shift from sexuality being largely overlooked toward its recognition as a relevant aspect of holistic palliative care.

At the same time, actual implementation in daily care practice remains limited. Unfortunately, practice shows that this change in ideology has difficulty finding adaptation with care practitioners (Hjalmarsson & Lindroth, 2020). Previous studies seem to fail to provide a holistic approach to sexuality that goes beyond the medical approach. Research in this area often concentrates on patient groups with gender-specific cancers that impact sexual organs, such as breast cancer among women or prostate cancer among men (Matthys et al., 2024; Offerman et al., 2025). Studies that do acknowledge the multifaceted nature of sexuality often describe sexuality as embedded in emotional, relational, and contextual factors. However, these studies tend to remain at a relatively abstract level, focusing on general themes or broad recommendations. As a result, they offer limited guidance on how such insights can be translated into concrete forms of support within palliative care practice (Donz et al., 2024).

This project addresses two main gaps:

1. A limited holistic understanding of sexuality in the context of incurable cancer, as existing research often prioritises medical or functional aspects over relational and emotional experiences; and
2. a lack of translation of these insights into actionable support solutions.

This project therefore combines context-mapping to generate a holistic understanding with iterative prototyping to translate insights into a concrete supportive concept.

1.2 PROJECT GOAL & SCOPE

Following the identified gap, research at Erasmus Medical Center (EMC) was initiated by project lead Evi Bakker to “better understand the experiences and needs of people with incurable cancer and their partners regarding sexuality, relationships and intimacy, and how these needs can be best addressed.”

This report from the graduation project at the Delft University of Technology forms one design-focused part of the broader EMC research program. While the main EMC project aims to generate a deeper understanding of lived experiences with respect to sexuality in palliative care, this graduation project combines independent design research with qualitative methods to both generate and interpret insights. These insights are then translated into an actionable design direction through iterative design exploration. The central assignment guiding this graduation project is:

> “Design and develop a prototype (physical, digital, or otherwise) to support the sexual well-being of people with incurable cancer and their relatives.”

Within this scope, the project explores how design can meaningfully support individuals and couples during the last phase of life, and how sensitive insights from qualitative research can be translated into tangible forms. The project includes exploring user experiences, generating concept directions, iteratively refining a chosen concept, and formulating strategic recommendations for future development.

The project does not aim to test clinical effectiveness. However, potential future application in healthcare settings is left open, and insights gathered in this project may contribute to later implementation.

1.3 PROJECT APPROACH

This project follows the Double Diamond framework introduced by the British Design Council (2005). This structured method supports a thorough examination of the problem space and guides the creation of solutions backed by evidence (Humble, 2025). The model structures the design process into four phases: Discover, Define, Develop and Deliver (See Figure 1).

The four phases are structured by alternating cycles of divergence and convergence. While the framework provided the overall structure, each phase was adapted to the specific needs of researching sexuality in the context of incurable cancer.

Discover — Understanding experiences, needs and context

This phase used qualitative research methods commonly applied in public health and design. Semi-structured in-depth interviews, contextmapping techniques and sensitizing materials were used to explore how people with incurable cancer and their partners experience sexuality. These methods were chosen because they help reveal personal and emotional experiences that are difficult to express directly.

In parallel, expert and market-oriented interviews were conducted with sexologists and people with commercial experience in the industry of sexual wellness. These conversations provided insight into existing support tools, current gaps in care, practical barriers to implementation and taboos around sexuality and illness. Together, these user and expert perspectives shaped the understanding of the problem space and informed the focus of the later design brief.

Define — Synthesizing insights into a clear design brief

Data from the interviews was analyzed inductively and clustered into themes. These themes were then triangulated with findings from literature and expert interviews. This process led to a focused problem statement, a design goal and design requirements that guided the rest of the project.

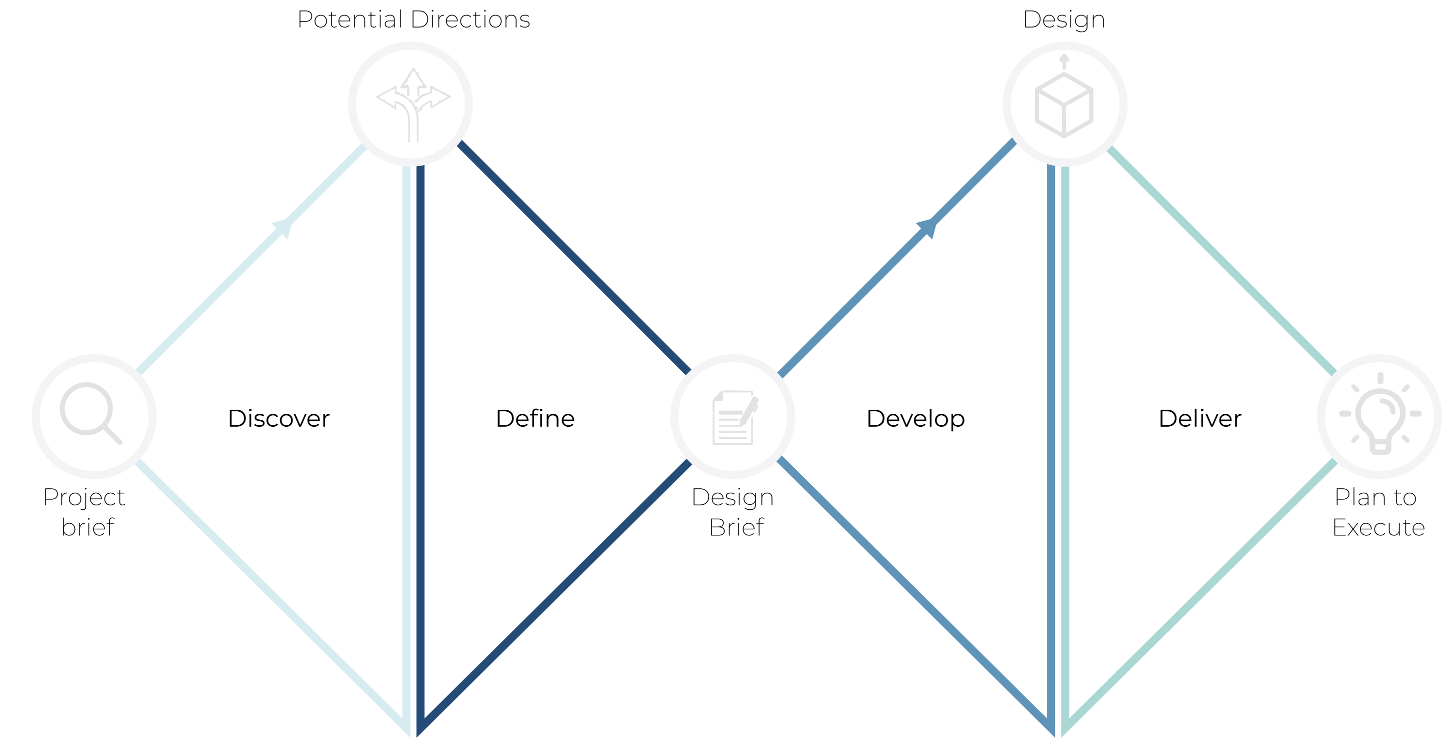


Image 1: Double diamond framework

Develop — Exploring and Refining the Concept

To explore the design space and generate a broad range of potential solutions, several methods were combined. How Might We questions were used to reframe the themes into opportunity areas, followed by a morphological chart to map functional possibilities and structure the design space. Concept generation then emerged from combinations within this chart, resulting in eight initial concept directions. A selection method (Harris profiles) was applied to identify one concept for further development.

This selected concept (the Pillow Partner) was subsequently refined through two iterative cycles. In Iteration 1, expert interviews were conducted to examine feasibility and clarify relational and functional requirements. In Iteration 2, semi-structured user interviews using simple prototypes provided insights into desirability, relational meaning, and how well the concept supported autonomy and communication.

Deliver — Final refinement and strategic recommendations

The final phase focuses on refining the concept based on all insights and translating it into a clear concept proposal with guidelines for implementation. In this step, recordings and notes from earlier expert interviews were re-analyzed to extract strategic insights about viability, adoption, and integration within healthcare and commercial ecosystems.

1.4 POSITIONALITY STATEMENT

My position in this project is shaped by my background as an industrial design engineer and by working within a public health (Maatschappelijke Gezondheidszorg) research environment. As a designer, I often work iteratively, combine information early, and use methods such as contextmapping that focus on emotions, lived experience and imagined futures. These tools support exploration of sensitive topics, but they may also encourage early attention to possibilities and solutions. I tried to balance this by keeping the exploration broad, delaying decisions, and grounding choices in multiple forms of data.

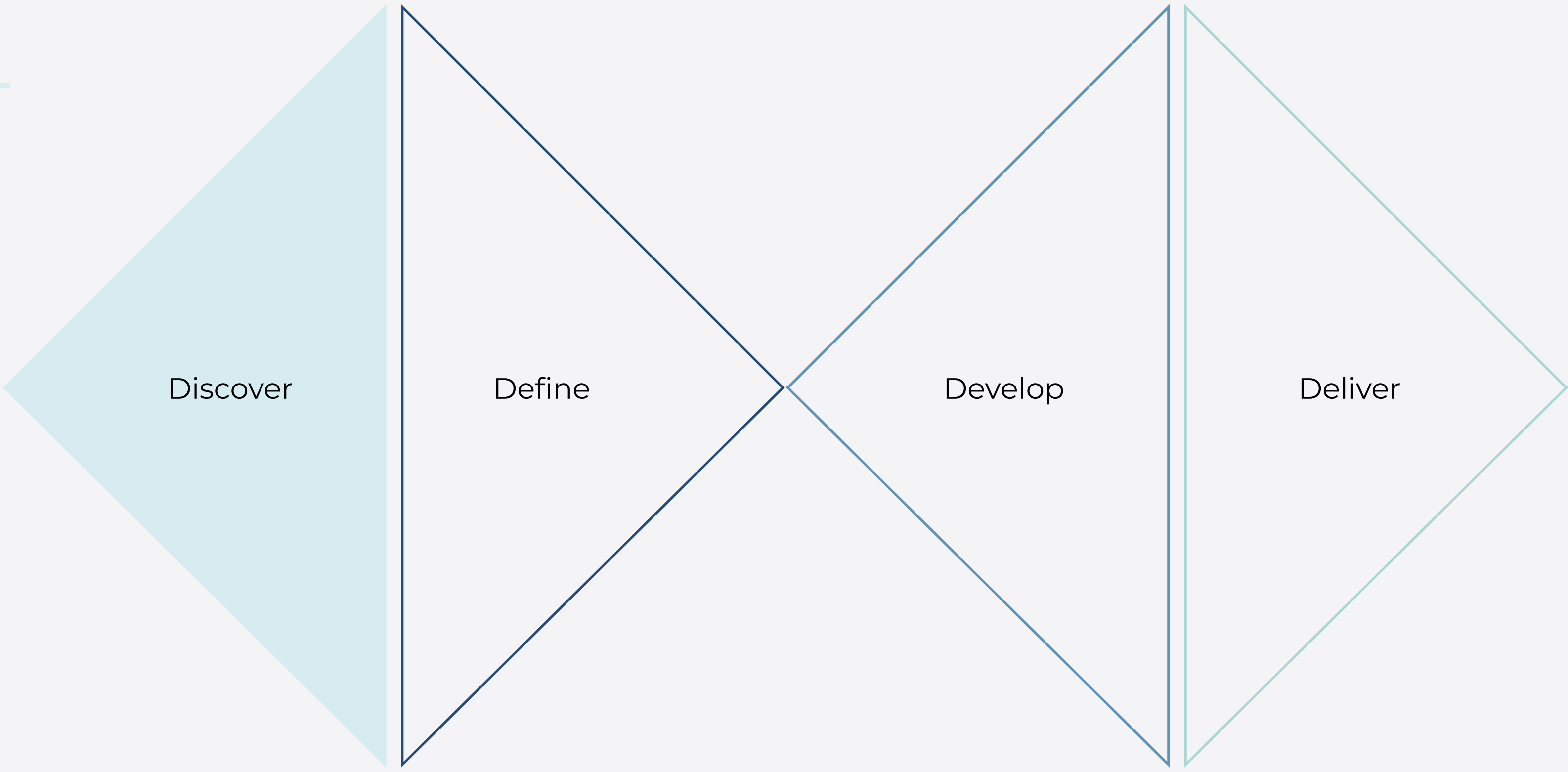
Working in a public health context also made me aware of the ethical and emotional sensitivity of topics such as sexuality and incurable illness. This required careful attention to power dynamics during interviews and to supporting participants' comfort and sense of control.

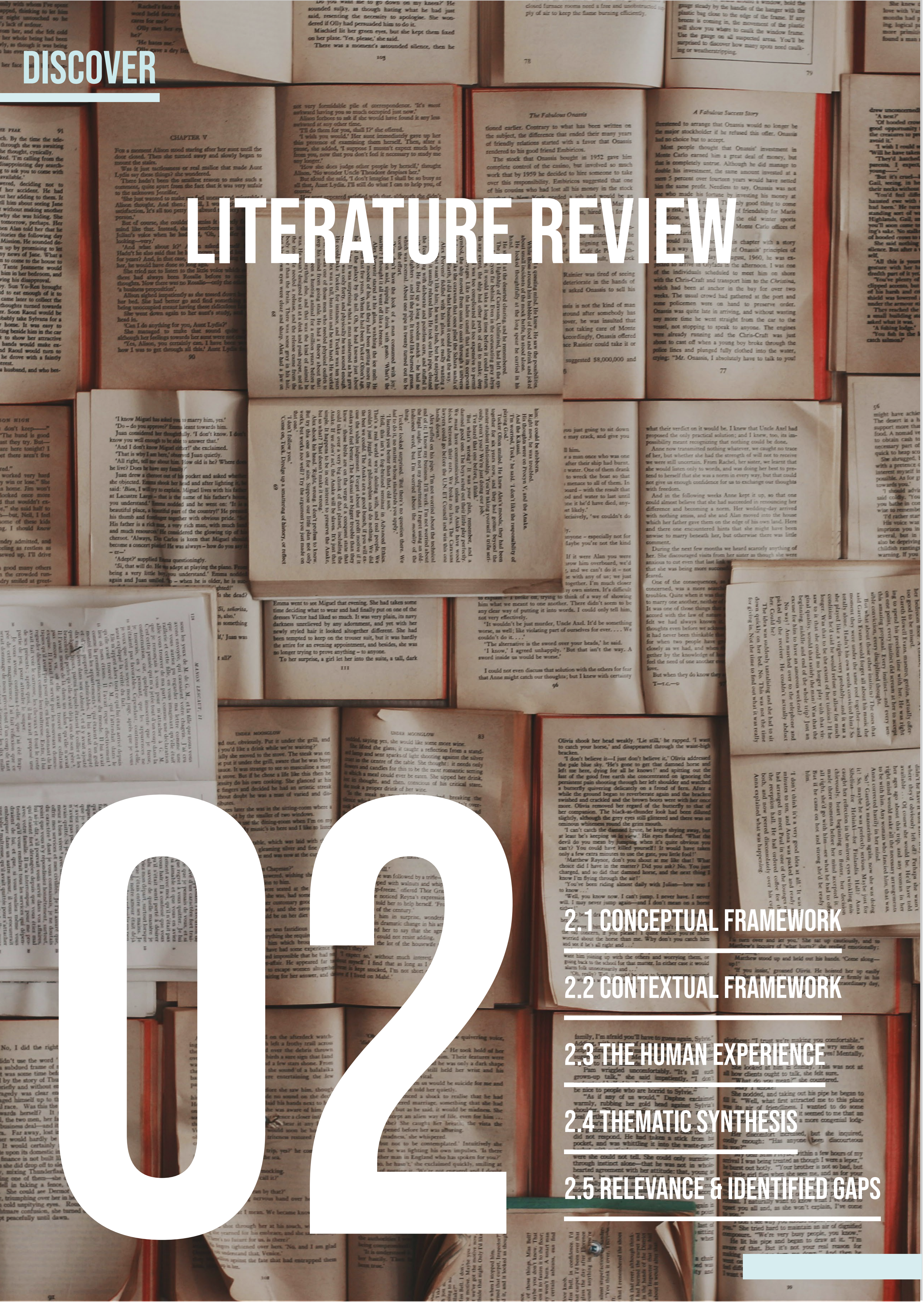
I also recognize that my personal background influences this work. As a white, heterosexual man, my own experiences of sexuality, relationships and care differ from those of many participants. This position may shape which experiences feel more familiar to me and which require conscious reflection. To address this, I aimed to approach interviews openly, to listen carefully to perspectives different from my own, and to remain aware of how my position could influence interpretation and design decisions.

My role as both researcher and designer creates a natural tension: I seek to understand people's experiences while also translating insights into design directions. By making my process explicit and separating analysis from ideation, I aimed to remain reflexive about how my perspective shaped the project.

PART I

DISCOVER





LITERATURE REVIEW

02

This chapter provides an overview of the existing literature relevant to sexuality in the context of incurable cancer. Because sexuality is shaped by biological, psychological, social, and cultural factors, understanding this topic requires insight into both the conceptual foundations and the lived experiences of patients and partners. The literature reviewed here helps clarify the relevance of addressing sexual well-being in the palliative phase, identifies current assumptions and taboos, and outlines what is already known and what remains unclear. With the literature reviewed, this chapter further defines the scope of this project and guides the direction of the subsequent research activities.

2.1 CONCEPTUAL FRAMEWORK

Sexual well-being is a complex and multifaceted concept, and existing literature shows considerable overlap and inconsistency in the use of terms such as sexuality, sexual health, and sexual well-being (Edwards & Coleman, 2004; Giami, 2002; Lorimer et al., 2019). Rather than engaging in an extensive definitional debate, this project adopts a clear working definition to provide conceptual clarity and consistency for the design process.

In this project, sexual well-being is defined as a state of physical, emotional, mental, and social well-being in relation to sexuality. This definition is grounded in the principles of the World Health Organization's definition of sexual health (WHO, 2006), which emphasizes well-being rather than the absence of disease and highlights the importance of respect, safety, pleasure, and sexual rights. This shift away from a purely medical perspective aligns with critiques in recent literature, which note that sexual health is still often approached primarily through clinical or biomedical frameworks (Douglas & Fenton, 2013; Mitchell et al., 2021).

Sexual well-being, as used in this project, refers to the extent to which individuals are able to experience sexuality in ways that are emotionally supportive, relationally meaningful, and aligned with their personal values and needs, within the constraints of illness and care. This includes intimacy, emotional closeness, communication about sexual or intimate needs, and the ability to express or withhold sexual desires without guilt or pressure. Such a holistic and relational understanding of sexual well-being is consistent with contemporary perspectives that frame sexuality as embedded in everyday life, relationships, and emotional experience rather than isolated sexual function (Ozer et al., 2022).

While this working definition is grounded in established international guidelines and supported by recent literature, it is important to acknowledge that sexual well-being cannot be reduced to a single universal experience. Its meaning varies between individuals and over time, shaped by personal values, lived experiences, relational contexts, and self-reflection (Kromojahjo et al., 2025; Offerman et al., 2025). For this reason, sexual well-being is approached in this project as a subjective and relational concept, rather than as a fixed or measurable outcome.

This conceptual framing aligns with the design focus of the project, which aims to support autonomy and communication within intimate relationships affected by incurable illness.

2.2 CONTEXTUAL FRAMEWORK

Palliative care

This project is situated within the context of oncology, where care is commonly distinguished between curative and palliative approaches. While curative care aims to treat disease and achieve recovery, palliative care focuses on alleviating symptoms and improving quality of life for individuals living with serious illness (Fekete et al., 2024).

Rather than understanding palliative care as a clearly bounded phase at the very end of life, contemporary literature increasingly describes it as a holistic and person-centred approach that can coexist with disease-modifying or life-prolonging treatments. Lynn and Adamson (2003) conceptualised this shift as a continuum of care, in which the emphasis gradually moves from curative intent toward symptom management and supportive care. More recent definitions similarly argue that palliative care should begin when cure is no longer feasible or when increasing vulnerability indicates a growing need for supportive, quality-of-life-oriented care (Palliatieve zorg, 2025).

Importantly, not all non-curative treatments should automatically be classified as palliative. Fekete et al. (2024) argue that interventions aimed at prolonging life without curative intent should be distinguished from care that primarily seeks to relieve suffering and enhance well-being. This distinction helps prevent conceptual ambiguity and clarifies the specific role of palliative care within oncology.

In line with these perspectives, this project adopts a holistic working definition of palliative care that emphasises well-being and symptom relief rather than cure. Palliative care is understood as an approach that aims to improve quality of life by addressing physical, psychological, social, and spiritual needs, while also recognising the involvement of family and loved ones in the care process (Higgins & Hynes, 2019; Donz et al., 2024).

This working definition provides the contextual foundation for the project and clarifies the care setting in which the subsequent research and design activities are situated. By framing palliative care as a form of “total care” for both the individual and their close relationships, the project moves beyond a purely medical perspective and creates space to address intimate and psychosocial aspects such as sexuality and emotional connection.

Phases of palliative care

Palliative care is often associated with the terminal phase of illness, particularly in public perception (Nederlandse Zorgautoriteit, 2025). However, palliative care can be understood as unfolding across multiple phases, from early supportive care alongside treatment, through terminal care, and into aftercare for loved ones.

Figure 2 illustrates this temporal progression, showing how curative, palliative, and aftercare approaches may overlap over time. This representation helps clarify that palliative care is not limited to the final days of life, but can play a role earlier in the illness trajectory.

2.3 THE HUMAN EXPERIENCE

Although there is a lot of research to find about the complex biopsychosocial drivers behind sexual & intimate behavior (Malary et al., 2015; Meston & Buss, 2007), these studies often provide rather general insights. There is little research about the more specific experience of sexuality focusing on people confronted with incurable diseases. (Benoot et al., 2017; Schmalz et al., 2024; Traverse et al., 2025). The few studies that do exist suggest that sexuality changes drastically for patients with incurable cancer (Benoot et al., 2017; Lemieux et al., 2004). They even suggest that sexuality in incurable diseases is more limited than in curable diseases (Ananth et al., 2003).

These broader findings underline the need to look more closely at the concrete challenges that patients with incurable cancer face in their sexual lives. One important area involves the physical changes caused by cancer and its treatment. Physical changes that are linked to cancer include erectile or orgasm problems, pain, or general malaise (Leung et al., 2016). These changes can have great impact on a patients sexual well-being. Not just directly, but also by causing mental changes such as decreased sexual desire, impaired body image, and a feeling of disembodiment (Benoot et al., 2017). Additionally, contextual conditions such as immobility, a one person hospital bed or a lack of privacy can form challenging barriers to express sexuality (Manne & Badr, 2008).

Despite these barriers, research indicates that the level of importance placed upon sexuality changes minimally with cancer, but moreso the type of sexual expression is likely subject to change (Lemieux et al., 2004). Often there is a shift from physical desire towards more emotional desires and a need for deeper connection which can be expressed by holding hands, hugging and dancing (Cagle & Bolte, 2009; Higgins & Hynes, 2019; Meer et al., 2025). Especially if the remaining time with loved ones is limited, connecting intimately through closeness and touch becomes even more important (Higgins & Hynes, 2018).

These evolving forms of intimacy, especially when a disease like incurable cancer introduces physical, emotional & contextual changes, are also shaped by how couples respond to the illness together. As a result, relationships can change in different ways. Where some couples grow apart others find new ways to connect in their relationship (Taylor, 2014). Couples who are sexually active can better adapt to the changes and find new ways to maintain their intimacy (Macedo et al., 2019). This characterization of sexually active partners, emphasizes the relational importance of sexual well-being. In fact the consequences of cancer are not limited to the ill person but can also affect the spousal relationship (Matthys et al., 2024). Caregiving partners may struggle with role changes, feel guilty about sexual desires or fear hurting the ill person (Higgins, 2013).

Because these relational dynamics play such a central role in how intimacy is maintained or disrupted, they underline the need for adequate support from healthcare providers. They are in a key position to recognize that during the end of life, expressions of sexuality are interrupted by the illness or its treatment (Macedo et al., 2019). However, studies up until now mainly highlights the barriers experienced by healthcare professionals in addressing the topic, including lack of skill, knowledge, discomfort, and taboo (Donz et al., 2024; Hjalmarsson & Lindroth, 2020; Wang et al., 2018). In line with this a third of patients with advanced cancer and partners reports

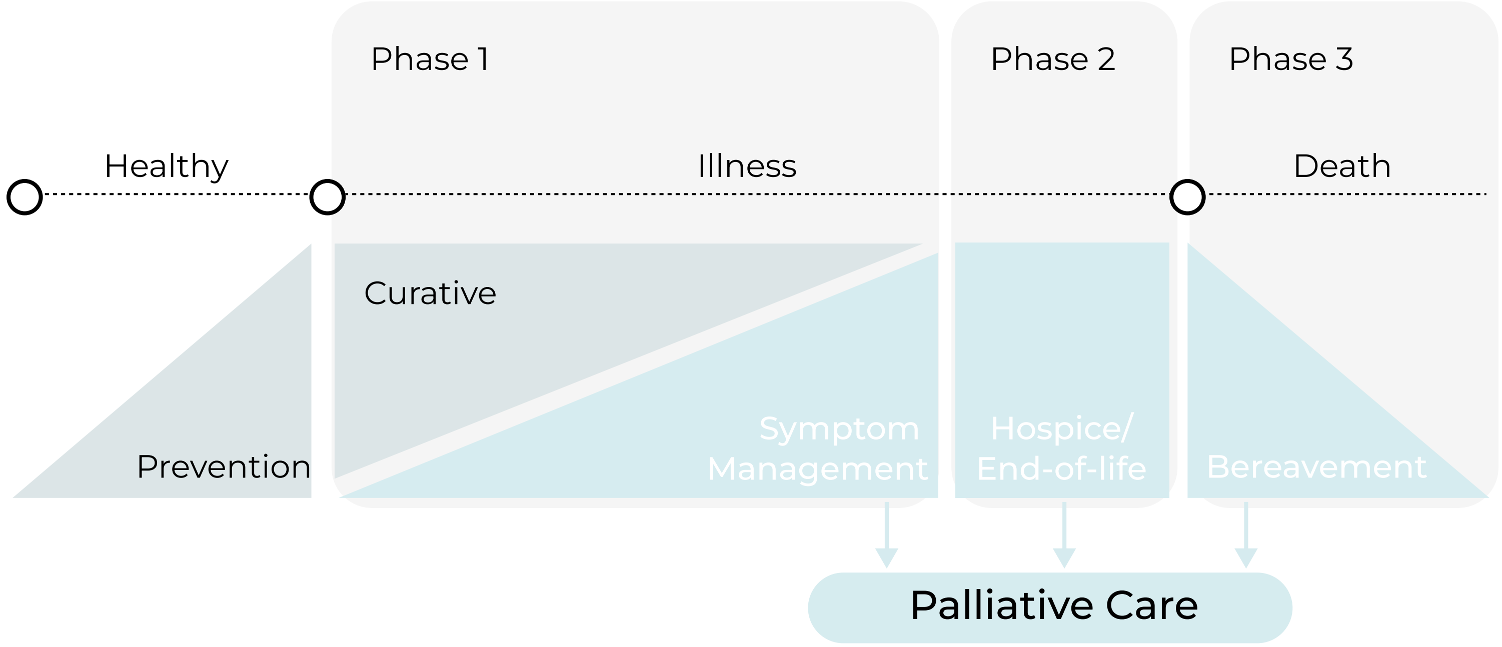


Figure 2: Phases of palliative care and their relation to curative, palliative, and aftercare approaches over time.

to experience unsatisfied care needs with regards to sexual well-being (Van Roij et al., 2022).

These unmet needs may be reinforced since sexuality and intimacy remain difficult topics to discuss, especially near the end of life. Because both intimacy and dying are often treated as taboo subjects, they tend to receive little attention in clinical practice and remain insufficiently studied (Donz et al., 2024; Wang et al., 2018).

Such silence is further strengthened by persistent societal myths about sexuality in older or seriously ill individuals. It is a common myth that the need for sexual expression inevitably decreases with aging. Similar to that, it is regularly assumed that ill people are less interested in sexual intimacy (Hjalmarsson & Lindroth, 2020; Hordern & Currow, 2003; Leung et al., 2016). These misconceptions also reflect the narrow way in which sexuality is often understood, both in society and in healthcare. Sexuality is frequently viewed in a limited way, with emphasis placed primarily on physical elements and penetrative sex (Benoot et al., 2017). This contrasts with the World Health Organization's much broader definition, which includes not only sexual activity but also gender identities and roles, sexual orientation, pleasure, intimacy, eroticism, and reproductive aspects (World Health Organization: WHO, 2019).

In response to these challenges, several interventions have been developed to help healthcare professionals address sexual well-being in this demographic group. One well-known approach is the PLISSIT model, which provides a structured way for healthcare professionals to address sexual concerns in a stepwise manner. A recent thematic review found positive outcomes associated with the use of this model, suggesting it can be a helpful tool in practice (Arends et al., 2024). However, the PLISSIT model is primarily designed for application within healthcare contexts, making it less suited for use in the home environment and limiting its broader implementation. Moreover, the personal and complex nature of sexual well-being means that no single framework can fully capture the diverse needs of individuals and couples, indicating that there is still room for further development in this area (Kromojahjo et al., 2025).

2.4 THEMATIC SYNTHESIS

Resulting from the literature review are the following main themes:

1. Conceptual ambiguity and individuality

The literature shows that sexual well-being is a complex and highly individual concept. Terms such as sexual health, sexuality and sexual well-being, are often used interchangeably, which makes it difficult to establish a single definition. While organizations like the WHO describe sexual health broad as a state of physical, emotional, mental, and social well-being, the term is still regularly approached from a medicalized perspective. Those who hold opposing views argue that sexual well-being cannot be reduced to this medicalized view. Instead, they propose sexual well-being heavily depends on personal values, life experiences, and cultural background. This suggests that any approach to sexual well-being should recognize its subjective and evolving nature, rather than trying to create one universal model.

2. Holistic yet fragmented care

Palliative care aims to support patients holistically across physical, psychological, social, and spiritual dimensions. Sexuality and sexual well-being cut across multiple of these dimensions, as they relate to bodily comfort, emotional experience, relational connection, and meaning-making. However, despite this cross-cutting relevance, sexuality and sexual well-being receive limited explicit attention in palliative care practice. They are often treated as taboo topics or regarded as less relevant toward the end of life. This reveals a gap between the holistic ideals of palliative care and the fragmented way in which care is often delivered in practice.

3. Shifting intimacy and relational adaptation

When people face incurable cancer, their experience of sexuality changes. Physical symptoms such as pain or fatigue can limit sexual activity, but emotional closeness often becomes even more important. Many couples shift from more classical expressions of sexuality (such as penetrative or oral sex) towards more intimate forms of connection, such as holding hands or simply being close. Some couples grow apart, while others develop new ways of intimacy. These findings suggest that sexual well-being in palliative contexts is not only about more traditional conceptualizations of sexual activity, but also about maintaining emotional connection.

4. Communication and care barriers

Healthcare professionals play an important role in supporting patients' well-being, but many feel uncomfortable or unprepared to talk about sexuality due to barriers such as limited knowledge, time pressure, or fear of saying the wrong thing. At the same time, ill people and their partners often find sexuality difficult to discuss themselves, due to embarrassment, guilt, or uncertainty about whether such topics are appropriate in care settings. This mutual hesitation means that intimacy-related needs frequently remain unaddressed, reflecting not only practical barriers but also broader cultural taboos around sexuality and death.

2.5 RELEVANCE & IDENTIFIED DESIGN GAPS

The literature review highlights why attention to sexuality in the palliative phase is not only important, but fundamentally different from non-palliative contexts. People nearing the end of life face a double taboo: the taboo surrounding death and the taboo surrounding sexuality. This combination makes conversations about sexual well-being even more difficult and contributes to the persistent assumption that sexuality becomes irrelevant when someone is older, seriously ill, or approaching death. However, existing research contradicts these assumptions. In the general Dutch population, 11–15% report dissatisfaction with their sex life (Seksuele Gezondheid in Nederland, 2017), whereas 42% of people with advanced cancer and 33% of their partners are dissatisfied (Matthys et al., 2024). Sexual problems are among the six most common issues in Dutch patients with advanced cancer (Verder leven met of na kanker, hoe is dat voor jou?, 2024), and one third of patients and partners experience unmet care needs regarding sexual well-being (Van Roij et al., 2022). These findings show that sexuality remains meaningful in the palliative phase, even though its expression may change.

This contrast between societal assumptions and the lived experiences of patients and partners reveals important design gaps. First, there is little comprehensive insight into what support for sexual well-being currently exists. While many publications discuss the importance of sexuality in palliative care, they do not map the available tools, interventions, or resources in a systematic way. For designers, understanding the existing landscape is essential to avoid duplication and to identify opportunities for innovation. Therefore, this project includes a market analysis to clarify what is currently offered and where structural gaps remain.

Second, the literature shows that experiences and needs related to sexuality in incurable cancer are still poorly understood. Many studies focus only on genital cancers, approach sexuality from a purely medical perspective, or examine only the viewpoints of patients and healthcare professionals, thereby often overlooking partners and relational dynamics. Because sexual well-being in the palliative phase is shaped by physical decline, emotional closeness, shifting relational roles, and existential concerns, a more nuanced understanding is required. To design an outcome that is truly meaningful, desirable, and grounded in real needs, this project will therefore conduct interviews with patients and their partners to gain insight into their lived experiences.

Together, these two gaps demonstrate the relevance of this project: the double taboo surrounding death and sexuality leads to unmet needs that existing frameworks do not yet address. By exploring both the organizational landscape and the human experience, this research aims to generate knowledge that can support better, more holistic care and inform the design of interventions that genuinely matter at the end of life.

MARKET RESEARCH

03

The objective of this chapter is to map the current market of support tools for sexual well-being and to identify potential gaps and opportunities through expert validation. To achieve this objective, the study was designed in two consecutive phases. Phase 1 focused on desk research to systematically collect and categorize publicly available information on existing sexual support tools. Phase 2 aimed to validate and refine the findings from Phase 1 through consultations with field experts, enabling a more comprehensive understanding of the market and the identification of overlooked areas or emerging opportunities.

3.1 PHASE 1 - DESK RESEARCH

PHASE 1 – METHODOLOGY

To approach the research objective the boundaries were kept broad. Limiting the study to sexual support within the specific context of palliative care for people with incurable cancer would likely exclude a significant amount of relevant information. Existing support for sexual well-being is rarely developed exclusively for palliative care and is often situated in broader healthcare, relational, or consumer contexts. Broadening the scope of the market analysis therefore allows for a more comprehensive understanding of current strategies, while still enabling reflection on their relevance for palliative settings.

Phase one of the market analysis consisted of desk research to collect and analyse secondary data that was publicly available. Data was gathered through targeted online searches across websites of retailers, online platforms, forums, and relevant articles. Search terms included combinations of keywords related to sexual well-being, intimacy, relationships, illness, and emotional support. The aim was to identify a broad range of existing products and services rather than to be exhaustive. The collected data was synthesised into a schematic overview representing different categories.

In the overview, the different categories were further described based on two different aspects. The first aspect was the type of palliative care to which the sexual support might be applicable (curative & palliative care, terminal palliative care, and aftercare). The second aspect was who the sexual support would be aimed at (patient, partner, and healthcare professional).

PHASE 1 - RESULTS

The desk research identified a variety of sexual support tools, including physical, conversational, contextual, audiovisual, explorative, and medical interventions. These findings were summarized in an overviewproviding a visual representation of the findings.

PHASE 1 - DISCUSSION

The desk research provided a preliminary overview of sexual support tools, revealing a diverse range across several categories but also suggesting preliminary gaps, particularly in partner-focused support and contextual interventions. As the data relied solely on publicly available sources, it may not capture all practical applications or expert perspectives. The synthesized overview, however, offered a structured foundation for Phase 2, enabling expert validation and the identification of additional insights beyond the initial categories.

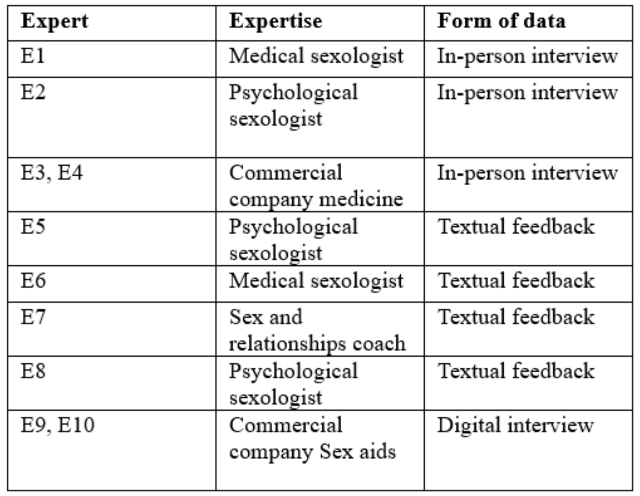
3.2 PHASE 2 - EXPERT VALIDATION

Building on this preliminary mapping, Phase 2 focused on expert validation to refine the categories, verify their relevance, and uncover broader perspectives on the market for sexual support tools.

PHASE 2 - METHODOLOGY

In the second phase of the research, the overview from the desk research in phase one was presented to people considered experts in the field of sexual support. Recruitment of experts was done through personal networks of the research team. The different fields of expertise included medical sexologists, psychological sexologists, sex and relationship coaches, commercial pharmaceutical companies, and commercial sexual device retailer (see Table 1). Each expert participant was anonymized and coded as expert (E1–E10).

The initial overview of sexual support categories, that was synthesized from desk research in phase one, served a dual purpose in the design of phase two. The initial purpose was to collect content-related feedback and validation on the overview. A second aim of the overview was to facilitate expert feedback and expert discussions to provide broader insights.



Expert	Expertise	Form of data
E1	Medical sexologist	In-person interview
E2	Psychological sexologist	In-person interview
E3, E4	Commercial company medicine	In-person interview
E5	Psychological sexologist	Textual feedback
E6	Medical sexologist	Textual feedback
E7	Sex and relationships coach	Textual feedback
E8	Psychological sexologist	Textual feedback
E9, E10	Commercial company Sex aids	Digital interview

Table 1: Experts that participated in phase 2

Data in the second phase was collected in three main ways: written responses via email, in-person interviews, and digital interviews. While no formal questionnaire was prepared, the interviews followed a semi-structured format in which discussions were guided by the overview of predefined market support categories. This overview structured the feedback process.

Content-related feedback from notes and textual emails was collected and implemented directly into a new overview throughout the data collection. By doing so, the overview evolved over time and was constantly adapted to provide broad feedback and the desired validation.

To uncover themes in the data collected from the expert feedback in phase two of the market analysis, a brief qualitative thematic analysis was done. The conversational notes and textual emails were summarized, clustered, and structured into themes. To support this process, Figma was used as the primary workspace due to its flexibility in visual organization.

PHASE 2 - RESULTS

Categories identified

The expert validation provided content-related insights which suggested a reconsideration of the names (see Figure 3) of certain categories to more considerate names. “Physical sex toys” was replaced by “sexual devices” and “explorative tools” was replaced by “informative/educational tools” to be more inclusive. An additional category was created for sexual care since many experts saw fit for this. Content-related feedback was also provided in the form of practical examples to make categories more complete. These examples were mainly aimed at general information sources such as “sickandsex.nl” and “seks en zorg podcast”.Lastly some medical terminology was corrected, for example Viagra was explained to be a brand rather than the underlying chemical Sildenafil (PDE-5 blocker).

1. Conversational tools

This category consists of tools developed and used to initiate the conversation about sexuality. Theoretical frameworks such as the PLISSIT model and ISEP-tool are often used in more practical translations such as “Roze olifant”, Onder4Ogen and IntiME. Practically these toolkits often consist of somewhat guided sessions with workbooks, card games, or visual materials. These conversational tools are almost always aimed at the healthcare providers to inform, educate or initiate the conversation.

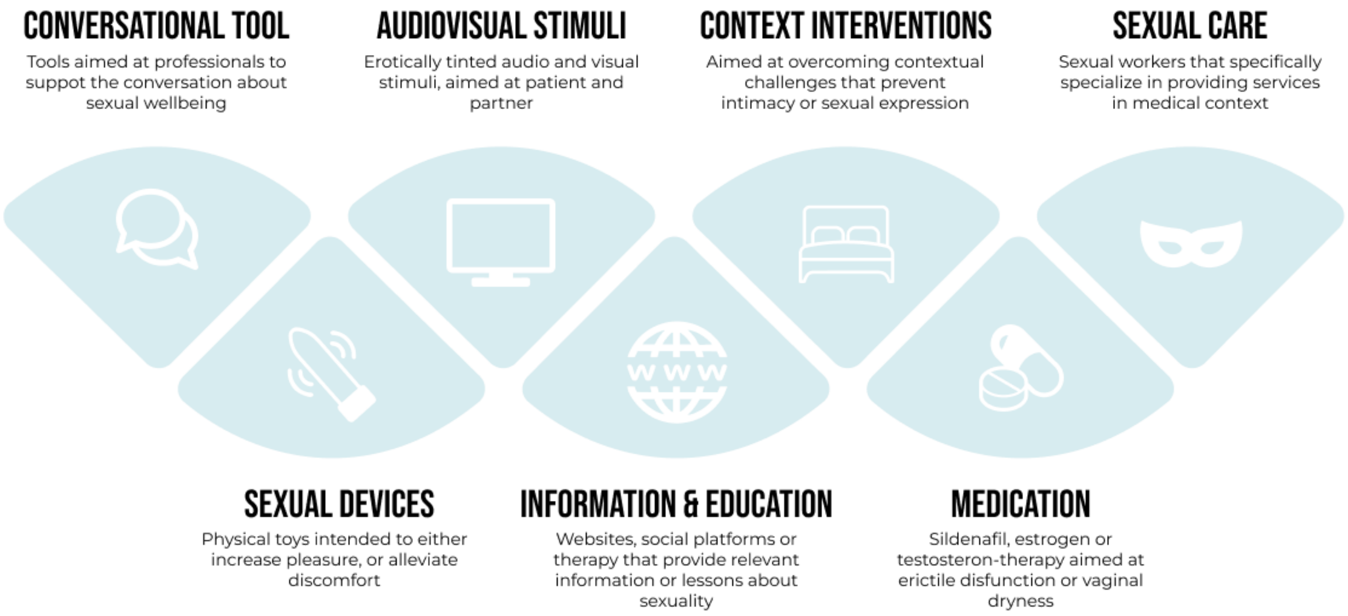


Figure 3: Market analysis synthesization after conversations with experts

2. Sexual devices

Physical sex toys are perhaps the most popular tool related to sexuality. These toys include Masturbators, lubricant, erection pump, prostate stimulator, cock ring, ohnut (to prevent deep penetration), strap-on devices, sleeves, sex pillows, sensory tools (like feathers) and many more. Although the value of these tools is often promoted by medical sexologists, the tools are almost rarely covered by insurance, which forms a financial barrier for patients. Even though this category is so large, it is difficult to categorize these toys based on their purpose since this is very personal. For one person a sex pillow could primarily be used to alleviate some discomfort where for the other person the same pillow could be used to increase pleasure. This category in the context of people with incurable cancer is primarily aimed at patient and partner.

3. Erotic audiovisual stimuli

Erotic media such as audio or visual stimuli are often associated with pornography and all of its stereotypes. Other types of audiovisual stimuli do however exist. Audio stories (Audiopodesires & Dipsea), or sensitive female friendly porno are great examples. Even in elder care homes a projector (Qwiek-up) is used to project these types of erotic stimuli on the ceiling of private patient rooms. Although this category can be used by anyone, this project considers the tool mostly for patient (and partner).

4. Informative & educational tools

Informative or educational tools are often in the frontline of support for sexual well-being. Informative initiatives such as SickAndSex (website) help inform patients and partners about their situation. It can help, break taboos, feel acknowledged and provide relevant tips and tricks. SickAndSex for example published an overview of sexual disfunction that might be the result of certain medicine and their side effects. Besides information there is also a relatively new media of educational apps that provide support in learning about one's sexuality. A well known psychological approach to (re)discovering sexuality and intimacy is the sensate focus therapy. This approach sex therapy technique developed by Masters and Johnson involves touching exercises to help individuals and couples improve communication, reduce sexual anxiety, and deepen connection by focusing on the experience of touch rather than performance or goal-oriented sexual activity.

5. Context interventions

As mentioned, contextual changes such as a one person bed in a hospice or the lack of privacy in a hospital can pose barriers for sexual expression. The "koppelbed" is a recent initiative that allows relatives or partners to be together in the last phase of life. Privacy facilities in hospitals or clear communication about private hours are other examples of interventions. It is important to note that these interventions are not solely meant to facilitate coitus sexual acts, but are perhaps more so meant to provide physical and mental connection which is in line with our working definition of well-being.

6. Medication

This category was not the most prominent in palliative care, but in the general support for sexual well-being it is a well-known category. Medication typically serves two purposes in this context. The first is vaginal dryness and the second is erectile function. Vaginal dryness in the palliative care phase would likely be treated with local estrogens since in this medical situation possible side effects are valued less important. Erectile function is often treated with sildenafil or PDE-5 inhibitors. In the palliative phase of people with incurable cancer, medication is viewed with different perspectives by experts Some considered it medically inappropriate in the late stages, as it can be quite invasive, while others viewed it as suitable for palliative care, since possible side effects can be seen as more appropriate considering the meaningful goal at that stage.

7. Sexual care

When people think of sex and problems it is often associated with sex workers. However, in the professional context of healthcare it is often considered a taboo. However, surrogate partners are an example of sex workers that specifically focus on people with sexually supportive needs. Flekszorg is similar but focusses on people with specific disabilities. In the context of palliative care, this type of support would most likely be aimed at the patient.

Themes identified from expert feedback

Five themes emerged from the analysis of expert feedback. These themes are not directly tied to specific sexual support tools in the market but instead reflect the experts' broader perspectives on sexuality, healthcare practices, and the commercial landscape.

1. Sexuality is undervalued in healthcare

Sexuality remains an undervalued aspect of healthcare. Sexual support tools are often not covered by insurance forming a barrier for ill people to access care. Many people with incurable cancer experience unmet needs because sexual well-being is rarely addressed openly by professionals. This lack of attention reflects a slow cultural change within healthcare institutions, where sexuality is still seen as a sensitive or secondary issue. Recognizing sexual needs as part of holistic care is essential for improving quality of life and reducing frustration among people with incurable cancer. It is also considered that acknowledging sexual needs and frustration can reduce the number of uncomfortable care situations where for example disabled or elder people in care facilities show unwanted sexual related behavior towards staff.

> "There is absolutely too little recognition of sexual needs in healthcare in general. Luckily this change is starting to take place, but such a cultural change is very slow and takes a lot of time." (E02)

2. Sexual care is inconsistently embedded in healthcare systems

Sexual care is inconsistently embedded in healthcare systems, creating unequal experiences for patients and providers. The lack of clear norms and guidelines often leads to barriers in access, privacy, and practical implementation. Even when facilities for privacy exist, they are frequently limited by unhelpful or uncomfortable procedures, such as having to request access in public spaces. This inconsistency reflects how cultural and institutional differences shape sexual care practices. Moreover, the recognition of sexual needs among healthcare professionals often depends on personal attitudes and experiences rather than shared professional standards. As one participant observed,

> "Privacy facilities are very different per location. If there are private facilities these are often still met with very unpractical barriers. Think about having to reserve a room or having to ask for a key at a public desk while everyone can hear it." (E02)

while another expert noted,

> "It is interesting that the acknowledgement of sexual needs among healthcare providers is also very personal." (E03)

3. Broadening sexual practices and expectations beyond penetration

This theme highlights the different ways in which sexuality can be experienced. Currently the cultural conceptualization of sex is often through PIV (penis in vagina). However, the potential of sexual experiences goes beyond this normative conceptualization. Especially when medical conditions limit the sexual possibilities, the redefinement of sexuality beyond PIV sex, can help. Sensate focus is a sex therapy which implements this and is gaining popularity. The sensate focus aims to shift the focus of sex from performance and orgasm driven, towards more sensual arousal. Although the redefining of sexuality after a limiting intervention occurred can offer great relief in some cases it is also met with challenges. Expectations should be tempered and gradual constructive approaches are important to avoid disappointment and people stop attempting. In the context of palliative care with an approaching death and a sense of time running out, this gradual approach can be very difficult to prioritize.

> “For example oral sex could be an alternative for PIV sex, but some cultures do not approve it, causing people to find it dirty which can make adaptation to new forms of sexuality very difficult” (E01)

4. Individual nature of sexuality

Although the normative conceptualization of sexuality is often considered PIV sex, it can still be experienced and expressed in many ways unique to the individual. Culture and past experiences can shape these unique individual perspectives. The tailored nature of care itself and the route a patient has traveled deepens this complexity of an individual’s extremely personal situation and needs. This naturally asks for sexual support that is tailored to the specific situation and needs of the ill person. Completely personalized support is economically and practically difficult to realize, resulting in a selection being made often benefiting individuals best at navigating the healthcare system and individuals best at expressing a sexual support need.

> “These sexual support interventions are not for everyone. There has to be a desire and a need expressed. If a patient is throwing up from chemo, this is probably the last thing you are waiting for.” (E01)

5. Role of partner is unrecognized in sexual support

The relational dimension of sexual wellness is underrecognized in healthcare. Healthcare is aimed at a patient and this individualistic approach is not always sensitive to the relational dimension of sexuality. Often partners of ill people take on a caring role for. This role can place a strain on partners and intimacy in the relationship affecting the ill person as well. The new caring role of a partner in addition to the primary focus of support on the ill person makes that partners are often unrecognized in their needs.

> “It is quite strange that healthcare is traditionally taught and aimed at the individual patient when sex is often in context of a relationship” (E02)

PHASE 2 - DISCUSSION

The results from the study provide a rich and comprehensive overview that sheds light on the different categories of sexual support available. Interestingly, there seemed to be consensus that the first line of care should be communication focused. Some sexologists with psychological background expressed that sexologists with medical background would prioritize medication over communication. It turned out that actually all sexologists with medical backgrounds prioritized communication as a first line of care in sexual wellness.

Opposing this consensus, seemingly opposing themes were also described. Theme 2 (inconsistent care implementation) and theme 4 (individual nature of sexuality) seem to conflict with eachother since standardization and customization can be considered opposite ideas. Different expert perspectives were also found elsewhere. For example, disagreement among experts arose regarding the visualization. Some experts agreed with the suggestion that some support categories are more suitable for palliative phases of care than others. Yet, others completely disagreed with this and noted that every type of care should be considered in every stage. The different perspectives included in the interviews provide a diverse base for the overview and additionally provide the overview with a certain level of validation.

However, the study shows potential for more academic rigor as interviews were not recorded. The inclusion of full interview transcripts could have strengthened the study’s methodological rigor and facilitated greater transparency and replicability in the analytical process.

Experts in the field of sexuality can be difficult to reach, that is why all experts were contacted and recruited for the study through the personal networks of researchers involved in the project. Although this did help to find enough experts, this approach may have limited the representativeness of the sample for the entire sexual support system.

Since the experts did not always have the time and availability for an interview, some of them provided feedback over email. The four experts that provided feedback via email, mostly focused on small content-related elements of the generated overview draft. Although this content-related feedback is valuable, the six experts who provided interviews were able to go beyond the overview. They shared more nuanced perspectives on sexuality, healthcare, and experiences. Perhaps if all data was collected through the form of interviews, this would add to the depth of the results. On the other hand, doing so could result in a more narrow focus in the resulting insights.

Additionally, setting the scope for the market analysis to sexual support in general did help to foster a holistic approach. On the other hand, setting the scope broad-made it difficult to draw conclusions on how the categories are experienced specifically in the context of palliative care and incurable cancer. Also, trying to describe support categories based on their intended user arbitrary and conflicting results.

Lastly, the goal of the study was not to provide quantitative insights into the effectiveness of certain types of sexual support. This qualitative study focused on the objective to generate a comprehensive overview of the support available. That does however mean that with the resulting overview, it remains difficult to draw conclusions on the implementational success of the different support categories. A more quantitative benchmark study providing these results could be interesting to get an even better understanding of how the different support categories are used in practice.

3.3 PHASE 1 & 2 - CONCLUSION

This study set out to map the current market of support tools for sexual wellbeing and to identify possible gaps and opportunities based on expert validation. The findings show that the market for sexual support is diverse but fragmented, with limited integration into healthcare systems and a strong presence of commercially driven products. While a wide range of tools exists from educational and conversational materials to medical and contextual interventions experts emphasized that sexuality is still undervalued in healthcare, and sexual care is inconsistently embedded in practice. They highlighted the need for broader definitions of sexuality beyond penetrative sex, more attention to the role of partners, and sexual care that is sensitive to the individual’s needs. These insights point to opportunities for design and innovation in creating more holistic, inclusive, and person-centered sexual support solutions.

INTERVIEWS

04

4.1 AIM

The second main gap identified in the literature review is the lack of information about the needs and desires of people with incurable cancer and their partners in the domain of sexuality. In an attempt to fill this gap and provide relevant design insights, a qualitative interview study is conducted.

This study aims to explore how people with incurable cancer and their partners experience intimacy and sexual well-being, and how best they can be supported in this area.

4.2 METHODOLOGY

Study design

This study used a qualitative design with semi-structured, in-depth interviews to explore experiences, needs, and wishes related to sexuality, relationships, and intimacy in the last phase of life. The goal was to better understand how people with incurable cancer and their partners experience intimacy and sexual well-being, and how they can be supported in this area.

Interviews were conducted individually or as couples, depending on participants' preferences. They could take place face-to-face or online, and the location was chosen by the participant (for example, at Erasmus MC or at home). Interviews followed a semi-structured topic list that included the meaning of intimacy, experiences and needs, and wishes for support.

At the beginning of each session, a visual representation of the research team's working definition of intimacy and sexuality was presented. It has to be noted that the term intimacy was additionally used because of the lesser explicit nature of the word. By doing so the respondent had a choice of what vocabulary to use, so that the interviewees could adapt their language. The visual illustrated the broad and multifaceted nature of the two concepts, ranging from physical touch and sexual activity to emotional closeness and communication. Introducing this representation is meant to help participants understand that “intimacy” and “sexuality” are not limited to physical or sexual acts, but include emotional connection, trust, and non-verbal affection. It serves to create a safe and inclusive atmosphere and encourage participants to share experiences that resonate with their own personal definitions.

To help participants express their thoughts more easily, contextmapping was used during the interviews. This technique, developed in design research, invites participants to share their experiences through visual and reflective tools such as drawing a timeline. This exercise supports associative thinking and helps reveal underlying needs and emotions. Because sexuality can be a sensitive topic, this approach was expected to make conversations more open and reflective. Building upon the methodology, contextmapping was concretely implemented in three ways with the aim to gradually immerse participants into their lived experiences and make abstract emotions more tangible and discussable in the interview.

1.Sensitizing booklet

Prior to the interview, each participant received a sensitizing booklet (appendix C) designed to encourage reflection on their daily life, emotions, and relationships. The booklet included small open-ended prompts, writing tasks, and visual exercises (“what does intimacy mean to you?”, “Could you take pictures of things that you associate with intimacy throughout two days?”). Completing the booklet over several days helped participants to become more aware of their own experiences and made it easier to articulate sensitive feelings during the interview session.

2. Exploring present, past and future

The topic list (Appendix C) used for the interviews, implemented a conversation technique that initially asks about the present and the current situation, where people are asked to share concrete and familiar experiences to build trust. Then the technique asks the respondent to reflect on the past to provide storytelling that reveals deeper values and patterns. Finally, the technique transitions to the future, encouraging respondents to imagine possibilities grounded in their lived experiences. The idea behind this technique is that it eases cognitive effort, builds confidence, and stimulates creativity by moving from concrete experiences to imaginative thinking. Because the last step in the sequence transitions to the future, which could be considered insensitive to ask incurably ill people, this was reshaped into asking respondents to directly imagine possibilities without constraints.

3. Creating tangible object

To externalize thoughts, emotions, and insights, a tangible timeline was created during the interview. This artefact served as a conversational bridge, allowing participants to speak freely and where desired through the object and thereby access deeper, more personal layers of meaning. In practice one of researchers that conducted the interview was in charge of creating the timeline to allow the participant to speak freely as much as possible.

Together, these three components aimed to implement contextmapping into the interview sessions ensuring these sessions were both sensitive to the participants and rich in insights and unmet needs.

Participants & recruitment

The study included adult patients with incurable cancer and their partners. To take part in the study, participants had to meet specific criteria. Patients had to have incurable cancer, meaning that no curative treatment options were available and only life-prolonging or palliative treatment was possible. Partners could either be the current partner of someone with incurable cancer or a bereaved partner of someone who had died of cancer. People were not eligible to participate if they were younger than 18, unable to provide written informed consent, or unable to read and speak Dutch.

Participants were recruited through palliative care networks, patient organizations, and personal networks. Stakeholder organizations were asked to share information about the study in their newsletters, on websites, through social media, and by using leaflets. People who were interested in taking part could contact the research team by email. After contacting the researchers, they received an information letter by email. When participants confirmed their willingness to take part, an interview was scheduled. Depending on participants' preferences, interviews were conducted either face-to-face or online. Informed consent was provided digitally before interviews using LimeSurvey or physically by signing a printed informed consent form before the start of the session. Before each interview, respondents were asked to complete an online survey to collect background information.

Data collection

Data for this study was collected through audio recorded interviews with people with incurable cancer and their partners. During the interviews, participants created a visualization of their experiences, by drawing a timeline on paper.

Data analysis & procedure

All interviews were audio-recorded and transcribed verbatim. The transcripts, together with relevant materials such as visual artefacts (timelines), were thematically analyzed using Atlas. An inductive approach was used for coding, keeping the initial codes close to the participants' words in the open coding. The analysis focused on identifying meaningful patterns and themes across all types of participant input.

4.3 RESULTS

Two individual interviews were conducted with partners of people with incurable cancer. The two interviewed both identified as woman. The analysis of the transcripts in Atlas.ti generated over 400 open codes. These codes were grouped into five main themes and 13 subthemes, capturing key patterns in participants' experiences, needs, and perspectives regarding intimacy and sexual well-being in the last phase of life (see Figure 4).

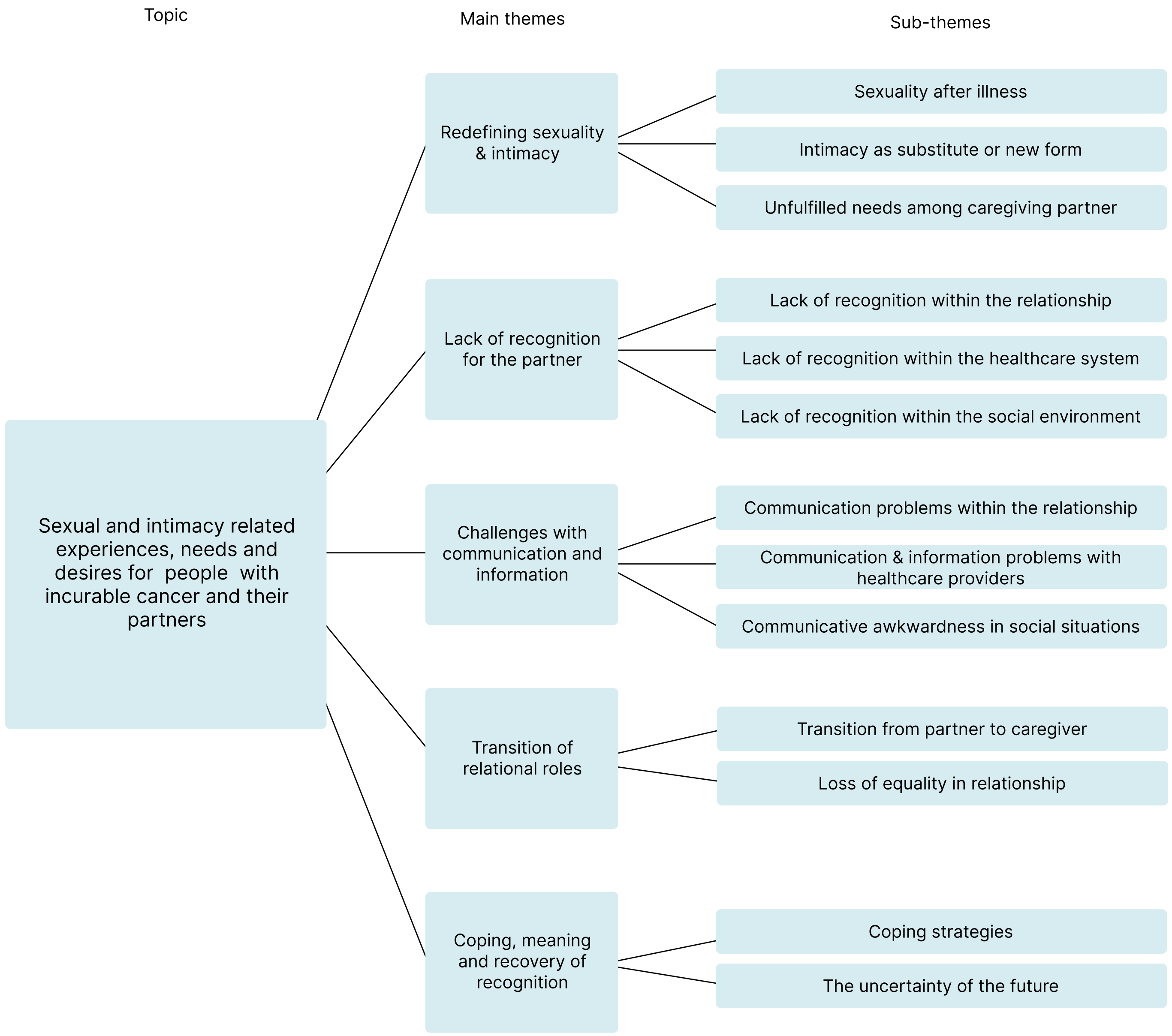


Figure 4: Resulting thematic coding tree from analysis

1. Redefining sexuality & intimacy

1.1 Sexuality after illness

The ill partner in the relationship is directly affected by the disease and its curative, palliative, or life-prolonging treatments. These interventions have physical, emotional, and contextual consequences. Physically, partners described fatigue, pain, malaise, and sexual side effects such as erectile difficulties. One caregiving partner noted:

> "We were told that the hormone injections would reduce the size of his penis, but he can't even find it anymore." (P02)

Emotionally, treatment led to changes in mood, self-image, and confidence, with some ill partners struggling with feelings of inadequacy. Contextual impacts were also significant, as daily life became more restricted due to reduced mobility and energy. As one participant expressed:

> "Our world has become so much smaller, I never thought I would enjoy a 50m walk through the forest as much as I do now." (P02)

These combined changes often resulted in a substantial reduction (or complete loss) of sexual desire among the ill partner. Caregiving partners described how this absence of desire made the ill partner feel guilty or distressed, while at the same time limited opportunities for sexual expression within the relationship. This imbalance in needs and desires could lead to tension or emotional strain for both partners.

1.2 Intimacy as substitute or new form

Participants saw sex and intimacy as two very separate things. Expressions of sexuality beyond penetration or oral sex were often labeled as 'intimate'. These 'intimate' expressions were suggested as alternative, substitute or new form of connecting and included dancing, hugging, kissing, deep conversations, symbolic expressions, and caregiving moments. These forms of 'intimacy' were mentioned as potential ways of connecting, and it was even suggested by one of the participants that the heavy emotional nature of topics such as death helped intensify their intimate relationship. As one noted:

> "The love has always been there, but perhaps now we go deeper into conversations. We didn't have those conversations about death when we were 40." (P01)

However, one of the participants specifically mentioned that although these moments of 'intimacy' are valued, they should not be presented into the relationship with the intent to replace more classical forms of sex:

> "You can't downplay sex and place it in a line with 10 forms of intimacy. It is big and important." (P02)

1.3 Unfulfilled (sexual and intimate) needs among caregiving partners

Where ill partners seemed to have reduced needs for sexual interactions, the caregiving partners expressed to still have similar needs as before the disease entered their relationship. The lack of initiative from the ill partner was said to make it difficult for the caregiving partner to satisfy these needs without feeling as though they are a burden to the ill partner. These unfulfilled needs were very personal. They could be purely sexual with the focus on (oral) sex and masturbation, but could also be more 'intimate' with the focus on gentle touch, hugging, and verbal communication. Attempts of the ill partner to fulfill these needs without feeling the needs personally were labeled by the caregiving partner as unauthentic causing them to lack any effect. In time this disbalance in needs and reluctance to keep taking initiative was suggested to result in a shortage of legitimate sexual (or 'intimate') moments for caregiving partners .

> "I am thinking of looking at sex work to fulfill my sexual needs in different ways" (P01)

2. Lack of recognition for the caregiving partner

2.1 Lack of recognition within the relationship

The ill partner does not feel the sexual desires anymore as they once were. The caregiving partner still has similar sexual desires as before the disease was introduced, but these cannot be met by the ill partner. This leads to the partner feeling as though their needs are not recognized anymore in the relationship. Not just with regards to sexual needs the caregiving partner feels as if the focus is on the needs and life of the ill partner, also with regards to attention in general the caregiving partner feels as if everything is focused on the ill partner. One of the participants noted:

> "A disease makes the patient selfish in a way." (P02)

This "selfish" behavior can lead to the caregiving partner feeling less recognized and feeling unseen in the relationship.

2.2 Lack of partner recognition within the healthcare system

Looking at the healthcare system, there is too little recognition of the caregiving partner in the relationship. Caregiving partners themselves mentioned experiencing the healthcare system as if their perspective was insufficiently taken into consideration. They describe feeling as a 'shadow patient'. As one of the participants described:

> "The main focus is that he is sick and what that means to him, but that is not asked to me. No-one asks me what this means to me." (P01)

Healthcare is mainly focused on the needs of an ill individual. This makes it difficult for caregiving partners to fulfill their own needs for support and care.

2.3 Lack of recognition within the social environment

Caregiving partners of people with incurable cancer show a need for feeling understood. However, the situation of incurable cancer that couples find themselves in, is a very personal situation. The personal nature of sexuality adds to this individuality and makes it even more difficult to understand. Although friends and family may try to understand the effect and pain of the situation, caregiving partners expressed that they feel as though they are not understood. They claim that their situation is so specific, that it becomes hard to share this in social situations.

> "My mom believes she has experience and that she understands me, because my dad died from cancer too. She thinks she gets me but that is her pain and sorrow." (P01)

This feeling of not being able to share experiences was strengthened by the idea that the ill partner is the rightful center of attention and that caregiving partners should not complain.

The socially isolating situation can in fact result in the couple growing closer together. There were also notions of caregiving partners not wanting to share their problems with ill partners to prevent unwanted stress. In general these barriers can cause situations where caregiving partners , despite feeling the need to share their stories, are afraid to do so with friends, family and even their partner. They are scared of being a burden to them by doing so and fear they won't understand, leading to situations where partners can feel very isolated.

3. Challenges with communication and information provision

3.1 Communication problems within the relationship

Communication within the relationship can change drastically by the introduction of the disease. Effects from treatment can for example lead to a more agitated personality. This agitation was often directed towards the caregiving partners in the relationship. One of the participants mentioned:

> “As a partner I am the easy place for him to vent his anger and frustrations, but he knows that it is safe with me.” (P02)

From the perspective of the caregiving partner a big barrier was described in communication about their sexual needs. Caregiving partners mentioned that ill partners had strongly reduced sexual and intimate needs (if any). Burdening the ill partner and confronting them with what their inability to perform or feel anything was too painful. Therefore the topic of sexuality and desires associated with it were rarely communicated:

> “I don’t want to confront him with my desires. He doesn’t feel anything and that makes him feel very guilty so I rather don’t confront him with that.” (P02)

3.2 Communication & information problems with healthcare providers

Communicative frustration between couples and healthcare providers was expressed. Mostly with regards to the lack of information that prepared for sexual consequences of treatment. This lack of preparation was not related to the volume of information, but more so to the contents of the information. Booklets and websites that were suggested often only provided very vague or euphemistic information about the consequences of the disease and treatment. This makes choosing the right treatment or preparation for the consequences very difficult. As one participant noted:

> “I don’t need 20 booklets, I would have wanted honest information, instead of saying it is possible that you will have erection problems... They should write it as it is!” (P02)

Although the idea of protecting a couple from confronting information was found reasonable, the need for honesty and concrete language was emphasized. The euphemized communication style also resulted in participants feeling unrecognized in their situation. One of the participants mentioned:

> “If at least the communication would be truthful about side effects then patients and their partners would at least be recognized in their difficult situation.” (P02)

3.3 Communicative awkwardness in social situations

The introduction of the disease and treatment was said to lead to communicative awkward situation in public social situations. The ill partner for example became more irritable after treatment. This was not only directed towards the caregiving partner, but also towards friends and family in public situations. It was said that the severity of the topic makes it difficult for friends to find the right way to communicate about it which often lead to confronting situations. Additionally caregiving partners often felt like they needed to protect the ill partner from awkward public situations. For example one participant mentioned the difficulty of cognitive side effects in social situations:

> “It’s easier when we’re together with just each other. If there’s other people, I feel like he can’t be left alone because he’ll repeat himself 10 times.” (P02)

Another complex situation occurred when caregiving partner felt the need to communicate the severity of the situation with others while the ill partner only shared a euphemized version of the experience situation. As one of the participants mentioned:

> “I would like the children to have a better understanding of how ill their father is, but you can’t force it on them” (P01)

Caregiving partners expressed that they do not want to speak for the ill partner, but find it difficult when the ill partner lies about the situation. Especially because the impact on their own life is so severe. The situation was said to make communication about the disease and the severity of it difficult. Not merely towards friends, parents, and children, but also towards healthcare professionals.

4. Transition of relational roles

4.1 Transition from partner to caregiver

An important transition in roles made within the relationships, was mentioned multiple times. One partner transitions into a care demanding role, becoming perhaps more selfish and consequently while the other partner turned into a care providing role, taking on the caring tasks. This transition in roles was described to be voluntarily:

> “I care for him and I can and want to” (P01)

The shift in roles was even described to serve as a form of intimacy:

> “Cleaning his catheter in a way can be very intimate as well.” (P02)

However, it was also described as problematic when setting boundaries became difficult. At some point in time the care started to feel like an obligation and replaced affectionate expressions of sexuality. One of the participants mentioned the following:

> “Loving someone is not always the same as caring for someone” (P01)

4.2 Loss of equality in relationship

Lastly, an important impact of this shift in roles that was mentioned, was the consequence that relational equality is lost. Even though true equality in a relationship is practically impossible to establish, loss of it was repeatedly mentioned by participants.

It was described that the ill partner in the relationship can have a very demanding effect on the caregiving partner, whose caregiving role can feel all-consuming. One participant mentioned:

> “It feels like I always step into the life of the patient and never get to live my own life anymore. Everything revolves around the patient” (P01)

In this situation the ill partner determines the pace, space, and topics discussed while the caregiving partner has to constantly adapt. This loss of autonomy also reflected on the sexuality in the relationship:

> “Pleasure is also more focused on him instead of me, it has also become one-way traffic” (P01)

All of a sudden the ill partner is faced with a loss in sexual or intimate desires. Since everything revolves around the ill partner this often means that the caregiving partner does not dare to act upon their desires and no longer initiates sexual contact. This loss of autonomy goes beyond the sexual expressions of the couple. Caregiving partners mentioned that self-pleasure through masturbation or the idea of sex-work to satisfy their needs was accompanied by a lot of guilt. One participant mentioned:

> “In the moment it is nice, it is a way to vent my emotions, but afterwards I am always so sad because it is not together with him.” (P02)

5. Coping strategies and uncertainty

5.1 Coping strategies

Several coping strategies to deal with the situation were repeatedly mentioned. Distraction was often found through activities such as arts, sports or meditation. Additionally small out of home activities were mentioned as the only moments where the disease could be forgotten. However, it was also noted that since the body is the medium of the disease it is always confrontationally present. The difficulty with these out of home activities do make one start to appreciate the little things more. The situation is also often received with a sense of (perhaps false) realism. Participants noted multiple times that:

> "It could have been so much worse." (P01)

Although this might be true in some cases, it shows a reaction which seems to contradict the need for prioritization of own desires.

5.2 The uncertainty of the future

The idea of the future was often mentioned in combination with a lot of uncertainty. Especially with regards to how long the current situation would still last. Preferences of it ending sooner rather than later, were expressed. Since it is so difficult to prepare for the future, the idea of it was associated with a lot of stress. The idea of having to deal with the current situation was so confronting for one of the respondents that she mentioned:

> "Perhaps the best solution would be if I get a hormone therapy too, or a pill that takes away all my desires. Then at least we feel the same." (P02)

4.4 DISCUSSION

The interview study provided rich and nuanced insights into how partners of people with incurable cancer experience intimacy, sexuality, and relational transitions in the last phase of life. Despite the small sample size, the depth and emotional openness of the conversations resulted in themes that closely align with the study's aim of uncovering lived experiences and unmet needs. The methodological choice to integrate contextmapping techniques appears to have contributed meaningfully to this depth. In particular, the sensitizing booklet likely enabled participants to reflect prior to the interview, resulting in detailed narratives and concrete examples supporting the analysis. The emergent themes were identifiable across both interviews, suggesting a certain level of thematic consistency despite the limited dataset.

At the same time, several methodological limitations must be acknowledged. First, only two interviews were conducted, both with female partners of male patients. This creates a gendered and heteronormative perspective and limits the representativeness of the findings. Additionally, one of the participants lived in a long distance relationship, introducing a relational dynamic that differs from cohabitating couples. While this uniqueness generated valuable insights, it also reduces comparability between cases. Additionally recruitment took place exclusively via Facebook, which may have introduced self-selection bias; participants willing to speak publicly about sexuality and illness may differ systematically from those who are less comfortable or less digitally connected.

Furthermore, no interviews were conducted with ill partners themselves, despite the study's aim to investigate the experiences of both ill and caregiving partners . As a result, the findings primarily reflect the partner perspective, especially regarding unmet needs, relational imbalance, and the emotional burden of caregiving. Although these insights are highly valuable, given that partner perspectives are often understudied, the absence of interviews with ill partners makes it difficult to fully explore relational dynamics from both sides.

Despite these limitations, the interviews provide an important step in understanding the complex and often overlooked experiences surrounding intimacy and sexuality in the context of incurable cancer. They highlight the need for partner-inclusive care, open and honest communication, and support that accommodates both emotional and sexual dimensions of relationships at the end of life.

4.5 CONCLUSION

The interview study set out to explore how people with incurable cancer and their partners experience sexual well-being, and how they believe they can best be supported. Although only two partners were interviewed, the results reveal a compelling picture of the relational, emotional, and sexual challenges couples face in the last phase of life. Participants described profound shifts in desire, relational roles and communication. These shifts often led to unmet needs, emotional isolation, and a sense of unrecognition within both the relationship and the healthcare system.

The themes highlight several key gaps in current palliative care practice. Partners feel overlooked and communication about treatment consequences is often euphemistic rather than honest and concrete. Furthermore, the transition from partner to caregiver restructures relational equality in ways that deeply impact intimacy and sexual connection. These findings underscore the necessity of partner-inclusive approaches to sexual well-being, clearer communication about expected changes, and interventions that help couples navigate shifting roles and desires.

TRIANGULATION

05

5.1 AIM

The aim of this chapter is to integrate the findings from the literature review, market analysis, and interview study in order to identify overarching themes that characterize the problem space of sexual well-being in the context of incurable cancer. While the previous chapters explored the topic through separate studies, each with its own focus and methodology, this chapter brings these perspectives together to form an integrated understanding that will guide the subsequent design directions.

5.2 INTEGRATION METHOD

To synthesize the findings across the three studies, an affinity mapping process was used. Themes from the literature review and market analysis were translated into individual post-its, while for the interview study the more fine-grained sub-themes were used in order to maintain nuance. All post-its were imported into Figma, where they were grouped step by step based on their similarities in meaning and content. This visual grouping process enabled the identification of shared patterns across the datasets and facilitated the development of higher-order themes.

To maintain transparency in how each main theme was constructed, a triangulation table was created (see Table 2). This table systematically indicates which study contributed to which overarching theme, supporting traceability and strengthening the validity of the synthesis.

5.3 RESULTS

In the affinity mapping, 26 themes were clustered into seven overarching themes. The following seven overarching themes were identified.

1. Taboos and Communication Barriers: Obstacles to Open Dialogue and Connection

Communicative barriers are both mentioned in literature and interviews. Literature highlights cultural taboos with regards to the topics of sexuality and death. Additionally, literature also reveals certain stigmas and stereotypes that surface when the two topics meet. For example, it is a com¬mon myth that the need for sexual expres¬sion inevitably decreases with aging. Simi¬lar to that, it is regularly assumed that ill people are less interested in sexual intima¬cy. These stigmas support the taboos around the topic and prevent open communication.

OVERARCHING THEME	SOURCE IN WHICH THEME APPEARED
1.Tabboos and communication barriers	Literature review, Interviews
2.Loss of equality and autonomy	Interviews
3.Unrecognition partner	Market analysis, Interviews
4.Shift in sexuality	Literature review, Interviews
5.Sexuality undervalued in healthcare	Literature review, Market analysis
6.Too much focus on penetration	Literature review, Market analysis
7.Individualistic nature of sexuality	Literature review, Market analysis

Table 2: Resulting triangulation table of affinity clustering

These stigmas support the taboos around the topic and prevent open communication.

The barriers to open dialogue and connection was confirmed by the interview study. It highlighted problems with open communication in relational, social, and healthcare settings. In relational settings communicative barriers revolve around trouble with expressing needs and not wanting to confront the other person in the relationship. In social context communicative barriers revolve around not being able to communicate the severity of the extremely individual situation to others and not wanting to burden friends and family too much. In the context of healthcare, communicative frustration was mostly expressed in the way information was being euphemized and insensitive to the true needs of the couple. These taboos and communicative barriers can lead to a sense of isolation for both partners.

2.Loss of relational equality and a losing sense of autonomy.

The introduction of incurable cancer in the lives of people often comes with a change in relational roles. Both the literature review and interview study described that the transition from partner to patient is accompanied by a transition from partner to caregiver. In these new relational roles the ill person can become selfish in the sense that they take up a lot of attention. The two participants both mentioned this feeling that everything revolves around the ill person and that the relationship has become one-directional.

The loss of relational equality is reflected on the sexuality of the individuals involved in the relationship. Sexual desires that caregiving partners may feel were not expressed with the fear of burdening or confronting the ill partner. Even solo attempts to satisfy these needs in different ways are often met with a feeling of guilt towards the partner.

The sense of losing autonomy over desires and loss of autonomy over life seem to be consequences of an incriesed relational inequality. Worries about the uncertain future that are presented by the disease and complexity of palliative care, appear to support this loss of autonomy, as it becomes difficult to couples and individuals to plan and dream beyond the disease.

3.Unrecognition of caregiving partners.

Expert interviews from the market analysis revealed frustrations about the unrecognized significance of the relational nature of sexuality. Healthcare is taught and designed to focus on the individual patient. By doing so healthcare is rather insensitive to the experiences and needs of the patient's partner. Especially in the context of sexuality and palliative care these needs of caregiving partners are suggested to be of great importance.

The feeling of caregiving partners being unrecognized in their situation goes beyond the shortcomings of the healthcare systemn but also prevails within the couples' relationship. As theme one highlighted the shift in roles within the relationship makes it hard to prioritize the needs of the caregiving partner.

Additionally, in social situations friends and family are also not always able to provide the partner with a feeling of being recognized. The complex individuality of both sexuality and palliative care can make experiences difficult to relate to for friends and family. The idea that others will not understand their situation adds to the sense of isolation experienced and expressed in interviews with partners.

This theme is closely related to the communicative barriers that are mentioned in theme one, but differentiates itself in its focus on the emotional isolation and unrecognized needs of the caregiving partner, both within healthcare settings, the relationship and social settings. It highlights how the caregiving partner's experiences and needs, are often overlooked, contributing to their sense of isolation and frustration.

4. Shift in sexuality and shift in needs.

The physical, emotional and contextual effects of the disease are felt deeply in sexuality and the relationship. The studies conducted show that the direct physical and emotional effects have large impact on the sexuality and desires of the ill person. Physical sexual ability is often greatly reduced by the disease and treatments. Emotional effects such as reduced sexual needs are also mentioned. This transition into a new state of limited physical and reduced emotional needs for sexuality, can be difficult to adapt to for the ill person but also for the partner. Adapting to a new form of sexuality as a couple and balancing sexual needs can be very challenging. Especially when caregiving partners experience unchanged sexual needs that are similar as the time before the disease was introduced into the relationship.

This unbalance that is described in multiple of the conducted studies can have many implications and links this theme closely to the loss of equal relationships described in theme 2 .

5. Sexuality is undervalued in healthcare and implemented inconsistently.

This theme highlights how sexuality is currently considered to be undervalued in healthcare. Although a small change in culture is said to be taking place, the speed and size of it are constantly being critiqued by pointing out the taboos on sexuality still present in healthcare.

Palliative care aims to support patients holistically across physical, psychological, social, and spiritual dimensions. However, sexuality and sexual well-being are rarely included in this holistic model. Although the ideology of palliative care emphasizes "total care," sexual well-being is often treated as a taboo topic or seen as less relevant at the end of life. This shows a gap between the ideals of holistic care and the fragmented way it is often practiced.

Although a biopsychosocial model is widely adopted among sexologist to approach sexuality in The Netherlands, sexual care implementation is still very fragmented lacking the desired standardization. The type of sexual support received by an ill person is still very dependent on the hospital, nursing home or practitioner involved. Additionally, literature shows that physical complaints are often prioritized in healthcare, which suggests that the multifaceted definition of sexuality is not completely being adapted across the different lines of healthcare.

Lastly sexual care is categorized as care that does not qualify to be covered by insurance. This demonstrates the disadvantaged position sexual care currently has in the healthcare system and highlights the need for recognition.

6. Too much focus on penetration.

The stereotypical conceptualization of sex focuses heavily on penetration. Literature and expert interviews both highlight the potential of sexuality to move beyond the focus on penetration. Sex therapy techniques such as sensate focus could help couples to shift the focus from goal-oriented sex to the sensory experiences of touch often.

Although literature presents a broad definition of sexuality that includes sensory experiences beyond penetration, the interview study suggested a clear distinction between sex and intimacy. Expressions of sexuality in the form of kissing, cuddling, holding hands, dancing or intellectual discourse are primarily labelled as acts associated with intimacy. Masturbation, oral satisfaction or sex with penetration were labelled as sex. When making this distinction sex and intimacy are often not valued the same. It is however important to notice that to some people the idea of redefining sexuality to a broader definition that includes acts labelled as intimate, can be experienced as an infringement attempting to replace their desire for acts labelled as sex. Therefore, the quest to explore the potential of redefining sex should be pursued with care. Truly seeing the concept as an addition instead of a replacement could help in the acceptance by couples.

The context of palliative care makes a transition in sexuality quite difficult. Incremental change and expectation management are suggested by experts and literature to facilitate the shift. Yet, with limited time and an approaching death these aspects are difficult to prioritize.

7. Individualistic nature of Sexuality.
This theme highlights the individualistic and evolving nature of sexuality found in both literature and the study on market analysis. Consequently, sexual well-being is a highly individual concept that makes standardized sexual healthcare very difficult. Regardless of the difficult implications that personalized care may bring with it, solutions should still aim to be considerate and sensitive towards the different ideas of sexuality individuals may have.

Taking that into consideration, single sexual support will interventions will not be able to help everyone. Especially within the group of people dealing with incurable cancer and their careging partners. To some, sex may be the last thing they want to think about. In contrast, with the approaching end of life, others may want to answer their desires for closeness, belonging, or spirituality through expressions of sexuality.

5.4 DISCUSSION

The triangulation process brought together insights from the literature review, market analysis, and interview study in order to obtain a more holistic understanding of sexuality and intimacy in the context of incurable cancer. While this synthesis produced meaningful overarching themes, the process also required a substantial level of abstraction. This abstraction is inherent to affinity mapping: clustering highly contextual, nuanced sub-themes into broader categories inevitably simplifies the data. Although this step is necessary to reveal structure across studies, it also introduces interpretative subjectivity. The resulting theme structure therefore reflects not only the data itself but also the researcher's analytical reasoning.

Another methodological challenge concerns the considerable conceptual overlap between themes. Issues such as communication, relational equality, and partner recognition are deeply interconnected, both theoretically and in practice. During analysis, some sub-themes naturally contributed to more than one overarching theme. In these cases, the sub-themes were deliberately placed in multiple clusters when they served different conceptual functions. This decision allowed important nuances to remain visible rather than forcing artificial separations for the sake of thematic neatness.

A third point of reflection concerns how different sources were weighed. Throughout the process, an effort was made to treat the three studies equally and avoid privileging one method or perspective over another. Nonetheless, the nature of the datasets required careful handling: the literature and experts offered broader systemic views, while the interviews provided deep but highly personal accounts from only two participants.

Finally, the triangulation demonstrates that although the seven overarching themes are analytically distinct, they remain closely interconnected. Communication barriers, emotional isolation, shifts in relational roles, and the undervaluation of sexuality in healthcare form a web of mutually reinforcing phenomena. Rather than viewing these themes as isolated findings, they should be understood as elements of a complex relational and systemic landscape. This complexity is central to the problem space and must be carried forward into the design phase.

5.5 CONCLUSION

The triangulation of the three studies resulted in seven overarching themes that together provide a coherent and integrated understanding of the challenges surrounding sexuality and intimacy in the context of incurable cancer. While the abstraction required for this synthesis introduces some subjectivity, the analysis demonstrates a strong convergence across literature, expert perspectives, and partner experiences.

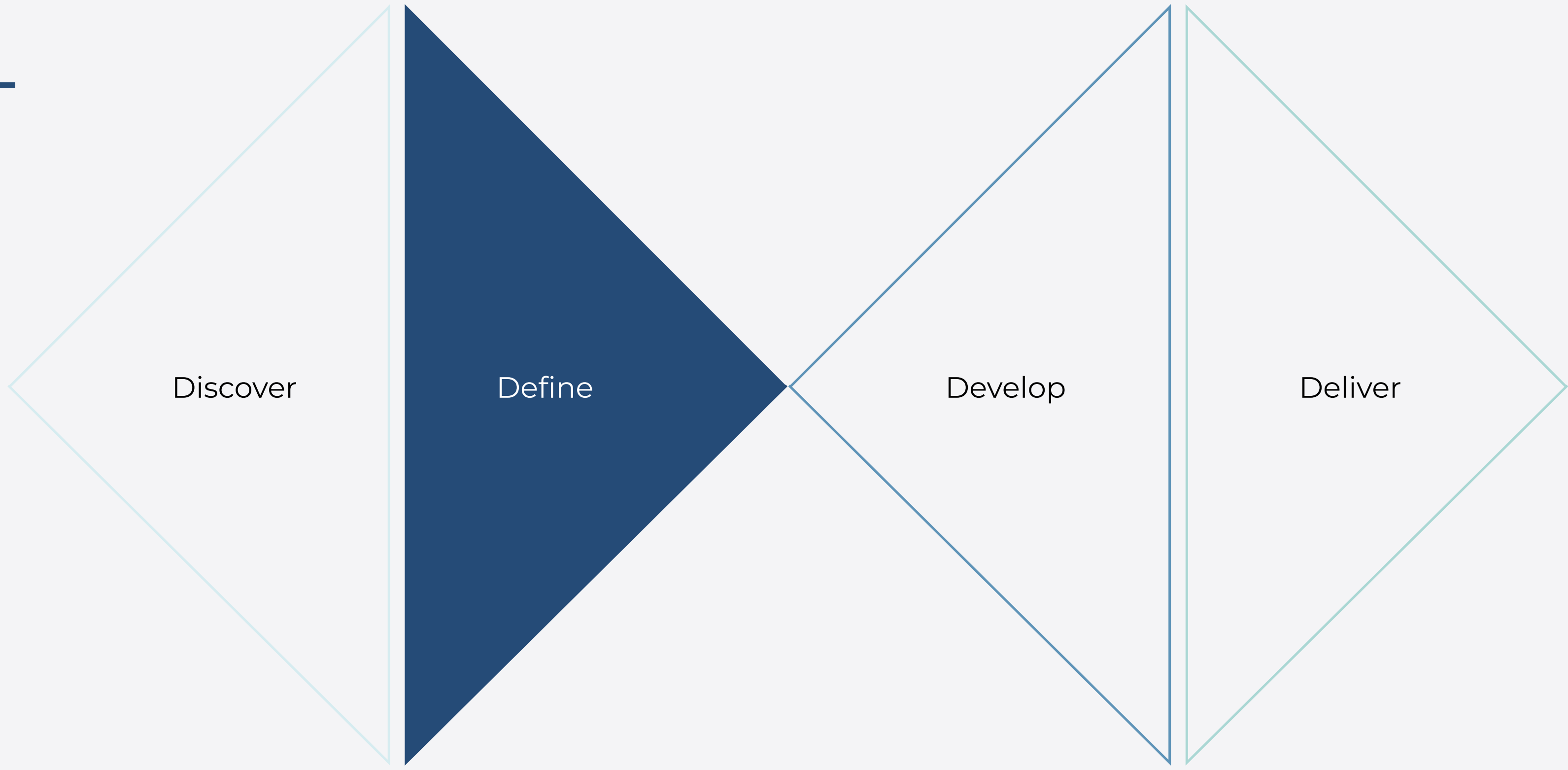
The themes show that sexuality remains undervalued and inconsistently addressed in healthcare; that communication is limited by taboos, euphemized language, and emotional barriers; that partners often feel unrecognized across relational, social, and healthcare settings; and that sexuality undergoes significant shifts due to the physical, emotional, and contextual impact of illness. At the same time, the results emphasize the relational and individual nature of sexual well-being, revealing the need for personalized and partner-inclusive approaches.

Importantly, the synthesis also illustrates that several of the identified issues such as the undervaluation of sexuality, limited training of professionals, and lack of standardized practices are systemic in nature. These structural blind spots cannot be resolved by a single design intervention. Instead, the design work that follows will focus on helping people with incurable cancer and partners navigate these systemic constraints, limit their impact, and find meaningful forms of connection within the realities of the current context.

Despite the interconnectedness of the themes, the triangulation offers a structured view of the problem space that can help guide the next design steps. The integrated insights provide a solid foundation for developing interventions that are sensitive to relational dynamics, acknowledge the individuality of sexual expression, and support couples in living with and through the limitations imposed by both illness and the healthcare system.

PART II

DEFINE



06

DESIGN DIRECTIONS

6.1 AIM

The aim of this chapter is twofold. First, it explains how the overarching themes identified in the triangulation analysis (Chapter 5) are translated into actionable design directions. Rather than reinterpreting or expanding on these themes, this chapter demonstrates how they inform design thinking by indicating where and how design can meaningfully intervene.

Second, this chapter justifies the selection of a focused design direction for the subsequent concept development phase. Although multiple design directions emerged from the research, pursuing all of them simultaneously would limit depth and clarity in the design process.

Because the triangulated themes and their underlying insights have already been discussed in detail in Chapter 5, this chapter does not revisit each theme extensively. Instead, it uses selected examples to illustrate the translation from research findings to design focus, while maintaining a clear and traceable link to the empirical data.

6.2 FROM TRIANGULATION THEMES TO DESIGN DIRECTIONS

The translation from triangulation themes to design directions followed a systematic and transparent process. Because the seven overarching themes already provided a clear and structured understanding of the problem space, the goal in this phase was not to reinvent or reinterpret these themes, but to recast them into more actionable, design-oriented statements.

For each triangulation theme, the underlying need, tension, or challenge was identified. These elements were then reformulated into a design direction by shifting the analytical focus from describing the problem to indicating how design could respond to it. This meant emphasizing aspects such as support, facilitation, adaptation, or empowerment, while keeping the original meaning of the theme intact.

Because the triangulation themes are strongly interconnected, overlaps between design directions were unavoidable and were deliberately maintained. Rather than forcing themes into isolated categories, this approach preserves the complexity of the problem space and ensures that each direction remains traceable to the research. The full set of seven design directions resulting from this process is included in Appendix D. In this chapter, two directions are discussed as illustrative examples, as they later form the core focus of the design phase.

1. Support Open Communication: Overcoming Taboos and Communication Barriers

Designing interventions focused on reducing the taboos surrounding sensitive topics like sexuality and death, and fostering open dialogue in relational, social and healthcare settings. This direction emphasizes tools that promote communication between partners, but also with friends, family and healthcare providers, aiming to reduce isolation. It should be nuanced however that this design direction does not aim to completely eliminate taboos surrounding sexuality and death. This direction moreso aims to provide individuals that need to communicate and connect, the appropriate tools to do so.

2. Supporting Sexual and Relational Autonomy: Addressing the Loss of Equality in the Relationship

This design direction focuses on supporting partners and couples in situations where incurable cancer has disrupted relational balance and reduced the autonomy of one or both partners. It addresses the shift from partner to caregiver and the feeling that life begins to revolve around the ill person. A particular emphasis is placed on the loss of autonomy over sexual and intimate needs, which are often suppressed out of fear of burdening the ill partner or causing guilt.

6.3 COMPARING AND NARROWING DESIGN DIRECTIONS

The previous section outlined how the triangulated research themes were translated into a set of seven design directions. Because the underlying issues addressed by these directions are deeply interwoven, each direction touches upon multiple aspects of the problem space. This makes it challenging to isolate one direction as more important than the others. Nevertheless, moving from analysis to design requires making a deliberate and well-reasoned choice.

Choosing a focused design direction does not imply that the other directions are irrelevant. Rather, it allows the design process to gain depth instead of breadth. A focused design trajectory enables meaningful exploration, targeted prototyping, and clear iteration, which would not be feasible if multiple directions were pursued simultaneously. This focus strengthens the coherence of the project and supports the development of a robust and research-grounded design outcome.

To support this selection process, a SWOT analysis was conducted to compare the seven design directions in a structured and consistent manner. For each direction, strengths and weaknesses were examined as internal qualities, such as alignment with the research insights, clarity of focus, and feasibility within the project scope. Opportunities and threats addressed external factors, including cultural developments, practical constraints within healthcare settings, and potential risks related to emotional sensitivity and user acceptance.

A full SWOT analysis was carried out for all seven design directions. Presenting each analysis in detail within this chapter would result in substantial repetition and reduce clarity. For this reason, the complete SWOT tables are included in Appendix E. This chapter therefore focuses on explaining the comparative logic and decision-making process, rather than reproducing the full analytical output.

Across the seven directions, the SWOT analysis revealed recurring tensions between feasibility, emotional sensitivity, and strategic impact. Directions operating at a system or policy level showed high societal relevance but limited feasibility within the scope of this project. In contrast, more intimate and relational directions offered greater concreteness and sensitivity to users' lived experiences, making them more suitable for further design exploration.

The insights from this comparative analysis form the basis for the selection of a focused design direction, which is discussed in the following section.

6.4 SELECTED DESIGN FOCUS

Following the SWOT analysis, an additional evaluative step was carried out to narrow the seven design directions into a workable focus for the design phase. While the SWOT analysis provided insight into the relative strengths, weaknesses, opportunities, and threats of each direction, this evaluative step supported a more deliberate and transparent decision-making process.

Each design direction was assessed against three key criteria derived from the research aims and practical considerations of this graduation project.

1. Potential for meaningful impact
The design direction needed to demonstrate clear potential to improve partners' lived experiences in the context of incurable cancer. This included offering emotional, communicative, or relational value that aligns with the needs and challenges expressed by participants throughout the research.

2. Feasibility within project constraints
The direction needed to allow the development of a concrete and testable concept within the available timeframe, technical possibilities, and scope of this graduation project. Directions that required large-scale systemic change or long-term institutional implementation were therefore considered less suitable.

3. Designer context fit
Finally, the design direction needed to align with the researcher's design expertise and with the ethical and emotional sensitivity required in palliative care. This ensured that the design work could be carried out responsibly, respectfully, and effectively.

Based on the comparative analysis two design directions emerged as the most suitable focus for further concept development: supporting open communication and strengthening sexual and relational autonomy. These directions were selected because they directly address the most recurrent and emotionally salient challenges identified across the literature review, market research, and interviews.

1: SUPPORT OPEN COMMUNICATION: OVERCOMING TABOOS AND COMMUNICATION BARRIERS

This direction shows strong potential because it directly addresses one of the most recurrent themes identified across the literature, market research, and interviews. Its main strength lies in its broad applicability across relational, social, and healthcare settings, making it relevant to multiple contexts in which couples affected by incurable cancer navigate intimacy and communication.

At the same time, this breadth also presents a weakness. Because communication can be approached in many different ways, the direction risks becoming diffuse if not clearly framed within a specific relational context. Opportunities for this direction include the growing societal acceptance of conversations about intimacy and mental well-being, which creates space for supportive tools that lower communication barriers. However, threats remain in the form of persistent cultural taboos surrounding sexuality and death, which may limit user acceptance and willingness to engage with such interventions.

2: SUPPORTING SEXUAL AND RELATIONAL AUTONOMY: ADDRESSING THE LOSS OF EQUALITY IN THE RELATIONSHIP

The second selected direction builds directly on the strong theme of relational imbalance identified in the interviews, in which partners described a loss of autonomy over their own emotional, intimate, and sexual needs. Its main strength lies in its focus on supporting partners in expressing these needs without guilt, while simultaneously acknowledging the constraints imposed by illness and caregiving responsibilities.

A central limitation of this direction is that the structural inequality created by incurable cancer makes full relational equality unattainable. This inherent imbalance cannot be resolved through design alone. Nevertheless, opportunities arise from a growing awareness of the emotional burden experienced by partners in palliative contexts, which opens space for tools that help couples navigate changing roles, needs, and desires. At the same time, this direction carries potential threats, as interventions that surface unmet needs may unintentionally increase emotional pressure on either partner, particularly if conversations become confronting or overwhelming within an already vulnerable situation.

Taken together, these two directions address closely connected aspects of the same underlying problem. Open communication enables partners to articulate needs, boundaries, and emotions, while relational autonomy depends on having the space and support to express these needs without fear or guilt. Their combination therefore offers a coherent and grounded focus for the design phase, allowing the project to engage deeply with the relational challenges identified in the research while remaining feasible within the scope of this graduation project.

6.5 DISCUSSION

Translating the triangulated themes into design directions required a degree of abstraction, which is inherent to moving from research insights toward actionable design. Because the seven themes identified in Chapter 5 are strongly interconnected, overlaps between design directions were unavoidable and, in some cases, intentionally preserved.

An important consideration in this process was the decision to keep the design directions closely tied to the original triangulation themes, rather than reframing them into entirely new categories. This choice ensures transparency and allows readers to trace each design direction back to its empirical foundations. Although this approach resulted in a relatively one-to-one mapping between themes and directions, it avoided unnecessary conceptual fragmentation and supported coherence between research and design.

The selection process further showed that it was not possible to focus on a single design direction without losing important parts of the research findings. The triangulated themes are closely connected, and this interdependence was also reflected in the SWOT evaluation. In particular, the directions related to open communication and sexual or relational autonomy appeared strongly linked. Communication enables partners to express needs and desires, while autonomy depends on having the space and ability to articulate these needs without fear or guilt. Separating these directions would risk oversimplifying the relational challenges identified in the research.

Although the remaining design directions were not selected as the primary focus, they still carry important insights. They continue to inform the design process as boundary conditions and considerations. Themes such as the individual nature of sexuality, the role of caregiving partners, and shifts in sexual expression remain relevant and shape the criteria that any suitable design outcome must respect.

6.6 CONCLUSION

This chapter translated the overarching themes from the triangulation phase into a set of actionable design directions and justified the selection of a focused design direction for the design phase. By combining the directions of supporting open communication and strengthening sexual and relational autonomy, the project retains the complexity of the research findings while establishing a clear and manageable focus for further development.

The selected direction captures the core emotional and relational challenges identified across the different studies, particularly the difficulties partners face in expressing desires, navigating unequal relational roles, and maintaining a sense of self within the context of incurable cancer. At the same time, the remaining design directions continue to function as important considerations that ensure the design process remains inclusive, sensitive, and grounded in the broader research context.

Together, the design directions form the conceptual bridge between research and design. In the next chapters, this focus will be further translated into concrete design criteria that guide ideation, prototyping, and the development of a meaningful design intervention.

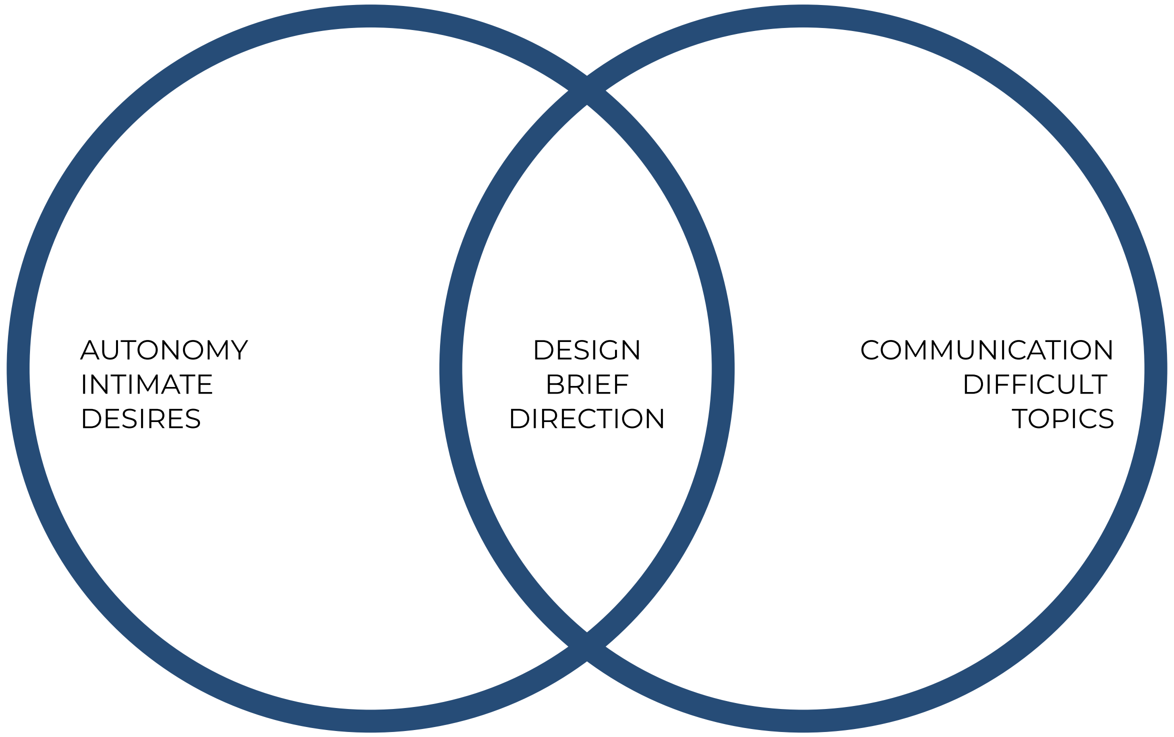


Figure 5: Two chosen design directions based on themes from triangulation

DESIGN BRIEF

07

The aim of this chapter is to bridge the analytical research phase and the design-oriented exploration that follows. Building on the insights and themes identified in the previous chapters, this chapter translates the research findings into clear and actionable design directions. In doing so, it marks the transition from understanding the problem space (the first diamond) to exploring possible solution spaces (the second diamond), and prepares the foundation for the subsequent design exploration.

7.1 PROBLEM STATEMENT

The problem statement combines two main themes identified in the studies. The first theme highlights challenges with maintaining autonomy over sexuality. When incurable cancer is introduced in a relationship, sexuality for both individuals changes drastically. Dealing with such a drastic transition is especially difficult for caregiving partners , whose needs increasingly move to the background as relational inequality grows. This inequality in need prioritization is also reflected on needs and desires in sexuality. Consequently caregiving partners lack a sense of autonomy over their sexuality.

The second theme highlights the barriers experienced in communication about sexuality. When people are not free to communicate, it can create a sense of isolation that negatively affects their relatedness. People in the context of incurable cancer experience communicative barriers in the form of cultural taboos on the topics sex and death make communicative barriers even bigger.

> Ultimately, communicative barriers may undermine intimacy, relatedness, and sexual well-being in relationships affected by incurable cancer, potentially impacting overall quality of life.

> In summary, the problem addressed in this project can be described as follows:
>
> When incurable cancer enters a relationship, sexuality may be significantly affected. Shifts in roles, unequal attention to needs, stigma, and cultural taboos can create communicative barriers that make it difficult for couples to express intimate and sexual experiences, which can negatively influence their sense of autonomy, relatedness, and sexual well-being.”

7.2 DESIGN SCOPE

The design scope of this project started with a broad and holistic perspective. Even though the design phase of the project still aims to be sensitive to the complex domain of this project, the studies conducted help with specifying the scope. First and foremost it is important to keep in mind that this project aims to support the sexual well-being. The themes identified in the research can be interpreted beyond the scope of sexual well-being. For example communicative and autonomy problems can easily be placed out of sexuality context and still have potential for impactful solutions. However this project scopes the themes and problems identified in the context of sexuality and supporting sexual well-being.

The conducted studies show that people experience communication barriers in different contexts: within their relationships, in social settings, and in healthcare. For this design project, the focus will be on communication within the relationship, as many previous interventions have attempted to address communication barriers in healthcare contexts. While social or societal recognition also influences sexual well-being, the strongest potential for impact appears to be in relational context.

Additionally, the literature review of this project also showed that healthcare differentiates three phases of palliative care. The first two phases of palliative are care symptom management and end-of life. They form the main focus of the design process. This because the bereavement phase that starts after the ill partner has passed away focusses on relatives of the deceased person. The nature of this phase and lack of insightful results from the research, make it difficult to focus the design scope on the bereavement phase. Since the problem as defined can be experienced by someone in both the symptom management phase as well as the end-of life phase, both are considered within the scope of the project.

7.3 TARGET GROUP

At the start of the project, a holistic approach identified the ill person, partner, and healthcare professionals as the three main stakeholders. While all of these stakeholders remain relevant, the design process benefits from focusing on one primary user to enable depth and clarity in the design phase.

Based on the conducted studies, caregiving partners of people with incurable cancer often experience limited recognition of their own emotional, relational, and sexual needs. Although both partners are affected by changes in intimacy and sexuality, care and support structures tend to focus primarily on the ill person. For this reason, the design phase of this project uses the perspective of the caregiving partner as the primary point of entry. This choice does not imply that the design is intended for one person in isolation, as sexuality and intimacy are fundamentally relational. Consequently, a key design requirement is that any outcome remains sensitive to the ill partner and supports the dynamics of the relationship as a whole.

7.4 DESIGN GOAL

Building on the problem statement, the scope, and the target group a design goal has been established as the starting point for the design phase. This goal focused on autonomy of sexuality and communicative support to foster relatedness.

> “The design aims to support caregiving partners of people with incurable cancer in restoring sexual autonomy, understood as the ability to recognize, articulate, and act upon their own needs and desires without relational pressure. Through communicative support, the design will help partners meet their personal need for relatedness.”

7.5 DESIGN REQUIREMENTS

To effectively navigate the second design diamond, and deliver an impactful solution, specific design requirements were set up. Feasibility, viability and desirability are considered key aspects to guide the design process. These requirements ensure the solution not only meets the needs of the main design goal but also aligns with the themes that were found in the research. The requirements are the following:

Feasibility

1. The design should be technically feasible with mostly existing technologies.
2. The design should be sensitive towards the different palliative contexts and environments (home care, hospital care, hospice) that the user may find itself in.
3. The design should be sensitive towards the situation of the user and the short horizon they have due to the limited time left.

Viability

4. The design should be sensitive to individualistic nature of sexuality. It should ideally provide support for sexual well-being to individuals regardless of their conceptualization of sexuality.
5. The design should be sensitive towards the relational aspect of sexuality. Despite focusing on the partner as a main user, it should still be considerate towards the use and implementation in a relationship.

Desirability

6. The design should support in communication about difficult topics such as sexuality and the related needs.
7. In doing so the design should still be sensitive towards implications of existing taboos, that might reduce the desirability if not taken into consideration.

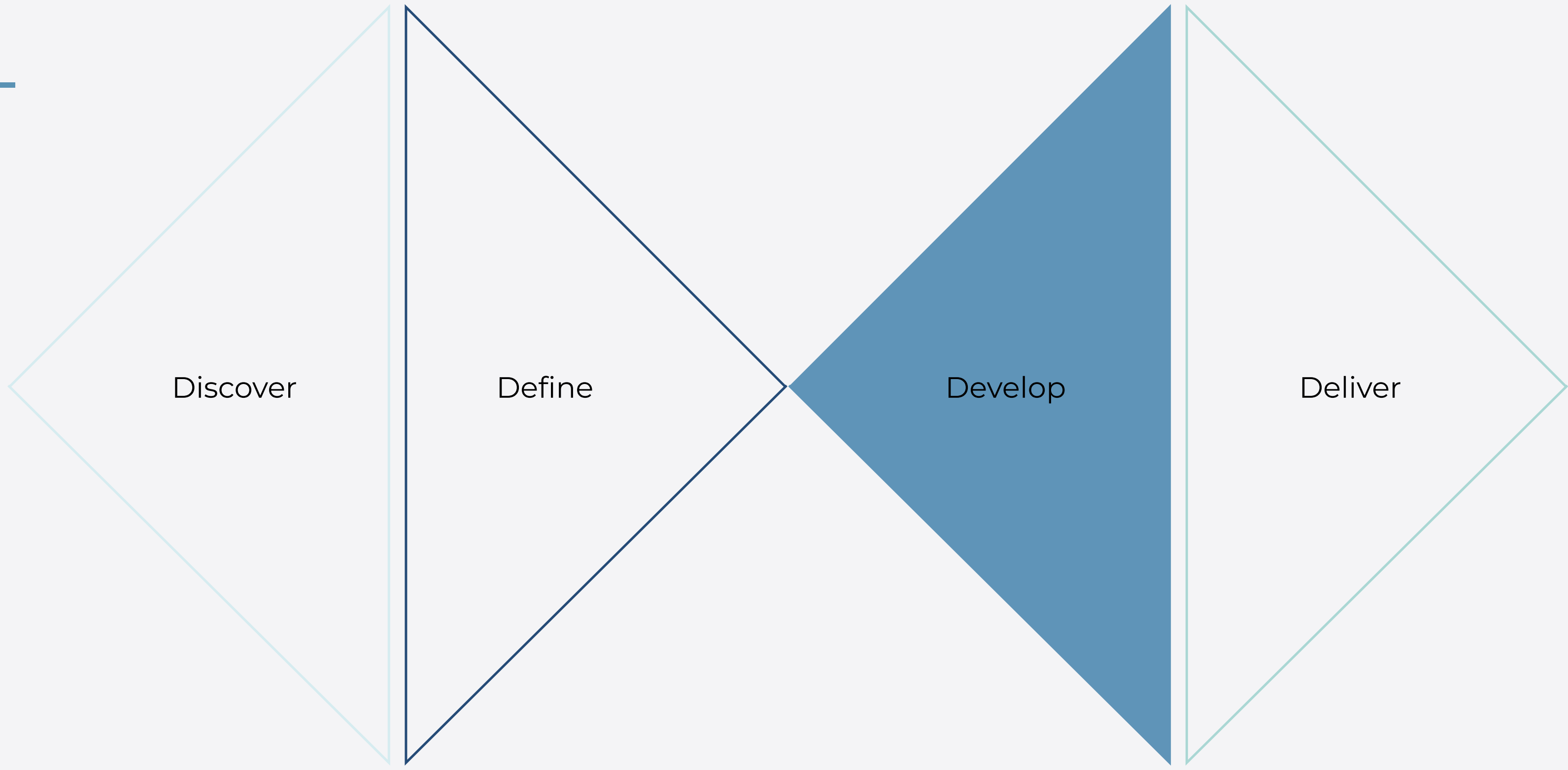
8. The design should help the user gain autonomy over their sexual desires and needs.
9. In doing so the design should remain desirable by being sensitive towards the complex situation of the user who is dealing with barriers in the form of a partner with sexual disabilities, reduced sexual desires and contextual logistical challenges.

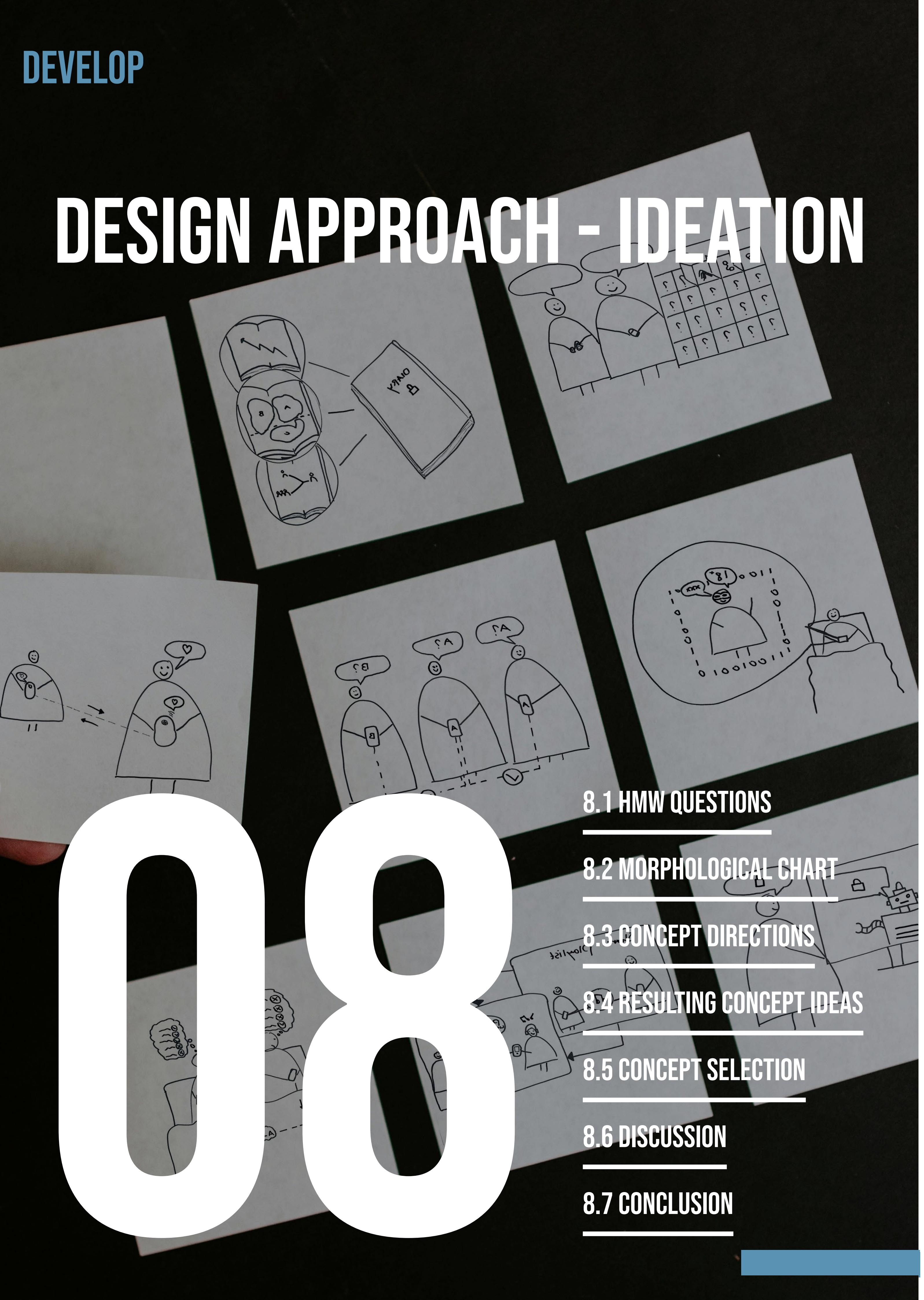
7.6 CONCLUSION

In this design brief, the insights from the preceding research phases were translated into a focused and actionable foundation for the design process. By synthesizing the identified challenges the brief establishes a clear problem definition and describes a scope that is both sensitive to the complexity of sexuality in palliative care and feasible within the constraints of the project. The decision to center caregiving partners reflects both the empirical evidence gathered and the opportunity to create meaningful impact where current support is lacking. The resulting design goal and requirements provide a coherent and research-grounded framework that will guide the subsequent development of concepts, ensuring alignment with the needs, contexts, and lived experiences of the users.

PART III

DEVELOP





DESIGN APPROACH - IDEATION

08

The aim of this chapter is to describe how the design brief was translated into a focused concept direction through a combination of divergent exploration and convergent selection. Given the complexity and sensitivity of sexuality and communication within palliative contexts, this phase deliberately moved from breadth to focus: first expanding the design space to explore multiple possible interpretations, and then narrowing this space to identify a workable and promising concept for further development.

The chapter therefore combines two closely connected design phases. The first phase focuses on ideation, in which the design space was broadly and systematically explored using How Might We (HMW) questions and a morphological chart. These methods supported a structured yet open-ended exploration, allowing abstract relational themes such as autonomy and communication to be translated into concrete opportunity areas and multiple low-fidelity concept directions.

The second phase focuses on concept selection. Using explicit design criteria derived from the design brief and research findings, the preliminary concept directions were compared through a Harris profile evaluation. This step introduced convergence by supporting a transparent and reasoned selection of one concept direction, while acknowledging the subjective nature of early-stage design decision-making.

Together, these phases form a coherent transition from research-driven exploration to focused concept development. The chapter shows not only which concept was selected, but also how and why this decision was made, providing a clear methodological bridge between the earlier research chapters and the subsequent refinement and prototyping phases.

8.1 FRAMING THE DESIGN SPACE THROUGH HMW QUESTIONS

The aim of this first step was to create a grounded but generative starting point for ideation. To do so, the key themes of the design brief (autonomy and communication) were translated into How Might We (HMW) questions. These questions helped reframe a complex relational problem into multiple opportunity directions and supported a broad, divergent exploration of the design space. To avoid relying only on intuition, the themes were anchored in well-established research on close relationships.

Autonomy Themes

Relational research describes autonomy not as independence, but as acting in line with one's own values and motivations while staying connected to a partner (Kernis & Goldman, 2006; LaGuardia et al., 2000). Two recurring elements of autonomy were selected as opportunity themes:

1. SUPPORTING INDIVIDUAL INTENTIONS:
Enabling people to act according to inner motivations rather than external pressure or expectations (Kernis & Goldman, 2006; LaGuardia et al., 2000)

2. FULFILLING BASIC PSYCHOLOGICAL NEEDS:
Supporting autonomy, competence and relatedness as core needs for well-being and healthy relational functioning (LaGuardia et al., 2000).

Communication Themes

Research shows that autonomy and communication in intimate relationships are mutually reinforcing processes. When partners experience autonomy, they tend to communicate in more open and authentic ways (Knee & Uysal, 2011). At the same time, supportive and safe communication creates the conditions in which autonomy can be expressed and maintained, as partners feel heard, respected, and emotionally secure (Kluwer et al., 2019; Anderson, 2019).

Studies further indicate that relationship quality improves when autonomy and relatedness operate together through supportive communication processes (Hardy et al., 2022). In this sense, communication is not only an outcome of autonomy, but also a key mechanism through which autonomy can be enabled in close relationships.

Because communication difficulties were a recurring barrier identified in both the literature and earlier research phases of this project, communication was treated as a distinct but closely related design theme. From this work, two communication-related themes were selected:

1. Enabling authentic communication:
supporting partners in expressing difficult thoughts or feelings honestly and safely (Anderson, 2019; Hardy et al., 2022; Knee & Uysal, 2011).

2. Maintaining interconnectedness:
fostering emotional closeness, mutual responsiveness and a secure bond that makes communication easier and less threatening (Kluwer et al., 2019; LaGuardia et al., 2000).

Role of the Themes in Framing HMW Questions

Together, these four themes offered a structured way to translate abstract relational theory into concrete opportunity areas. Autonomy supports communication, and communication supports autonomy; this mutual reinforcement made these themes useful conceptual anchors for generating the HMW questions used in the next step.

Main and Sub-HMW Questions

Based on these anchors, four main HMW questions were formulated:

1. How might we support individual intentions?
2. How might we promote psychological need fulfilment?
3. How might we enable authentic communication?
4. How might we maintain interconnectedness?

While these questions offered clear thematic directions, they remained too abstract for active idea generation. Early explorations showed that each question contained multiple possible sub-problems. Therefore, sub-HMW questions were developed to break the themes into smaller, actionable opportunity areas. This process resulted in the complete HMW tree in figure 6. It showed how abstract concepts from the literature could translate into concrete design opportunities. The tree then served as the basis for the structured exploration in Step 2.

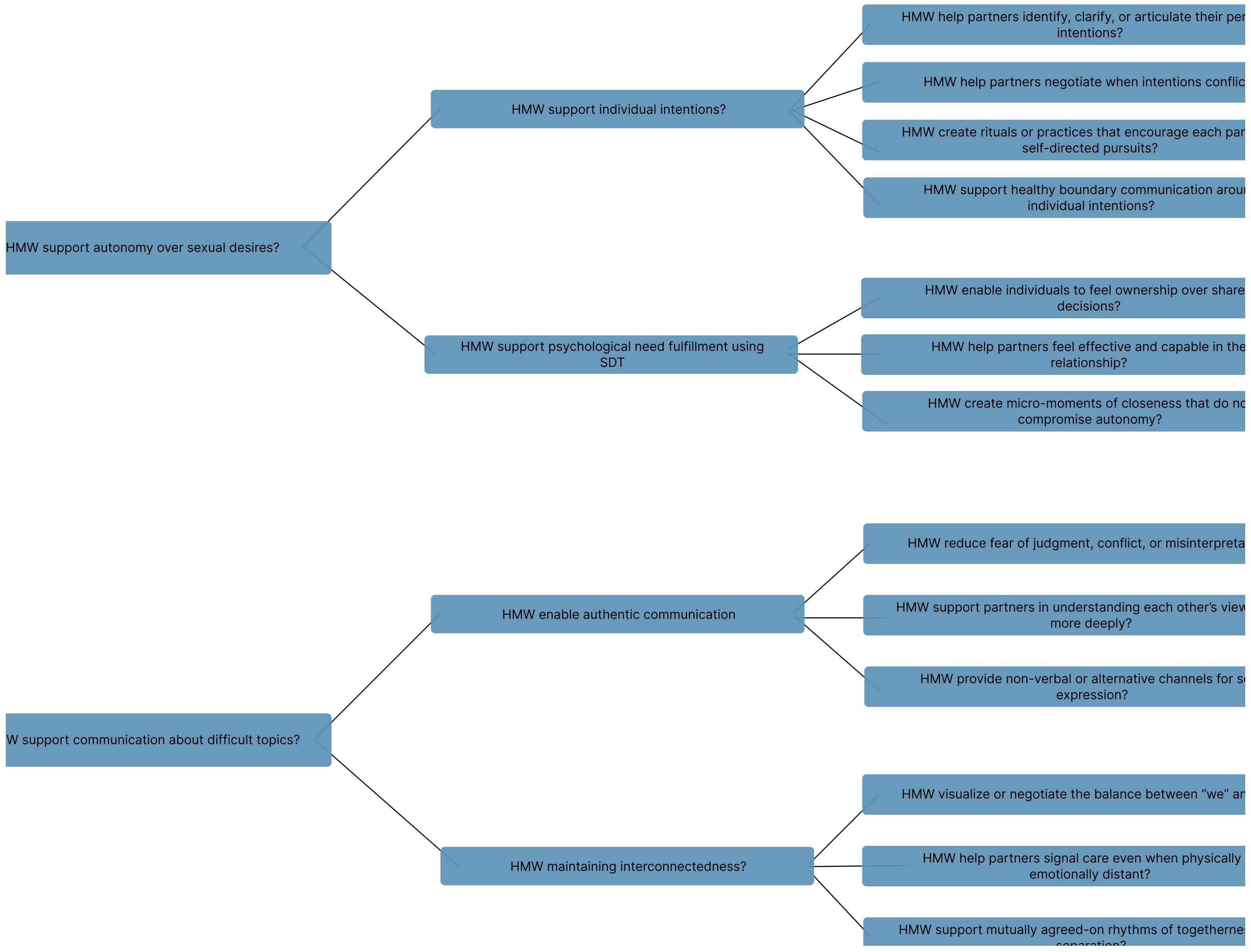


Figure 6: Resulting How Might We tree with main, bridging and sub HMW questions

8.2 TRANSLATING HMW QUESTIONS INTO A MORPHOLOGICAL CHART

The aim of this step was to structure the opportunity space generated during the HMW phase by answering the HMW questions and mapping it onto a morphological chart. Whereas HMW questions served to broaden the design space conceptually, the morphological chart enabled a structured and multidimensional exploration of possible solution components. This method was chosen because it makes explicit how different aspects of the problem space can be varied and recombined, thereby supporting extensive divergent thinking while maintaining traceability to the design brief.

The morphological chart (see Figure 7) was built using the sub-HMW questions from Step 1. After a brief clustering of overlapping HMWs each sub-HMW became one dimension in the chart and formed the left column of the matrix. For every dimension, several answer options were generated. These options came from quick ideation sketches.

No evaluation or filtering was done at this stage. All options were kept equal because the goal was to explore the design space as widely as possible. By placing the HMW dimensions in rows and the answer in columns, the chart made it possible to create many different combinations. This helped reveal a broad range of potential directions that would not appear through intuitive thinking alone.

HMW help partners identify, clarify, or articulate their personal intentions?	Self exploration	Mystery box 18+	Sex workshop	Bucket list	Goal prioritization	Intention positionality map
HMW help partners negotiate when intentions conflict?	Mediator	Explicit priority ranking	Explicit decision slider	Trade off token system	Intention translation app	
HMW support healthy boundary communication around individual intentions?	Physical boundary exploring	Boundary review cards	Explicit boundary game	Explicit traffic light emotion		
HMW enable individuals to feel ownership over shared decisions?	Individual ownership	Private place	Self care ritual	Solo vs shared choice indicator	Solo moment planner	
HMW help partners feel effective and capable in the relationship?	Competence logbook	Strength display board	Weekly micro challenges	Compliment exercises	Micro skill learning set	
HMW create micro-moments of closeness that do not compromise autonomy?	Reading alone together	Shared playlist	Shared show	Shared care project	Check in tokens signaling need	Mini note communication
HMW reduce fear of judgment or conflict by being trusted receiver?	Doctor/Professional	Friends	Diary	Person in same situation	Family	Robot
HMW reduce fear of judgment or conflict by indirect communication medium?	Record video	Online chat	Letter	Intermediary	Record audio	
HMW support partners in understanding each other's viewpoints more deeply?	Perspective labeling	Perspective switch exercise	Mirror response token			
HMW provide non-verbal or alternative channels for self-expression?	Music	Visualization (arts)	Physical (hugging)	Act of kindness		

Figure 7: Example of concept generation

The morphological chart brought together all 10 sub-HMW questions and their answers into one structured overview. This visual shows how broad the design space is and how many different directions can be created by combining the rows and columns. The chart does not present finished ideas, but it makes clear where interesting opportunities appear across the themes of autonomy and communication.

8.3 GENERATING CONCEPT DIRECTIONS FROM THE MORPHOLOGICAL SPACE

The aim of this step was to turn the possibilities from the morphological chart into a small set of early concept directions. These concepts were meant to show the breadth of the design space while staying low in fidelity, so that the focus remained on the idea itself and not yet on detailed execution.

The morphological chart from Step 2 was used as a direct starting point for generating concepts. Different answer options from the chart were combined to explore many possible directions (see Figure 8). Some combinations were chosen because they matched the themes of autonomy and communication, while others were selected to explore more unexpected or creative routes.

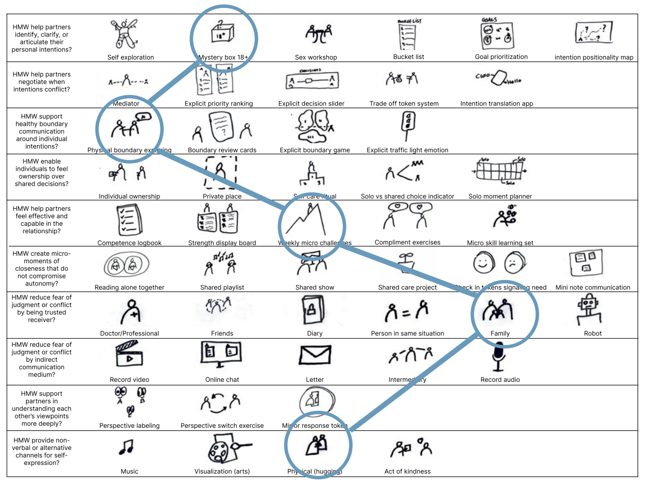


Figure 8: Example of conceptualization using morphological chart

The goal was to create concepts that were:

- Broad enough to stay flexible,
- Different enough to represent distinct ideas, and
- Concrete enough to discuss and refine in the next phase.

No feasibility limits were used, because this step was still fully divergent.

This process resulted in eight early concept directions, each built from different combinations within the morphological chart. Together, they show a wide range of possible ways to support autonomy, and communication about difficult topics in the context of incurable cancer. A short functional description of each concept is provided below.

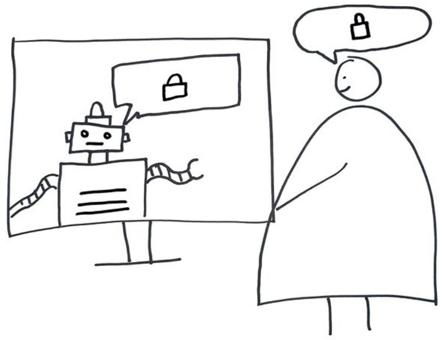
8.4 RESULTING CONCEPT IDEAS

Concept idea 1 – Advent calendar

The advent calendar contains stimulating items regarding sexuality. The idea is that these new items stimulate both in exploratory ways and communicative ways. By introducing potentially new items into the relation it invites users to experiment in new ways of sexuality beyond penetration. By doing this it allows people to discover boundaries and make them explicit. Not just for themselves, but it also stimulates people to start the conversation about these boundaries with each other.

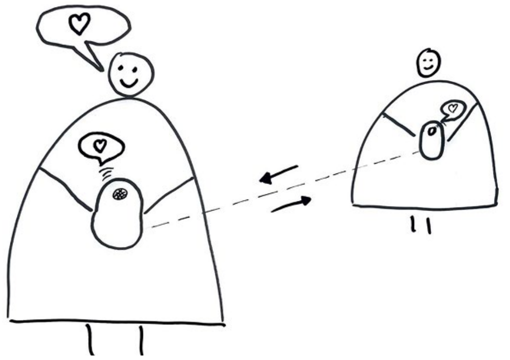
Concept idea 2 – Safe chatbot

The chatbot provides a way of communication for partners in that need to vent their emotions. It is an unconditional listening ear in times when it is much needed. Users don't have to feel burdened to share their emotions and are provided with relevant feedback to their situation. Since the chatbot is not a real person and the information is not publicly available the users don't need to be as scared of judgement as they would be with friends or family.



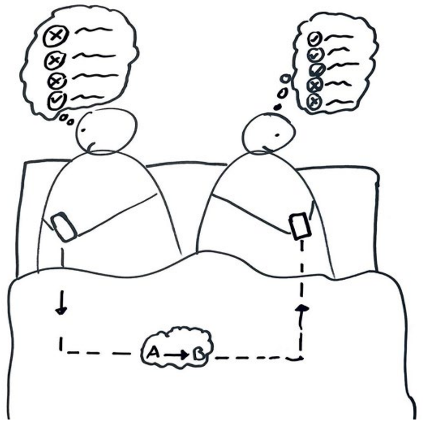
Concept idea 3 – Pillow Partner

The Pillow Partner is a set of pillows, one for each partner. They allow the user to record loving messages when cuddling the pillow and since they are connected to each other the user is also able to retrieve loving messages from the pillow that the partner recorded. This allows users to be able to vent and access intimate emotions on demand, without being dependent on the willingness or ability of the other partner. By being an intermediary communication device it potentially lowers the threshold for users to talk about difficult topics. In turn this could also benefit the direct communication between partners about these difficult topics.



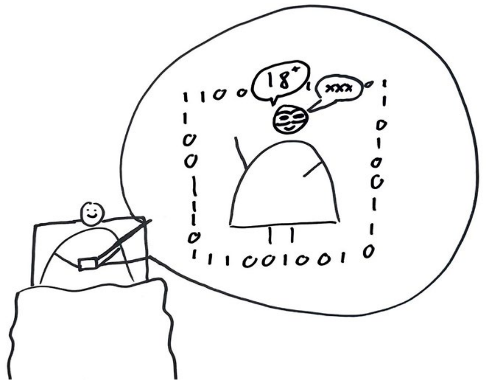
Concept idea 4 – Sensate Mediator

The Sensate Mediator is an app that allows users to provide each other with constructive feedback without restricting users on their need to vent their emotions. Users can simply type how they feel about recent sexual activity, what they liked, and especially what they did not like. This can be about sexual actions, but also about communication or general actions in a relationship. The typing exercise provides a moment of reflection for the users. After the feedback is submitted, the app goes to work and translates it where needed into constructive feedback points for the receiving partner. The new perspective provided in a constructive way is the starting point of relevant authentic conversations about difficult topics.



Concept idea 5 – Artificial Partner

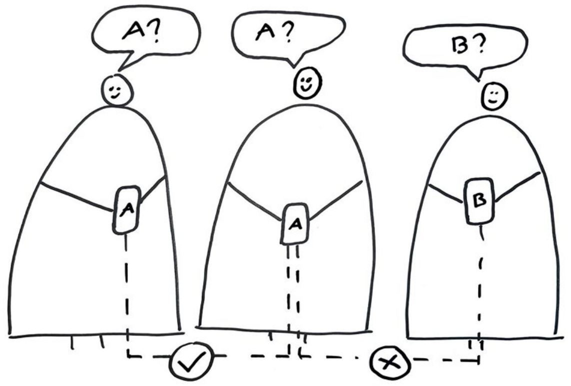
This concept allows users to vent their sexual and intimate desires without the dependency on the partner. This concept provides an artificially generated stimuli (visual and/or audio) from the partner. By doing so it allows the user to fulfill cropped up needs without burdening the partner.



The format could be visually and pornographic, but could also be audio and more emotionally comforting.

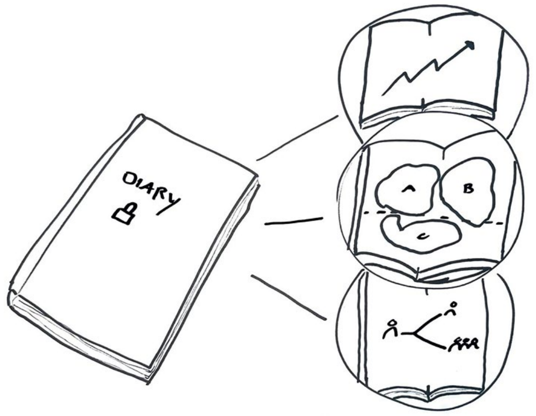
Concept idea 6 – Situation based buddy

The situation based buddy is a platform that helps individuals wanting to talk but feel their situation is too specific for friends and family to understand. The platform allows people to connect with each other based on their situation and the topics they want to discuss. What follows can be an online anonymous conversation or it could be a real life meetup to converse, but it should allow users to feel heard in their specific situation and lower the boundary to talk about it.



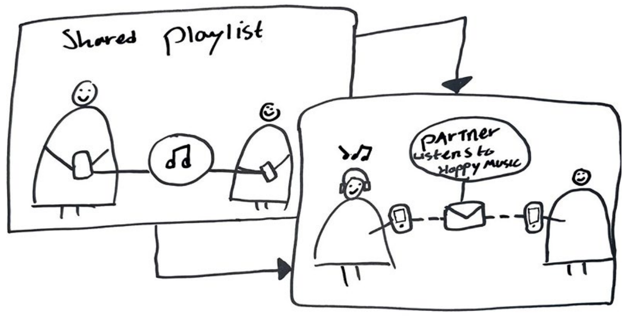
Concept idea 7 – Diary exercises

This concept provides users with exercises that could benefit their well-being by supporting aspects of the Self Determination Theory. These diary exercises could include tracking successes to make one feel more competent. Other exercises can help make boundaries explicit or help identify what choices were made for whom that day to help make the balance in the relationship explicit. These writing exercises offer moments of reflection and by having personal safe ownership of the book the boundary to conceptualize emotions and thoughts is potentially lowered.



Concept idea 8 – Shared playlist

This concept consists of two main elements. The first is a shared playlist of songs for both partners where they can add songs that mean something special. This allows to access these special moments on demand. The second element is the part where partners have insight into each other's listening behavior. This listening behavior is conceptualized in the form of a `wrapped´ overview that gives insight into the types of songs listened to that day by the other person and what this might mean to their emotional status. This intermediary and abstracted format of communication could be the starting point of difficult conversations.



8.5 CONCEPT SELECTION

This selection step marks the transition from divergent exploration to convergent decision-making, narrowing the design space to a single direction for further refinement.

To support a structured selection process, the design requirements from the design brief were translated into criteria for a Harris profile evaluation. Harris profiles were chosen because they offer a balance between quick comparison and specific scoring, which fits the early and still exploratory nature of this phase. The criteria came directly from the research themes and the design brief requirements:

Feasibility

- Foster autonomy over sexual needs and desires
- Support communication
- Feasible with existing technologies

Viability

- Sensitive to palliative care contexts
- Sensitive to limited time

Desirability

- Sensitive to the individualistic nature of sexuality
- Sensitive to both partners in the relationship
- Sensitive to existing taboos
- Sensitive to shifted sexuality due to illness

Each concept was scored individually on these criteria. No weighting was added, because the goal was to create an initial differentiation.

The Harris profiles (see Figure 9) showed a clear difference between the concepts, and the Pillow Partner received the highest overall score. This concept consists of two connected pillows that allow partners to record and receive intimate messages. It allows both partners to decide when they access the intimate messages and when they express their intimate feelings, without being dependent on each other´s emotional state or energy levels. The idea is that by doing so this concept supports autonomy over primarily intimate needs. At the same time the concept functions as an intermediary communication tool which enables indirect communication within a relationship. The concept clearly showed the most potential to support both autonomy and communication at the same time, the two core themes of the design brief. Next to the two core themes of the design brief, the Pillow Partner also scored high on other criteria.

For example, the Pillow Partner also scored higher than the other concepts when comparing practical feasibility and contextual sensitivity. It is feasible with existing technologies, while concepts such as the Sensate Mediator (concept 4), which would need active AI-based translation of emotional feedback, are positioned further outside the technical scope of this project. The Pillow Partner is also usable across almost all palliative care contexts including home care, hospital care and hospice whereas some ideas depend strongly on specific settings.

The concept is suitable for users with limited time, because it requires very little setup or learning. It is also sensitive to both partners in the relationship. For example, concepts based on creating a digital or artificial copy of the partner risk being emotionally confrontational or insensitive, especially for the ill partner.

Finally, the concept is respectful of existing taboos around sexuality and death. Explorative concepts such as the advent-calendar may introduce new sexual stimuli in ways that some users could find uncomfortable or overwhelming. The Pillow Partner avoids this risk by offering intimacy in a softer, indirect format, while still allowing space for sexual expression in different forms.

For these reasons, the Pillow Partner was selected as the concept direction for further development.

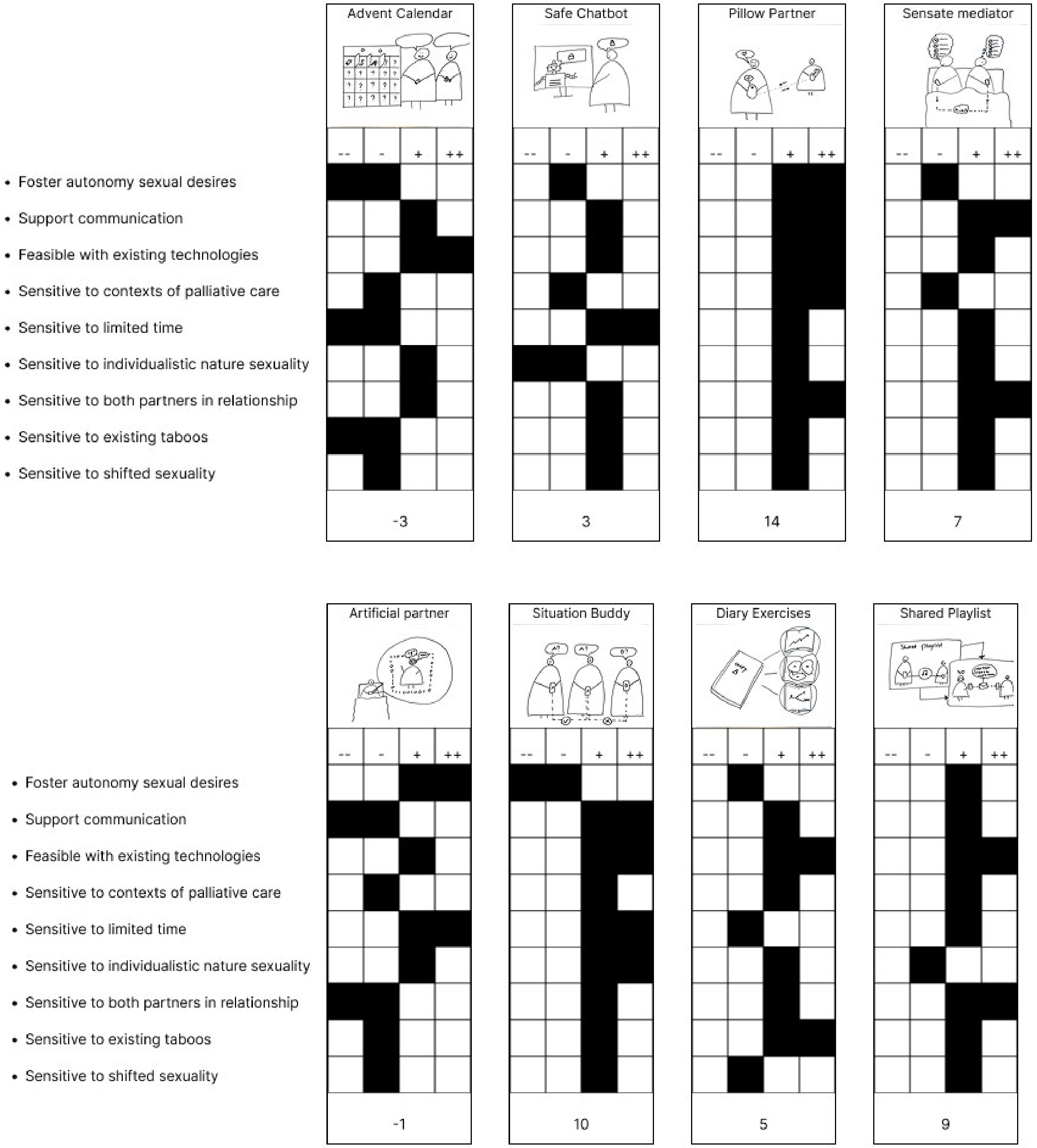


Figure 9: Results of selection Harris Profiles

8.6 DISCUSSION

The design exploration and concept selection presented in this chapter are inherently subjective and exploratory. Both the ideation phase and the selection phase relied on designerly judgement, interpretation, and creative decision-making. Methods such as How Might We framing, morphological mapping, and Harris profiles do not aim to produce objective or exhaustive outcomes. Different designers might have formulated alternative questions, dimensions, or concept combinations, or might have weighted selection criteria differently. The results should therefore be understood as one possible and situated outcome of the design process, rather than a definitive mapping of all possible solutions.

At the same time, the use of structured design methods helped ensure that this subjectivity remained transparent and traceable. The ideation phase was grounded in research insights, design directions, and sub-HMW questions derived from the triangulation analysis. The morphological chart supported a systematic exploration of the design space, translating abstract relational mechanisms into concrete opportunity areas and eight preliminary concept directions.

Similarly, the concept selection phase applied explicit design criteria and a comparative method to support decision-making. Although Harris profiles depend on interpretation and judgement, the large differences in scores between concepts provided a reasonable and transparent basis for selection at this stage. Rather than eliminating subjectivity, the process made evaluative choices explicit and grounded them in previously defined criteria.

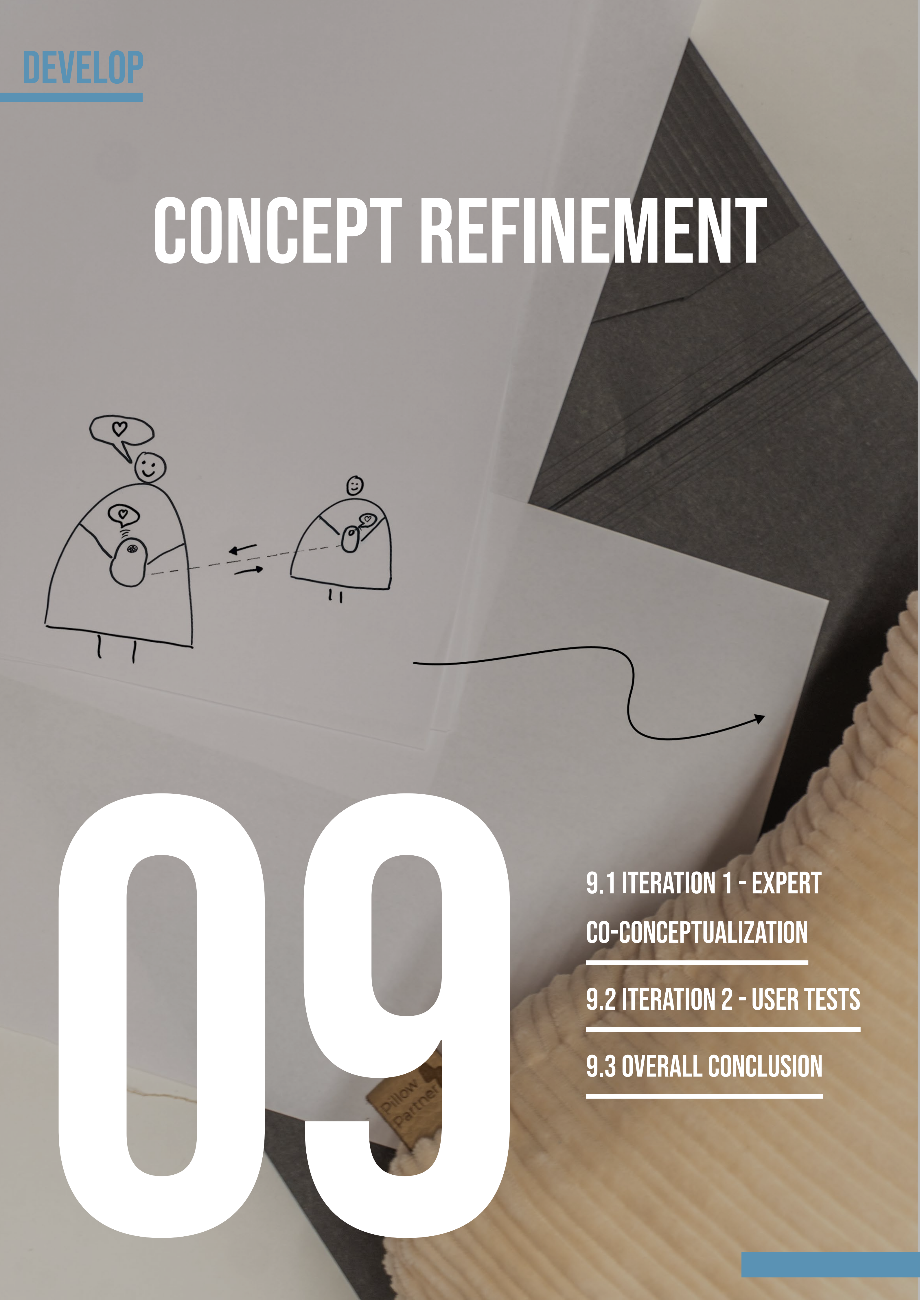
An important outcome of this combined phase is the recognition that early-stage design benefits from both breadth and focus. The divergent exploration allowed multiple interpretations of how autonomy and communication might be supported, while the convergent selection step enabled depth by identifying one concept direction to develop further. The selected concept, the Pillow Partner, emerged as a direction that balances emotional sensitivity, relational relevance, and feasibility, while remaining open to refinement.

8.7 CONCLUSION

This chapter combined divergent ideation and convergent concept selection into a single, coherent design phase. Through structured exploration methods, abstract research insights were translated into concrete opportunity areas and multiple preliminary concept directions. These directions provided a broad foundation for understanding how design could support autonomy and communication for partners of people with incurable cancer.

Using explicit design criteria and comparative evaluation, the Pillow Partner was selected as the most promising concept direction for further development. Although the selection process remains inherently subjective, the structured use of methods ensured transparency and alignment with the research aims. The chosen concept offers a balanced focus on intimate and emotional closeness, while retaining sufficient flexibility to address a broader range of sexual and relational needs in future iterations.

Together, the ideation and selection phases form a critical transition from research-driven exploration to focused concept development. The selected concept provides a grounded and adaptable starting point for refinement, prototyping, and evaluation in the subsequent stages of the design process.



09

CONCEPT REFINEMENT

9.1 ITERATION 1 - EXPERT CO-CONCEPTUALIZATION

9.1.1 Aim - Iteration 1

The aim of this first refinement step was to gather meaningful input on the selected concept and to further refine the design criteria for the next iteration. While broad exploration can generate valuable insights, focusing on one concept at this stage allowed for more specific, concrete and detailed feedback. The goal was to balance this focus with opportunities for open reflection, so that feedback could address both the underlying themes of autonomy and communication, and the early visulization of the Pillow Partner concept.

9.1.2 Method - Iteration 1

A semi-structured expert interview format was used. The structure was inspired by co-creation methods, moving step-by-step from broad reflections toward more concrete discussion of the concept (see figure 10). This approach was chosen to give participants enough freedom to share their perspectives while still supporting meaningful input on the concept's feasibility, desirability and viability. The interview consisted of three steps:

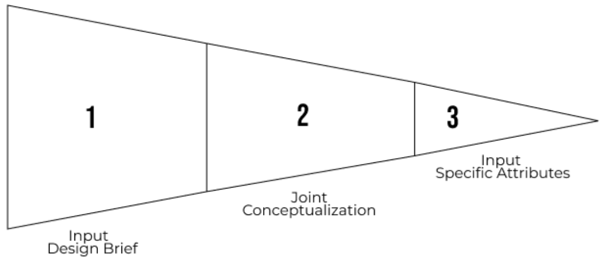


Figure 10: Study design including three types of input

STEP 1 — BROAD INPUT ON THE DESIGN BRIEF AND PROBLEM SCENARIOS

Experts were introduced briefly to the design brief. Three problem scenarios, based on anecdotes from earlier interviews, were used to ground the discussion (see figure 11). Experts were asked to reflect freely on the brief, the scenarios and what they believed a successful solution should achieve.

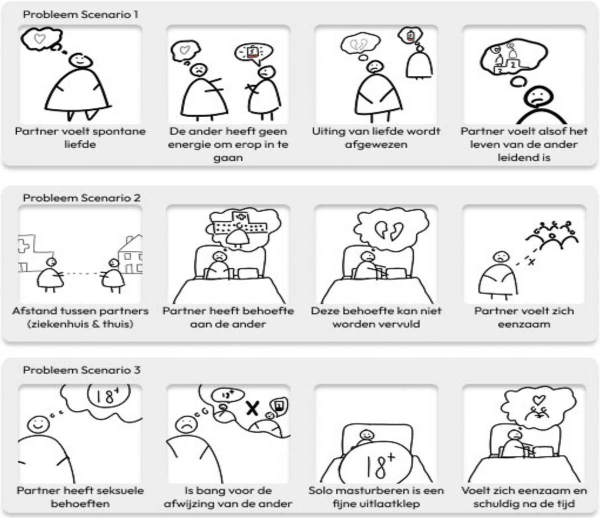


Figure 11: Problem scenarios introduced in step one based on anecdotes from interviews

STEP 2 — JOINT CONCEPTUALIZATION OF THE PILLOW PARTNER

The Pillow Partner concept was visually introduced only as a starting point (see figure 12). Experts were asked to build on the ideas they mentioned in Step 1 and translate these into possible functions or qualities of the pillow. This step aimed to support open-ended conceptualization within a gentle structure.

Figure 12: Visualization shown in step 2 for joint conceptualization

Step 3 — Specific feedback on implementation

The concept was then placed into the context of the three problem scenarios (see figure 13). Experts were asked which functions, qualities or behaviors the pillow should have in each scenario and why. Several example attributes were shown to support this process.

Throughout all steps, a balance was kept between broad reflection (on autonomy and communication) and more concrete feedback on the exectution of the concept.

Experts were recruited based on their professional expertise in sexuality-related healthcare, sexual well-being design, or the development of products and services for sensitive relational contexts (see Table 3).

Interviews were recorded through audio and supported by written notes. Visuals used during the sessions helped structure the conversation.

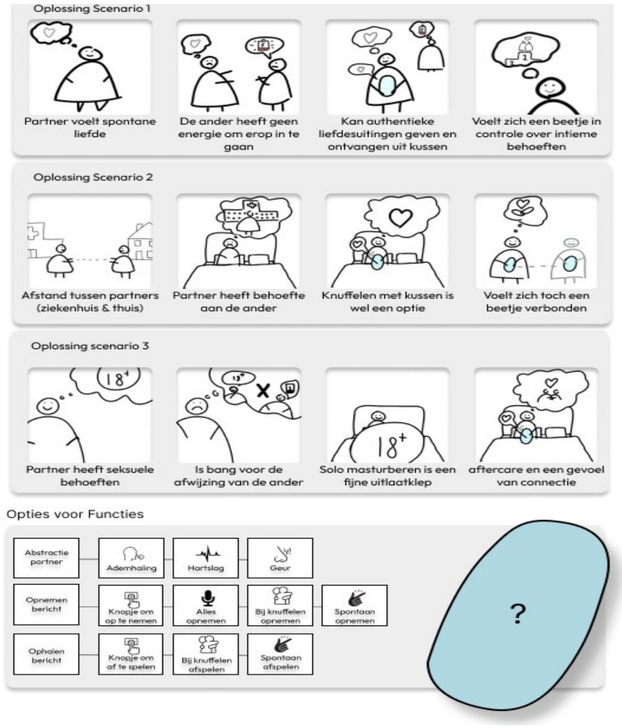


Figure 13: Solution scenarios shown in step 3 to generate specific feedback

The interviews were analyzed using a lightweight qualitative synthesis aimed at identifying practical insights for the next design iteration. Full transcription and formal thematic coding were not used, because the goal of this early refinement phase was to collect actionable design input rather than produce a detailed theory. Instead, the analysis followed three steps:

1. Note review: all written notes from the sessions were gathered and read to identify recurring ideas.

2. Selective audio listening: key sections of the audio recordings were replayed to verify important remarks and check nuance.

3. Insight clustering: similar observations were grouped into small sets of insights such as “simple, warm and non-medical appearance”.

9.1.3 Results - Iteration 1

The expert interviews resulted in a set of converging insights about how the Pillow Partner should be designed and experienced. Rather than producing isolated comments, the interviews led to a small number of recurring design expectations that were mentioned across experts and across interview steps.

Expert	Field of expertise	Type of interview
E01	Sexologist	In-person
E03	Develop sexual conversation tool in healthcare	Online
E10	Design for sexuality	Online
E11	Design for sexuality & cancer	Online
E12	Design for sexuality	In-person
E13	Design for robotics pillow (outlier)	In-person

Table 3: Experts included in the concept refinement

Through a process of clustering and synthesis, four key design elements were identified. These elements summarize what experts considered essential for the concept to be effective, acceptable, and sensitive within palliative contexts. They form the main outcome of this refinement step and guide the next design iteration.

1. Intimate and soft physical character

The pillow was repeatedly described as something that should feel comforting, soft, and close to the body. Experts associated intimacy with haptics, warmth, and familiarity, rather than with explicit sexual cues.

2. Sense of connection through form or interaction

Experts highlighted that the pillow should express connection, either through its physical form or through its interaction logic. This sense of connection was linked to emotional closeness and to the pillow’s role as an intermediary in communication.

3. Simple, warm, and non-medical appearance

Across interviews, experts stressed that the concept should not feel technological or clinical. A simple and warm aesthetic was considered important to reduce emotional distance and to increase acceptance, both for users and for healthcare professionals.

4. Gender-sensitive and inclusive form

Experts consistently emphasized that the pillow should avoid gendered shapes, colors, or associations. A neutral and inclusive appearance was seen as essential to ensure that the concept feels accessible to different couples and does not reinforce stereotypes.

These design elements were informed by different types of input across the three interview steps. In the first step, broad reflections on the design brief and problem scenarios highlighted communication barriers and unmet relational needs. In the second step, experts translated these reflections into desired qualities and roles for the Pillow Partner. In the third step, concrete feedback on form, materials, and interaction helped clarify how these qualities could be expressed in practice.

The examples discussed in each step should therefore be understood as illustrative rather than exhaustive. Together, they contributed to the four synthesized design elements presented above.

Step 1 — Broad reflections on the design brief

General insights from experts included:

- The solution should “bridge the distance between partners’ needs”.
- A lack of authentic communication was seen as a core problem.

Step 2 — Conceptualizing the Pillow Partner

Experts highlighted the following design needs:

- Space for positive messages, but perhaps also for difficult emotions such as anger or frustration.
- The pillow should act as a starting point for communication, not pretend to fix all problems.
- Easy to try out without commitment.
- should not not scream sex. This could help the acceptance among healthcare professionals.

Step 3 — Specific feedback on implementation

Experts discussed concrete qualities, including:

- A neutral color palette to avoid gendered associations.
- Warmth or soft vibration to create comfort and feeling of secure.
- Heartbeat or respiration imitation risked feeling “too medical”.

9.1.4 Discussion - Iteration 1

This refinement step showed both benefits and limitations. Focusing on one concept made it possible to receive deep and detailed feedback, especially on feasibility and viability. Experts were able to speak clearly about materials, emotional qualities and practical constraints. However, because only one concept was shown, several experts mainly reacted to the pillow itself and less to the broader themes of autonomy and communication. Follow-up questions were needed to touch upon the underlying reasons and broader themes as well. This effect was a natural result of narrowing the exploration early, and it may have reduced the variety of input and ideas that could have emerged.

The visuals also had a strong influence. The color and shape led experts to comment heavily on form and gender sensitivity. This feedback was useful, but it shows that the visual style may have guided the discussion more than intended. Additionally, for true co-creation, more supportive and creative facilitative tools would have been needed. In the current study, the visuals worked mostly as conversation starters rather than tools for making something together.

Some experts found it difficult to think beyond the given concept, especially those without a creative background. Still, the interviews generated insights about emotional needs, comfort, communication support and contextual sensitivity in palliative care. The sample also included some bias, because several experts knew the project from earlier phases or came from the designer's network. Yet this familiarity may also have helped them speak more openly. One participant was an "outlier": a designer with expertise in robotics pillows, not in sexuality. This expert was included because the experience in bringing similar and novel products to market. The expert's perspective did not replace the sexual-health expertise of others, but it added useful insights about implementation and viability strategies.

Experts did not always agree. Each of the three scenarios presented was seen as "very realistic" by some and "unlikely" by others. These differences show how personal and diverse perspectives are on sexuality. Interestingly sometimes experts agreed on overarching goals, but had different ideas on how to achieve those. For example two experts both mentioned that the design should be simple, but one of them mentioned doing this by excluding apps or external devices while the other said this would help keep the product itself simple and actually include external devices in the concpet.

Overall, the study produced valuable insights for the next iteration, even if it was not full co-creation. The step helped reveal what the pillow should feel like, how it might function, and how it should behave in sensitive emotional situations. This information will guide the next concept development stage.

9.2 ITERATION 2 - USER TESTS

9.2.1 Aim - Iteration 2

The aim of this second refinement step was to explore in what ways the two core relational mechanisms identified in the research phase (autonomy and communication) are best supported by the Pillow Partner concept. This step focused on gaining early, formative insights rather than evaluating effectiveness. The goal was to understand how users interpret the concept, how they imagine using it in their own relationship, and how these experiences can guide the next design iteration.

A central aim was to test whether users could recognize and experience the two core elements in the concept:

1. Autonomy over sexual and emotional needs

The concept allows each partner to express or access intimacy independently, without relying on the availability or energy of the other. This aims to support users in fulfilling or exploring their own needs in a non-demanding way.

2. Support for communication about difficult topics

The pillow functions as an indirect, less confrontational medium for emotional or intimate messages. This may help partners express thoughts or feelings that are harder to communicate face-to-face, making communication within the relationship safer and more approachable.

9.2.2 Method - Iteration 2

Design of study

The study followed a semi-structured, three-step interview format. Each step increased in focus, moving from first impressions to relational reflection, and finally to an evaluation of the concept's intended purpose. This structure allowed participants to respond openly before being influenced by the underlying design goals.

Step 1 — First reactions to the concept using tangible concept prototypes

The interview began with an introduction of the Pillow Partner concept, supported by simple physical prototypes (figure 14). The initially introduced prototypes consist of two dummy pillows which together with an explanation represented the concept.

Figure 14: Prototype of the pillow partner concept introduced to the participants

These prototypes were used as a conversational trigger to help participants express intuitive reactions. Participants were asked what the concept meant to them, how they interpreted the interaction, and what feelings or associations the prototype evoked.

Step 2 — Exploring relational use and imagined situations

After discussing their first impressions, participants were asked to imagine how they might use the Pillow Partner within their own relationship. This included reflecting on when, why and in which emotional situations they might record or listen to a message.

To help participants experience the interaction more concretely, a functional pillow which allowed participants to test basic voice-recording and playback functions was presented (figure 15). Participants were invited to record a short message as if it were meant for their partner, and then to play back a message from the functional pillow. The goal of this exercise was not to create realistic or personal content, but to let participants feel what the action of recording and receiving might be like in a real relationship.

Figure 15: Interaction prototype highlighting communicative aspects of concept

This step helped explore the emotional tone, usability and relational meaning of the interaction with the concept, still without introducing the intended design goals of autonomy or communication support.

Step 3 — Introducing the intended purposes: autonomy and communication

Only in the final step were the two core aims of the concept explained (supporting autonomy over intimate needs and desires & supporting communication about difficult or sensitive topics). Participants were then asked whether they recognized these functions in the concept, whether they felt meaningful in their own situation, and how the pillow might need to change to better support these aims. This step was meant to generate reflective feedback on alignment between user experience and design intention.

Participants & recruitment

In an ideal version of this study, interviews would be conducted with couples rather than only individuals. Interviewing with both partners at the same time makes it possible to test a core element of the concept: sending and receiving intimate messages between partners. This would practically be done with the third pillow that allows to record and replay short messages. This interaction is central to the Pillow Partner and provides insight into how the concept may support autonomy and communication in real relational dynamics.

However, recruiting couples for in-depth interviews can be challenging, especially because the topic is sensitive and requires a shared time commitment. For this reason, individual interviews are not excluded. Interviewing individuals still provides valuable insights into personal expectations, emotional responses and potential barriers, while also making it possible to include a sufficient number of participants.

The target for this study was 5–6 participants. This number seamed reasonable within the scope of this project and appropriate for qualitative, exploratory design research, where the aim is depth and richness of insight rather than statistical generalization.

The intended end-users of the concept (people living with incurable cancer and/or their partners) are the most valuable group for collecting meaningful feedback. However, due to the emotional sensitivity and practical demands of involving this group, they will be approached later in the interview sequence. Early interviews will therefore be conducted with "healthy" participants who are in a relationship. These early interviews can help identify unclear elements or usability issues that should be adjusted before engaging with the primary user group. This approach aims to protect the target population and ensures that their involvement contributes the most.

Data collection

Conversations are recorded and complemented by researcher notes. All data is pseudonymized during analysis, using a separate key file to protect participant identities.

Data analysis & procedure

The analysis followed a light and flexible qualitative approach fit for early-stage design research. No predefined coding template was used during the interviews, as this could restrict spontaneity and reduce sensitivity to unexpected insights. Instead, notes were taken freely during the conversations, and audio recordings were used afterwards to enrich and correct these notes.

After each interview, the recordings were reviewed and expanded into short analytic memos capturing: key statements, emotional reactions or hesitations, and potential implications for the concept.

These analytic memos were then compared across participants and grouped into emerging themes through a simple clustering process similar to affinity mapping.

The analysis followed a pragmatic qualitative approach fitting the phase of the project. Audio recordings and notes were reviewed, and key insights were clustered around the two core themes of the study: autonomy and communication. The goal of the analysis was to identify design implications rather than to develop a formal coding framework.

9.2.3 Results - Iteration 2

Three interviews were conducted which generated rich qualitative data about how participants perceived and experienced the Pillow Partner concept. Although the participants differed in health status and relational context, several recurring patterns emerged across the interviews. The results are presented as thematic findings, each illustrated with direct quotes from the participants.

1. The pillow as a source of physical comfort and emotional safety

All participants immediately engaged with the pillow as a physical object. They described holding, embracing or leaning against it, and associated this physical contact with comfort and emotional safety. One participant described how the shape and size invited closeness:

> "It really feels like something you want to hold. I immediately started hugging it." (R02)

Another participant linked the form to a bodily experience of being with someone:

> "If you hold it like this, it almost feels like someone laying on your chest." (R01)

The physical softness and warmth were repeatedly mentioned as important qualities. A participant with chronic illness connected this directly to emotional regulation:

> "I sleep with a hot water bottle because it helps when I panic. I can imagine that hearing a voice while holding something warm would really calm me." (R03)

Across interviews, participants contrasted the pillow with phones or digital devices, which they experienced as more distant or technical:

> "WhatsApp feels very different. This is soft, you can hold it, it feels much more intimate." (R03)

These responses suggest that the physical presence of the pillow plays a key role in making emotional expression feel safer.

2. Indirect communication lowers the threshold for expressing difficult feelings

Participants consistently described the pillow as a less confrontational way to communicate difficult or sensitive thoughts. Speaking into the pillow felt easier than speaking directly to the partner, while still maintaining a sense of connection. One participant explained:

> "If you want to say something difficult, it helps that you don't have to look at the other person, but you still feel like someone is there." (R01)

Another participant reflected on how the pillow could support communication during emotionally charged moments:

> "It's easier to say things through the pillow than face to face. Holding something makes it less hard." (R02)

Participants also noted that the pillow allowed them to reflect on their own words before sharing them:

> "It's kind of nice to hear yourself back first. You can think: is this really what I mean?" (R001)

This suggests that the pillow not only supports communication toward the partner, but also functions as a reflective tool for the speaker.

12.3 Control over timing and emotional exposure

A strong theme across all interviews was the importance of choosing when to speak and when to listen. Participants valued that the concept did not demand immediate interaction. One participant described this clearly:

> "It's not like a phone that rings and you have to respond right away. You decide when you're ready." (R03)

Another participant emphasized the importance of emotional pacing:

> "You can say something when you have the energy, and the other can listen when they're ready for it." (R01)

At the same time, participants were aware that communication always affects both partners. This led to reflections on responsibility and expectation:

> "You decide when to say something, but once the other listens, it does something. You can't fully control that." (R01)

Several participants suggested small design adaptations to manage this tension, such as confirming that a message had been listened to:

> "Maybe you could let the other know: I've listened, but I need some time to think about it." (R01)

These remarks show that control over timing was experienced as supportive, but also relationally complex.

12.4 Different meanings and uses within the same relationship

Participants described that the pillow might be used differently by each partner in a relationship. These differences were not seen as negative, but as reflecting individual needs. One participant explained:

> "For me it would be more practical, like a communication tool. For my partner it would really be a cuddle pillow." (R01)

Another participant emphasized personal ownership:

> "This one feels like mine. I can use it when I want, and the other has their own." (R02)

This separation was seen as valuable, especially in relationships where partners differ in emotional needs or energy levels.

12.5 Meaning beyond sexual communication

Although the concept was discussed in relation to intimacy, participants repeatedly framed its value in broader emotional terms. Comfort, warmth, reassurance and presence were mentioned multiple times. One participant stated:

> "This is not just about sex. It's about closeness, comfort, being there for each other." (R02)

Others described use in moments of illness, anxiety or grief:

> "If someone is gone, or you're alone at night, hearing their voice while holding something like this could mean a lot." (R03)

These responses indicate that participants understood the pillow as a medium for emotional connection across different situations and phases of a relationship.

9.3.4 Discussion - Iteration 2

This iteration has several limitations that should be taken into account when interpreting the results. First, only three participants were interviewed. Additionally, not all participants fully represented the intended end-user group. This limited sample size reduces the generalisability of the findings and means that the results should be interpreted with caution.

Although care was taken not to involve friends of the designer and instead to seek feedback from external and critical participants, the study setup still allows for potential bias. The designer was present during the interviews, which may have influenced how openly participants expressed critical feedback. Participants might have been more careful or restrained in their responses due to social desirability or the presence of the concept's creator. In a future and more robust user study, this bias should be addressed, for example by involving an independent moderator or using anonymised feedback methods.

Despite these limitations, the results of this iteration are promising. Even without explicitly communicating the design goals, most participants independently recognised and articulated these goals during steps 1 and 2 of the interviews. This suggests that the core intentions of the concept are clearly embedded in the design and are intuitively understood by users. The fact that the design goals were consistently identified indicates that the concept communicates its purpose effectively, which is a strong outcome of this refinement iteration.

9.3 OVERALL CONCLUSION

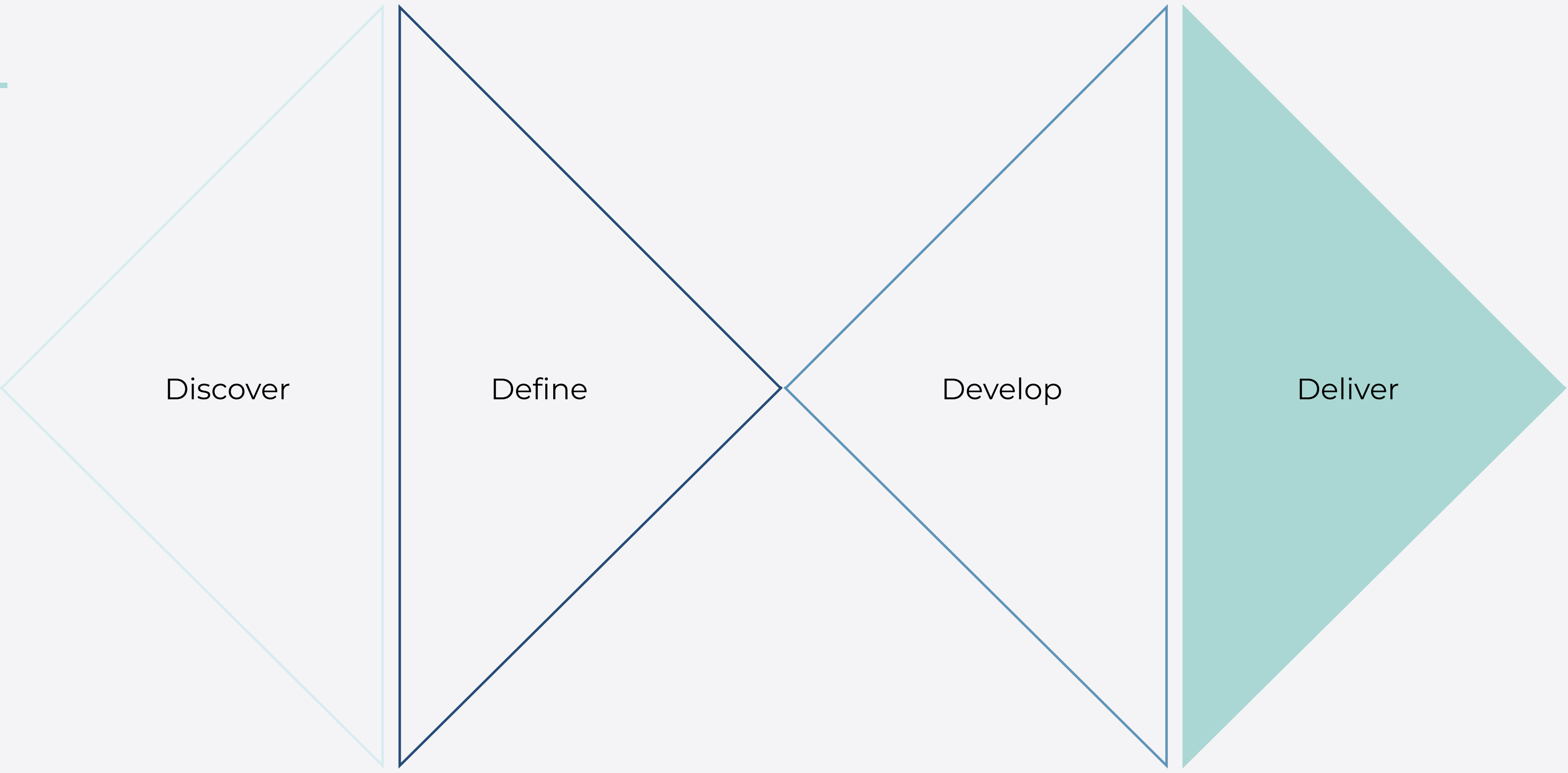
The two refinement iterations together provided complementary insights that strengthened the Pillow Partner concept both conceptually and experientially. The first iteration, based on expert co-conceptualization, clarified the essential design qualities needed for sensitivity, acceptance and feasibility within palliative and relational contexts. It resulted in four clear design elements that guided further development and helped translate abstract themes such as autonomy and communication into concrete design directions.

The second iteration focused on early user interpretation and experience. Despite a limited sample size, the user interviews showed that participants intuitively understood the core intentions of the concept, even before these were explicitly explained. Users recognized how the Pillow Partner could support autonomy, and communication within a relationship. This suggests a strong alignment between design intention and user perception.

Taken together, the iterations show an iterative refinement process in which expert-driven design principles were validated and enriched by user experiences. While further and more robust user studies are needed, the findings indicate that the Pillow Partner concept meaningfully embeds its relational goals and provides a solid foundation for the next development stage.

PART IV

DELIVER



FINAL DESIGN

10

10.1 AIM OF THIS CHAPTER

The aim of this chapter is to present the final design outcome of this project and to explain how the concept responds to the insights generated in the previous analytical and exploratory phases. This chapter describes how the Pillow Partner works, which design choices were made, and how these choices relate to the two core relational themes identified throughout the research: autonomy and communication. In addition, this chapter reflects critically on the scope and limitations of the concept, acknowledging what the design supports and what remains beyond its reach.

10.2 DESIGN RATIONALE: FROM RESEARCH TO CONCEPT

The final design is grounded in a synthesis of insights from literature, contextmapping studies, expert interviews, and iterative concept exploration. Across these phases, two recurring challenges became central: partners experienced limited autonomy over their intimate and emotional needs (figure 16), and communication about these needs was often inhibited by fear of confrontation, guilt, or emotional overload (figure 17).

The research showed that autonomy over intimacy in relationships is closely tied to having control over timing, expression, and emotional pacing, especially in sensitive contexts such as incurable illness. At the same time, communication was found to be highly relational and emotionally charged, often becoming more difficult when partners wished to protect each other from distress. Physical comfort, indirect interaction, and asynchronous communication repeatedly emerged as factors that could lower these emotional thresholds.

The Pillow Partner was designed as a response to these insights. Rather than offering direct guidance or explicit instruction, the concept aims to create conditions that make autonomy and communication more accessible within the relationship. It does so by combining a familiar, comforting physical object with a simple voice-based interaction that allows partners to express and receive messages at their own pace.

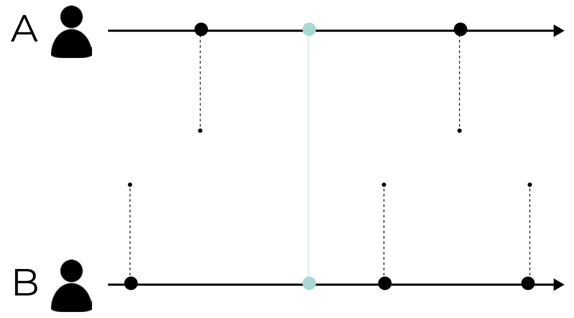


Figure 16: Individual timelines with moments of spontaneous intimacy are asynchronous.

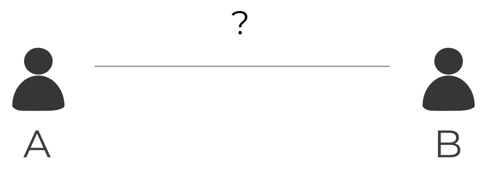


Figure 17: Uncertain relational communication in current situation.

10.3 CONCEPT OVERVIEW: THE PILLOW PARTNER

The Pillow Partner is a paired set of soft pillows designed for partners in an intimate relationship. Each partner has their own pillow, which can be used independently or in connection with the other. The pillows allow users to record short voice messages and to listen to messages recorded by their partner.

The concept is intended for use in situations where direct conversation feels difficult or overwhelming. This may include moments of emotional vulnerability, physical absence, illness-related stress, or times when partners have different levels of energy or readiness to talk. The pillow can be used privately, without the immediate presence of the other partner, and does not require synchronous interaction.

Unlike digital communication tools such as messaging apps, the Pillow Partner is deliberately physical and non-medical in appearance. It is designed to blend into everyday domestic environments and to be approached as an object of comfort rather than as a technological device. The concept does not aim to replace conversation, therapy, or care, but to function as a gentle intermediary that can support moments of connection and expression.

10.4 HOW THE DESIGN SUPPORTS THE CORE THEMES

1. Supporting Autonomy over intimacy

The Pillow Partner supports autonomy by giving users control over when, how, and whether they engage with intimate communication (figure 18). Recording a message does not require the immediate attention or response of the partner, which reduces pressure and allows users to choose a moment that feels emotionally safe. Similarly, listening to a message can be done when the receiver feels ready, rather than when a message arrives unexpectedly.

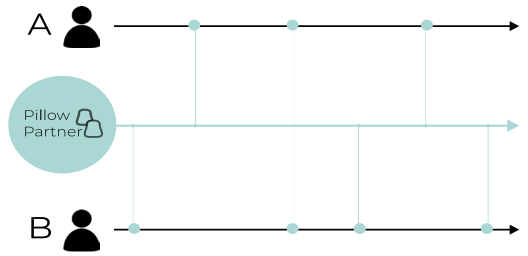


Figure 18: Pillow partner supports spontaneous intimacy at individual's pace.

The interaction with the pillow is intentionally simple and private. Users do not need to navigate complex interfaces or external platforms, which helps reduce cognitive effort and dependence on technology. The pillow can be used alone, without explanation or justification, reinforcing a sense of personal ownership. In this way, autonomy is supported not as independence from the partner, but as self-directed participation within the relationship.

2. Supporting Communication about difficult topics

Communication is supported through indirectness, physical comfort, and emotional safety (figure 19). The soft, familiar form of the pillow encourages touch and closeness, which can make emotional expression feel less threatening. Speaking into a pillow rather than directly to a partner can lower the barrier to articulating difficult thoughts or feelings, especially when fear of reaction or conflict is present.

Figure 19: Supported relational communication with Pillow partner in relationship.

The use of voice allows emotional nuance to be conveyed more clearly than text-based communication, while the absence of visual presence reduces confrontation. Because the pillow is associated with intimacy and care, messages exchanged through it are perceived as more personal and meaningful. Together, these qualities support communication as a gradual, relational process rather than a single confrontational moment.

10.5 DESIGN DECISIONS AND THEIR IMPLICATIONS

Form

The form of the Pillow Partner was deliberately designed as a synthesis of two morphological references. On the one hand, the object needed to evoke the physical and emotional qualities of a body: something that can be held, embraced, and pressed close, similar to the experience of hugging a partner. On the other hand, it needed to remain recognizable as a familiar household object, rather than a playful toy or an explicitly sexual artefact.

By combining these two references — the cuddle qualities of a body and the everyday familiarity of a pillow—the final form was developed (see Figure 20). This balance aims to make the object emotionally approachable without becoming overly symbolic or confronting.

Material choices further support this intention. Soft, tactile textiles were selected to encourage physical contact and comfort, while a neutral and inclusive color palette was used to avoid gendered associations or explicit sexual connotations. This neutral appearance lowers the threshold for use and supports introduction in sensitive contexts, but it also means that the object is not immediately recognizable as an intimacy-focused product. This ambiguity was accepted as a trade-off in favor of emotional safety and broad accessibility.

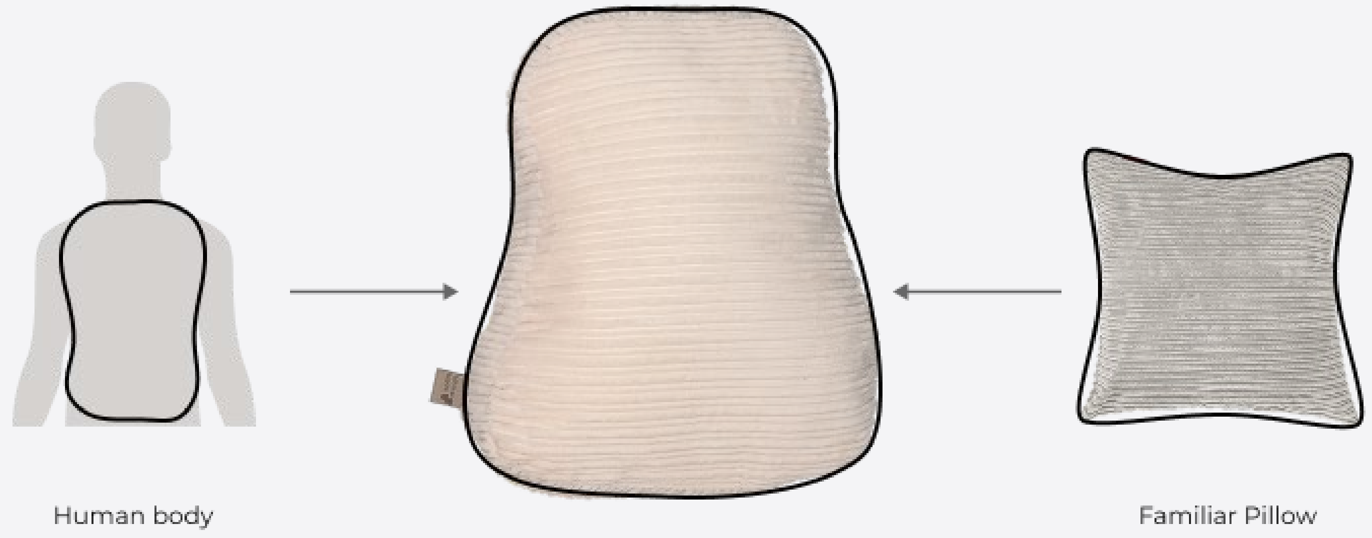


Figure 20: Morphological inspiration for the concept.

Function

In terms of function, the design aimed to balance simplicity of use with meaningful interaction. The interaction logic was intentionally kept minimal to reduce cognitive load and avoid a technical or medical feel. The user interface consists of a single button and a circular LED indicator, which together support recording, sending, and listening to voice messages. This limited interaction set allows users to focus on the emotional content of the message rather than on operating the device.

In addition to voice messages and the physical presence of the pillow, a warmth function was integrated. The pillow gently warms while a message is being played, adding a physical sensation to the auditory experience. This warmth was intended to support feelings of closeness and presence, capturing an abstract sense of nearness without becoming overly literal or confronting. Compared to features such as screens or visual representations, warmth adds little technical complexity

Figure 21: Functions of the concept

10.6 DISCUSSION

While the Pillow Partner addresses key challenges identified in the research, it does not function as a universal solution. The concept assumes a certain level of willingness to engage with emotional expression and may not be suitable for all relationships or stages of illness. It also cannot resolve deeper relational conflicts or replace professional support when needed.

The design intentionally limits its ambition to supporting the opening of communication and the experience of autonomy, rather than managing outcomes or guiding conversations. Emotional responses elicited by the pillow may require follow-up through direct conversation or care, and the concept should be understood as part of a broader ecosystem of relational and healthcare support.

10.7 CONCLUSION

This chapter presented the final design of the Pillow Partner and explained how it translates research insights into a concrete design outcome. By focusing on autonomy and communication, the concept addresses central relational challenges identified throughout the project. The design choices reflect a careful balance between sensitivity, simplicity, and functionality, while acknowledging the limitations inherent to such an intervention.

The Pillow Partner does not aim to solve intimacy-related problems, but to create space for expression, connection, and self-directed engagement within relationships affected by illness. As such, it forms a grounded and reflective design outcome that bridges analytical research and practical application, and provides a foundation for further development, testing, and implementation.

IMPLEMENTATION STRATEGY

11

11.1 AIM

The aim of this chapter is to explore the conditions under which the proposed concept could be meaningfully introduced, accepted and sustained in practice. Rather than evaluating the concept itself, this chapter focuses on the broader implementation context. The goal is to identify strategic considerations that influence feasibility, desirability and viability for intimacy-supporting interventions in palliative care. These insights are intended to inform not only the further development of the Pillow Partner, but also similar design interventions operating in sensitive healthcare contexts.

11.2 METHODOLOGY

To develop an implementation-oriented perspective, this chapter builds on a secondary analysis of expert (E01-E13) interviews conducted throughout the project. These interviews included professionals from sexual health care, palliative care, design for sensitive contexts, and commercial development of intimacy-related products.

All available audio recordings and notes from earlier expert interviews were revisited with a specific focus on strategic and contextual insights. Rather than analysing feedback on the concept's form or functions, this review aimed to extract recurring patterns related to introduction, positioning, timing, stakeholder roles and barriers to adoption.

The analysis followed a qualitative synthesis approach. Insights from all interviews were brought together and compared across contexts. Through iterative reflection and clustering, recurring concerns and conditions were grouped into a small set of implementation themes. These themes were not treated as fixed requirements, but as strategic conditions that shape whether a concept such as the Pillow Partner can be realistically introduced and sustained

11.3 RESULTS - STRATEGIC THEMES & KEY IMPLEMENTATION CONDITIONS

1. Low-threshold, non-medical positioning that supports introduction by healthcare professionals

Experts consistently emphasized that any intervention addressing sexuality and intimacy in the context of incurable cancer must lower barriers rather than add new ones. Both patients and healthcare professionals experience discomfort when approaching this topic, making a calm, neutral and relational positioning essential.

Because sexuality is already surrounded by taboo and vulnerability, experts warned against explicit, playful or sexualized framing:

> "You don't want to materialize or medicalize the problem around sexuality too much." E01

This low-threshold positioning was seen as especially important in incurable cancer contexts, where patients and partners often feel overwhelmed by medical interventions:

> "People with incurable cancer have already been through so much. They are often not waiting for something very medical or scientific anymore." E01

Closely connected to this was the role of healthcare professionals. Experts stressed that not all professionals feel trained or comfortable discussing sexuality, and that this should not be a prerequisite for introducing the concept:

> "The subject is incredibly difficult to communicate about. For patients, but also for specialists. That is the core of the problem." E03

Rather than requiring expertise, the concept was seen as something that could support professionals in opening the topic without making it too explicit or taking responsibility for solving it:

> “This could be a tool for professionals who don’t know much about it, don’t want to know, or have little experience - something they can easily introduce.” E01

The importance of non-medical language was repeatedly emphasized:

> “It’s much friendlier to say: there is a nice tool you can try to stay connected, instead of immediately talking about erectile dysfunction or medication.” E03

Together, these insights suggest that successful implementation depends on a positioning that is neutral, relational and supportive (figure 22), allowing both users and healthcare professionals to approach intimacy without added pressure or expertise requirements.

2. Balancing timely introduction with emotional readiness

Timing emerged as a critical strategic condition. Experts described a clear tension between introducing support early enough to prevent escalation, and avoiding introduction at moments when people are not emotionally receptive. On the one hand, experts emphasized the importance of early awareness:

> “I usually give a hint early on, so people know it exists. Then people can come back half a year later with interest.” E01

At the same time, introducing intimacy-related support too early may cause resistance:

> “At the first bad news conversation, people are often angry or overwhelmed. This is not the moment.” E01

Rather than a fixed timing, experts described introduction as a process, embedded within the broader care trajectory:

> “For one person it’s after a month, for another after a year, and for a larger group maybe never.” E01

Crucially, the concept was valued for being available without obligation:

> “It’s important that the pillow is already there, so you don’t have to ask for help at the moment it becomes really difficult.” E11

This suggests that the strategic value of the concept lies not in immediate use, but perhaps in lowering the future threshold for addressing intimacy when users are ready (figure 23).

3. Financial accessibility and non-medical market positioning

Experts identified financial barriers as a major risk for adoption and the products’ survival in the market. High purchase costs were seen as limiting accessibility and increasing expectations beyond what such a concept can realistically deliver:

> “If everyone has to pay a few hundred euros themselves, you reach only a very small group. Five hundred euros creates very high expectations. Then people expect the product to solve the problem.” E13

Drawing on experience with comparable products, experts emphasized alternative access models:

> “For our product, a big step was moving away from selling it as a product and offering it as a subscription.” E13

Several experts advised against positioning the concept primarily as a medical device (figure 24), especially given the limited size of the incurable cancer population:

> “As an academic exercise it’s great, but as an entrepreneur I would position it as a device for everyone — more like a wellness product.” E13

This broader positioning was seen as more viable, while still allowing use in care contexts:

> “Our product is a consumer device that also has medical applications.” E13

Soft claims and experiential value were considered more realistic than hard medical promises:

> “It’s something that already exists in another form, like a pregnancy pillow or a weighted blanket — but now focused on intimacy.” E13

Figure 22: The leaflet supports healthcare professionals in introducing intimacy-related support without requiring specialist knowledge or explicit conversation.

Figure 23: Waiting area where the concept is visibly present, allowing users to become aware of available support without requiring immediate engagement.

Figure 24: Positioning the concept in the public space as a consumer product rather than a medical device.

11.4 DISCUSSION

The findings of this implementation-oriented analysis show that the success of an intimacy-supporting concept in the context of incurable cancer depends less on technological sophistication and more on how the concept is positioned, introduced, and accessed. Across expert perspectives, implementation emerged as a relational and contextual challenge rather than a purely design or engineering problem.

First, the strong emphasis on low-threshold and non-medical positioning highlights a tension between intention and reception. While the concept aims to support autonomy and communication, experts cautioned that explicit or overly sexualized framing may paradoxically reduce openness. This underscores the importance of subtlety in design: a concept can only support communication if it does not itself become a source of discomfort. Importantly, this finding also reframes the role of healthcare professionals. Rather than positioning them as experts who must actively address sexuality, the concept can function as a shared entry point that lowers responsibility and emotional load for both parties.

Second, the insights on timing reveal that implementation cannot be understood as a single moment of introduction. Instead, intimacy-related support must be embedded within the broader care trajectory, allowing space for denial, adaptation, and shifting priorities. Experts described early awareness as valuable, but warned against introducing such concepts during moments of acute emotional overload. This reinforces the idea that feasibility in this context is not only about availability, but about temporal sensitivity: the concept must remain present without demanding immediate engagement.

Third, the discussion around financial accessibility and market positioning exposes a structural limitation of niche medical framing. While incurable cancer provides a meaningful and urgent context for use, experts questioned whether this group alone can sustain a viable product model. Positioning the concept as a broader wellness-oriented device, with soft claims and flexible access models, was seen as a way to balance emotional sensitivity with long-term sustainability. This approach does not deny medical relevance, but avoids burdening the concept with expectations of clinical effectiveness that are difficult to substantiate.

Taken together, these findings suggest that implementation in this domain is less about scaling a solution and more about carefully situating it within existing relational, professional, and economic systems. The concept's strength lies in its ability to remain optional, supportive, and adaptable across different moments and users.

11.5 CONCLUSION

This chapter explored the strategic conditions required for implementing an intimacy-supporting concept in the context of incurable cancer. Through a synthesis of expert insights, three key themes were identified: low-threshold and non-medical positioning, timely introduction within the care trajectory, and financial and strategic accessibility.

Rather than prescribing a single implementation pathway, these themes describe a set of boundary conditions that shape whether such a concept can realistically function in practice. They show that successful implementation depends on reducing emotional, professional, and financial barriers, while respecting the vulnerability and variability of users' experiences.

For the Pillow Partner concept, these insights imply that its value does not lie in solving intimacy-related problems, but in creating space for communication at moments chosen by the users themselves. By remaining subtle, optional, and broadly accessible, the concept can align with both the relational needs of couples and the practical constraints of healthcare contexts.

These conclusions provide a grounded foundation for translating the concept into an implementation approach that is sensitive, feasible, and sustainable, while leaving room for further refinement and validation in future work.

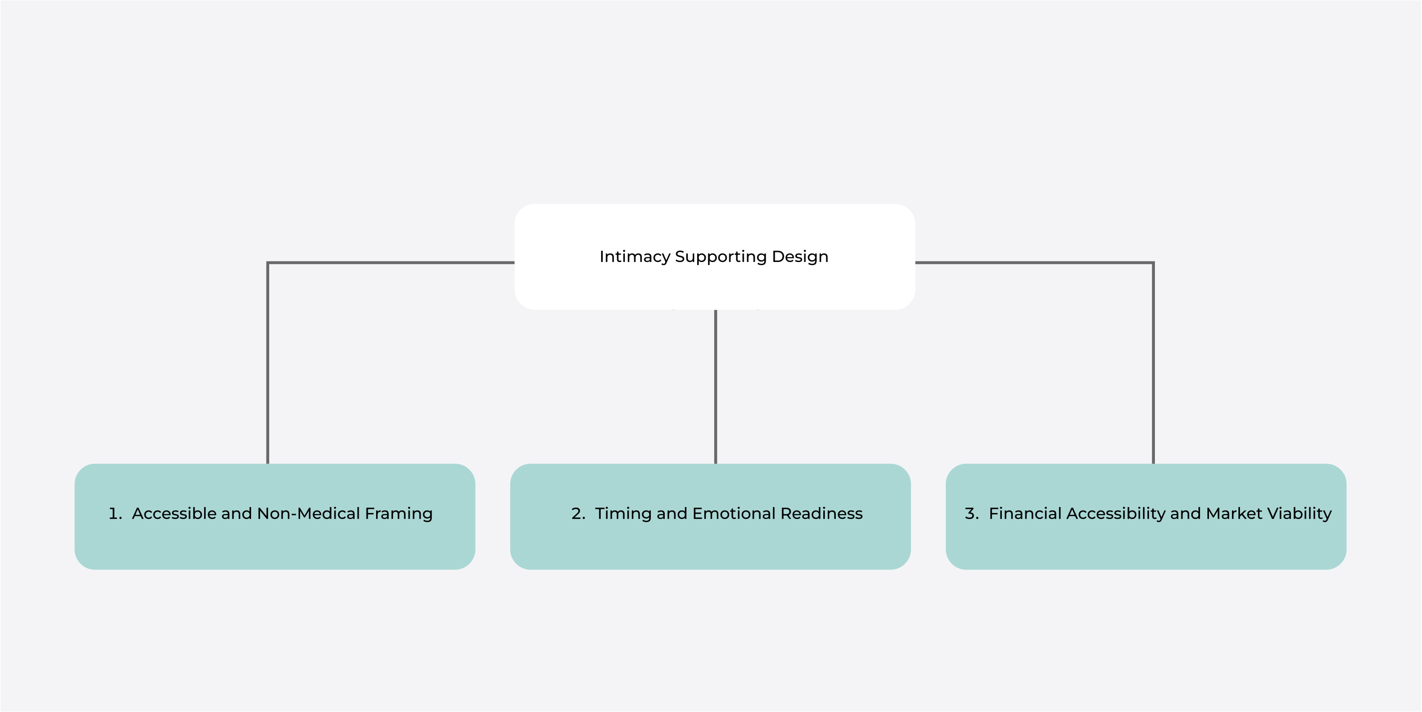


Figure 25: Key Conditions Shaping Implementation of Intimacy-Supporting Design
The conditions were identified through expert interviews as factors that influence whether an intimacy-supporting concept can be responsibly introduced and sustained in palliative care contexts. They should be understood as enabling conditions rather than guarantees of successful implementation.

RECOMMENDATIONS

12

12.1 AIM OF THIS CHAPTER

This chapter outlines recommendations for future work building on the outcomes of this graduation project. Rather than reflecting on the project itself, the aim is to indicate how the concept, the research approach, and the proposed implementation strategy could be further developed in follow-up design or research trajectories. These recommendations are intended to support designers, researchers, or care organizations who may continue working on similar interventions at the intersection of intimacy, relationships, and palliative care.

12.2 RECOMMENDATIONS FOR FURTHER CONCEPT DEVELOPMENT

While the Pillow Partner concept was refined and tested in an exploratory manner, several directions for further design development emerged.

First, future iterations could further explore graduated autonomy features. Interviews suggested that users value control over timing, emotional intensity, and exposure. Follow-up design work could investigate features such as staged listening, delayed responses, or explicit signals that a message has been received but not yet processed. These refinements could help balance individual autonomy with relational sensitivity.

Second, the sensory qualities of the object deserve deeper exploration. Warmth, weight, softness, and scent were repeatedly described as meaningful, yet these qualities were only lightly prototyped. Future work could investigate how different sensory configurations influence comfort, emotional regulation, and perceived presence over longer periods of use.

Third, the concept could be further tailored to different relational scenarios. The current concept addresses couples in general, but future design work might differentiate between early palliative phases, later stages of illness, and periods after loss. This could result in scenario-specific versions or modes of use, while maintaining a coherent core concept.

12.3 RECOMMENDATIONS FOR EMPIRICAL RESEARCH

From a research perspective, several follow-up studies would strengthen the evidence base around this type of intervention.

A first recommendation is to conduct longitudinal user studies. The current research focused on first impressions and short-term experiences. Longer-term studies could explore how meaning, use patterns, and emotional impact evolve over time, particularly as illness progresses or relational dynamics change.

Second, future research should more explicitly involve couple-based studies. While individual interviews provided valuable insights, dyadic research could reveal how autonomy and communication are negotiated between partners, how asymmetries arise, and how shared use influences relational processes.

Third, targeted studies with specific patient groups are recommended. Different diagnoses, disease trajectories, and care settings may shape needs and expectations in distinct ways. Carefully staged involvement of people with incurable cancer, in collaboration with care professionals, would be essential to ensure ethical and emotional safety.

12.4 RECOMMENDATIONS FOR IMPLEMENTATION AND SCALING

Building on the implementation insights gathered, future work could further develop and test concrete pathways for introducing such a concept into practice.

At a micro level, research could focus on how and when the concept is introduced within care trajectories. Small pilot studies could explore whether introduction during early consultations, follow-up conversations, or psychosocial support sessions leads to different uptake and use.

At a meso level, future work could explore the role of intermediate professionals, such as specialized nurses, psychologists, or sexologists, as mediators. Training materials, conversation guides, or demonstration tools could be developed to support careful and non-confrontational introduction.

At a macro level, alternative distribution and access models could be explored. These may include lending systems, temporary trials, or integration into existing care infrastructures. Such models could lower thresholds for use and reduce the need for users to actively request help during vulnerable moments.

12.5 METHODOLOGICAL RECOMMENDATIONS FOR DESIGN AND HEALTHCARE RESEARCH

This project explored the overlap between design research and qualitative healthcare research by combining contextmapping with reflexive practices. Future projects could further build on this exchange between fields.

Healthcare and public health research may benefit from design methods such as contextmapping, which help participants reflect on lived experiences and express abstract or sensitive topics in a more tangible and accessible way. In this project, contextmapping supported open conversations about intimacy and relationships by shifting the focus from direct questioning to experiential reflection.

At the same time, design research may benefit from adopting reflexive practices that are more established in qualitative healthcare research, such as explicit positionality statements and critical reflection on the role of the researcher. Making these influences visible can strengthen ethical awareness and transparency, especially when working with vulnerable populations.

Rather than proposing a new methodology, future work could focus on better understanding how design and healthcare research tools can complement each other, and on developing clearer guidance for when and how specific methods are appropriate in sensitive medical and relational contexts.

12.6 CONCLUSION

This chapter presented recommendations for future work related to concept development, empirical research, implementation, and methodology. Together, these suggestions show that the project does not conclude with a single design outcome, but rather offers a starting point for continued exploration of how autonomy and communication can be supported through design in palliative and relational contexts. Future studies and design trajectories can build on these insights to further develop responsible, sensitive, and meaningful interventions.

PART IV

FINAL REDLECTIONS

&

SUPPORTING MATERIAL

REFLECTION

This project offered a rare opportunity to engage directly, as a designer, with people living in a highly sensitive and underexplored context: sexuality and intimacy in the lives of people with incurable illness and their partners. Speaking openly with participants about such personal topics required care and humility, but it also highlighted how valuable it is to include these perspectives in design research. Many participants expressed appreciation for being asked about a topic that is often overlooked, which confirmed the relevance of the project despite its seemingly niche focus.

Throughout the project, I worked in an integrated role as a designer–researcher, where inquiry and creation continuously informed one another. My design training naturally encourages early exploration of possibilities and directions, which often supported sense-making and helped translate emerging insights into tangible concepts. At the same time, this orientation also carries the risk that certain interpretations or solution directions become more prominent too quickly.

I addressed this by consciously structuring the process into phases of exploration and refinement, making design choices explicit, and repeatedly grounding them in insights from different sources. This approach allowed design and research to function not as separate activities, but as complementary ways of understanding and engaging with the complex relational context of the project.

From a methodological perspective, the findings of this project are not statistically generalizable due to the qualitative nature and limited sample size. However, the insights may be transferable to comparable relational and healthcare contexts where intimacy, vulnerability, and communication play a role. The value of the research lies not in producing definitive answers, but in revealing underlying mechanisms and translating them into design principles that can inform future work.

An important learning outcome of this project was the realization that a strong idea alone is insufficient. While the concept of the Pillow Partner emerged as meaningful and resonant, its potential impact depends heavily on careful execution, positioning, and implementation. This became particularly clear when considering feasibility and long-term viability. The project revealed a clear tension between medical positioning and a more accessible wellness-oriented framing, as well as between addressing a specific target group and the need for scalability. These tensions do not have simple solutions, but acknowledging them is essential for responsible design in healthcare-related domains.

On a personal level, the project required learning to work with ambiguity, emotional complexity, and moments of not knowing. It demanded sensitivity in both research and design decisions, and encouraged reflection on ethical responsibility. At the same time, it supported growth in academic writing, critical reflection, and the articulation of design rationale. Ultimately, the project revealed that meaningful design research is not an end state, but an ongoing process of learning, questioning, and careful iteration.

CONFLICT OF INTEREST STATEMENT

The author declares that there are no known conflicts of interest related to this research or the resulting design project. The study was conducted independently and was not influenced by commercial, financial, or personal interests.

USE OF ARTIFICIAL INTELLIGENCE TOOLS

During the research and writing process, artificial intelligence tools were used in a limited and supportive manner. Elicit was used to explore and identify relevant academic literature and to support early-stage literature orientation. ChatGPT was used for language support, including spelling checks, clarity improvements, and consistency in academic phrasing. All substantive research decisions, interpretations, analyses, and design choices were made by the author.

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APPENDICES

A. PROJECT BRIEF

Personal Project Brief – IDE Master Graduation Project

Name student Sam van der Ploeg

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT
Complete all fields, keep information clear, specific and concise

Project title Supporting sexual wellbeing in palliative care

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

Introduction

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

Sexuality and intimacy are known to be important contributors to general well-being (Reese et al., 2017; World Health Organization, n.d.), even in the final phase of life. In palliative care for people with incurable cancer, these aspects are often overlooked despite their relevance for keeping human connection and dignity (3). Conversation about intimacy and sexual needs are often accompanied by discomfort and taboos which makes these conversations difficult for patients, partners and healthcare professionals (Donz et al., 2024; Hjalmarsson & Lindroth, 2020; Wang et al., 2017).

Following this, research at Erasmus Medical Centrum (EMC) is set up by project leader Evi Bakker with the aim to “better understand the experiences and needs of people with incurable cancer and their partners regarding relationships and intimacy, and how these needs can be best addressed”.

The IDE graduation project of the project brief you are reading will be part of the EMC research project. The main goal of the IDE graduation project is to “Design and develop a prototype (physical, digital, or otherwise) to support the sexual well-being for receiving palliative care, especially for people with incurable cancer and their relatives”.

The main stakeholders are people with incurable cancer and their partners or loved ones, whose interests likely lie in keeping emotional and physical connection as well as a sense of dignity in the final phase of life. Secondary stakeholders include healthcare professionals who aim to provide care but may struggle with addressing intimate topics due to discomfort. Other stakeholders include healthcare institutions and policymakers aiming to improve quality of life.

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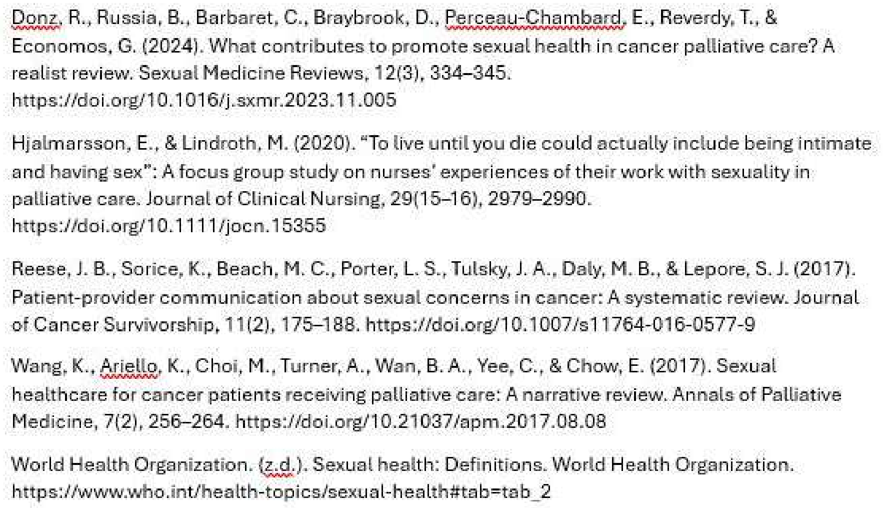
introduction (continued): space for images



Donz, R., Russia, B., Barbaret, C., Braybrook, D., Perceau-Chambard, E., Reverdy, T., & Economos, G. (2024). What contributes to promote sexual health in cancer palliative care? A realist review. Sexual Medicine Reviews, 12(3), 334–345. https://doi.org/10.1016/j.sxmr.2023.11.005

Hjalmarsson, E., & Lindroth, M. (2020). “To live until you die could actually include being intimate and having sex”: A focus group study on nurses’ experiences of their work with sexuality in palliative care. Journal of Clinical Nursing, 29(15–16), 2979–2990. https://doi.org/10.1111/jocn.15355

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World Health Organization. (z.d.). Sexual health: Definitions. World Health Organization. https://www.who.int/health-topics/sexual-health#tab=tab_2

image / figure 1

image / figure 2

Personal Project Brief – IDE Master Graduation Project

Problem Definition

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

The main problem addressed in this project is the lack of adequate support for people with incurable cancer and their relatives to talk about their relationship, intimacy and sexuality with each other, healthcare professionals and other close friends.

To design an efficient solution, it is important to understand the end-user as thoroughly as possible. The complexity of making a difficult topic, such as intimacy, open for discussion will likely pose challenges during the project. It could be difficult to create a situation where the target group is truly able to speak freely and show its true colors.

A diverse target group inherently brings diverse backgrounds, values and needs. Also with regards to the discussion of intimacy. With the nature of the project it can be challenging to balance inclusivity and impact. On one hand as a designer you want to include as many people as possible and make everybody feel heard. On the other, designing for everyone may consequently result in an outcome that is too diluted to benefit anyone.

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence)
As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:

Design and develop a prototype (physical, digital, or otherwise) to support the sexual well-being for people receiving palliative care, especially for people with incurable cancer and their relatives

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

Design should not be considered a linear process, however during the project there are four main phases to be identified. The planning for these phases was made based on the double diamond model.

1. The discover phase is used to understand the context and domain this project is working with (Benchmarking, understanding sexual well-being, patient journey mapping and of course understanding our main stakeholders). Referring back to the earlier comment made about balancing diversity and impact, it is likely that in this phase choices will be made with regards to the selected target group.
2. The define phase is used to identify the specific problem and come up with a design brief. To do this, the goal is to conduct a number interviews within the target group.
3. The develop phase is used to ideate and develop a design solution that fits the design brief. To do this, the goal is to conduct two to four co-creation sessions with the target group.
4. The deliver phase is used to reflect on important implications that the final design has.

Project planning and key moments

*To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting**, **mid-term evaluation meeting**, **green light meeting** and **graduation ceremony**. Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).*

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting 2 sept 2025

Mid-term evaluation 28 okt 2025

Green light meeting 16 dec 2025

Graduation ceremony 27 jan 2026

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	☐
For how many project weeks	
Number of project days per week	

Comments:

Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.
(200 words max)

Ambitions:
In this graduation project, I wish to familiarize myself more with the possibilities for designers in the medical industry. This also includes learning about the inner workings of EMC. Getting an inside look is therefore one of my ambitions.

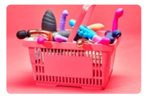
Secondly, I wish to create tangible results that go beyond merely insights about a situation, but push to make impact.

Thirdly, my aim is to navigate this project in a way that allows me to interact with final users. This will likely boost the results of the project significantly.

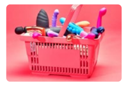
For me it will be interesting to prove my skills as a strategic designer and manager during this project. Skills that I have been able to practice with in the past and am comfortable with. The creative and visual skills are skills that I am insecure about, which is something I aim to potentially change in this project.

B. MARKET ANALYSIS

Benchmarking - supportive tools sexual wellbeing

Category	Physical sex toys	Conversational tools	Context interventions	Erotic audiovisual stimuli	Explorative tools	Medication
Examples	 Maturbators, lube, erection pump, sensory tools (feather, blindfold, warm or cold objects)	 Roze olifant, PLISSIT model, ISEP-tool, IntiME, Happy Family cardgam	 Koppelbed privacy facilities,	 Qwiek-up, Dipsea, Audiopodesires pornography	 Ferly, OMGYes	 Viagra, estrogen or testosteron-therapy
Primarily aimed at	patient: using toys to either increasing pleasure or reduce pain	Caregivers: Tools to support caregivers in having conversations about sexuality	Patient & partner: taking away barriers that the environment and context of care might bring with them	Patient: erotically stimulating patients through visuals & audio	Patient: exploring sexuality to improve sexual wellbeing	Patient: Erectile function, vaginal dryness & pain, libido/sexual desire
Possible use-phase of palliative care	Palliative care phase & terminal palliative care phase	Palliative care phase & terminal palliative care phase	Terminal palliative care phase	Palliative care phase & terminal palliative care phase	Palliative care phase & terminal palliative care phase	Rarely used in palliative phases

Market analysis - supportive tools for sexual well-being

Category	Conversational tools	Sexual devices	Erotic audiovisual stimuli	Informative/ educational tools	Context interventions	Medical	Sexual care
Examples	 Roze olifant, PLISSIT model, ISEP-tool, IntiME, Onder4Ogen Happy Family cardgame, Openhartig, Vertellis, Sextalk	 Masturbators, lubricant, erection pump, sensory tools (feather, blindfold, warm or cold objects)	 Qwiek-up, Dipsea, Audiopodesires pornography	 Ferly, OMGYes. Sick And Sex, Seksualiteit.nl, Seksindepraktijk.nl Seks & zorg podcast Sensate focus therapy	 Koppelbed privacy facilities,	 Sildenafil, estrogen or testosteron-therapy	Surrogate partners, Flekszorg, snoezelzorg, stichting schildpad
Primarily aimed at	Caregiver, partner & patient: Tools to support caregivers in having conversations about sexuality	patient (& partner): using toys to either increasing pleasure, reduce discomfort and improve function	Patient: Erotically stimulating patients through visuals & audio	Patient (& partner): exploring sexuality to improve sexual well-being	Patient & partner: taking away barriers that the environment and context of care might bring with them	Patient: Erectile function, vaginal dryness & pain, sexual desire	Patient: Providing physical or sexual care for people in special conditions
Possible use-phase of palliative care	Palliative care phase & terminal palliative care phase	Palliative care phase & terminal palliative care phase	Palliative care phase & terminal palliative care phase	Palliative care phase & terminal palliative care phase	Palliative care phase & terminal palliative care phase	Palliative care phase & terminal palliative care phase	Palliative care phase & terminal palliative care phase

CONVERSATIONAL TOOL
Tools aimed at professionals to suppot the conversation about sexual wellbeing

AUDIOVISUAL STIMULI
Erotically tinted audio and visual stimuli, aimed at patient and partner

CONTEXT INTERVENTIONS
Aimed at overcoming contextual challenges that prevent intimacy or sexual expression

SEXUAL CARE
Sexual workers that specifically specialize in providing services in medical context

SEXUAL DEVICES
Physical toys intended to either increase pleasure, or alleviate discomfort

INFORMATION & EDUCATION
Websites, social platforms or therapy that provide relevant information or lessons about sexuality

MEDICATION
Sildenafil, estrogen or testosteron-therapy aimed at erictile disfunction or vaginal dryness

Beste deelnemer,

Zoals in de informatiebrief is uitgelegd, sturen wij u voorafgaand aan het gesprek een document met extra materiaal.

Dit document bevat enkele vragen en een vrijwillige opdracht die u kunnen helpen om alvast na te denken over het onderwerp intimiteit.

Wij willen u verzoeken om voorafgaand aan het gesprek voor uzelf alvast over deze vragen na te denken.

Desgewenst kunt u het antwoord ook opschrijven en meenemen naar het gesprek.

Alvast hartelijk dank voor uw inzet!

Met vriendelijke groet,
Het onderzoeksteam

Drs. Evi Bakker
Dr. Arianne Stoppelenburg
Prof. dr. Judith Rietjens
Sam van der Ploeg

Erasmus MC
Universitair Medisch Centrum Rotterdam

<u>VRAAG 1: Wat betekent ‘intimiteit’ voor u?’</u>

Desgewenst kunt u het antwoord hieronder ook opschrijven of tekenen.

C. USER RESEARCH - TOPIC LIST

Interviewhandleiding DoubleTaboo Versie 02-10-2025

Introductie en doel van het gesprek
Wat fijn dat u tijd heeft gemaakt voor dit gesprek.
Ik zal mij eerst kort voorstellen en nog eens uitleggen waarom we hier zijn.
Mijn naam is Evi Bakker, en ik ben hier als arts onderzoeker van het Erasmus MC bij betrokken.
En mijn naam is Sam van der Ploeg en ik ben hier als ontwerper van de TU Delft bij betrokken.
Spreek ons vooral aan met je of jij. Wat vindt u prettig?

Wij doen dus een onderzoek naar relaties en intimiteit bij mensen met ongeneeslijke kanker en hun partners.
Ongeneeslijke kanker kan invloed hebben op iemands relatie en intimiteit.
Maar, toch wordt dit onderwerp vaak niet besproken.

Ons doel is om meer te begrijpen van de ervaringen en behoeften rondom relaties en intimiteit bij mensen die met ongeneeslijke kanker te maken hebben. Zo hopen wij hen beter te kunnen ondersteunen, waar dat nodig is.

Hierbij werken we samen met ontwerpers van de Technische Universiteit Delft.
We gaan zo niet alleen praten, maar ook samen uw ervaringen op dit papier zetten.
Dit kan ons helpen om het overzicht te houden. U hoeft niet creatief te zijn, we doen het samen.

Heeft u tot nu toe vragen? Bijvoorbeeld over de informatie die we u eerder hebben gestuurd.

Uitleg concept en visueel overzicht
Het onderwerp van dit onderzoek kan voor sommige mensen dichtbij komen. Dat is heel begrijpelijk. Daarom vinden wij het heel waardevol dat u met ons in gesprek wilt gaan.

Iedereen kan intimiteit en seksualiteit op een andere manier ervaren. Zoals u op dit plaatje kunt zien, zien wij deze onderwerpen in ons onderzoek op een brede manier.
Het kan gaan over lichamelijke dingen zoals knuffelen, zoenen of vrijen.
Maar, ook over je gevoelens delen en je verbonden of veilig voelen.
Ook je identiteit en seksuele oriëntatie kunnen van invloed zijn.
Misschien heeft u zelf ook nog aanvullingen.
Dit alles kan je alleen of samen met iemand anders ervaren.

Dan zal ik ook eerst wat uitleg geven bij het papier dat voor ons ligt.
U ziet een tijdlijn. Wij hebben alvast het moment van de diagnose en nu ingevuld.
Tijdens het gesprek gaan we proberen om samen gebeurtenissen rondom de onderwerpen relaties, intimiteit en seksualiteit op deze tijdlijn te plaatsen.
Dit geeft een overzicht en houvast tijdens het gesprek.

Vertrouwelijkheid van gesprek
Het gaat om uw ervaring en beleving. Er zijn geen goede of foute antwoorden.
U kunt het altijd aangeven als u het gesprek wilt pauzeren of stoppen.
Alles wat u zegt, wordt vertrouwelijk behandeld en anoniem verwerkt.

Toestemming
Vindt u het goed dat ik het gesprek opneem met een audiorecorder?
- Dan kan ik mij beter concentreren op het gesprek, zonder dat ik alles op hoef te schrijven.
- Het gesprek wordt later uitgeschreven en uw naam wordt vervangen door een nummer. Alle persoonlijke gegevens worden weggelaten.
- Als ik zo de audiorecorder aanzet, zal ik uw deelnemersnummer noemen en u nog een keer vragen om uw toestemming voor de opname.

Heeft u nog vragen voordat we beginnen?

Indien iemand nog geen IC formulier heeft getekend:
Wij hebben u via de mail een toestemmingsformulier voor deelname gestuurd.
Klopt het dat u deze nog niet had ingevuld?
Dan zou ik u willen vragen om het formulier nu te lezen; en te ondertekenen als u akkoord bent.

Informed consent form laten tekenen.

Indien de vragenlijst nog niet was ingevuld:
Klopt het dat u de vragenlijst om uw situatie beter te begrijpen nog niet had ingevuld?
Dat is geen probleem, dan wil ik die nu nog even met u doorlopen.

Vragenlijst doorlopen.

Heeft u nog vragen voordat we beginnen?

C. INTERVIEWS - TOPIC LIST

Topiclijst

Audiorecorder aanzetten

Dit is een opname voor een gesprek met respondent [X].
Geeft u toestemming om dit gesprek op te nemen en om uw antwoorden te gebruiken voor onderzoeksdoeleinden, nu en in de toekomst?
Dank u wel. Dan gaan we nu door met het gesprek.

1. **Kunt u om te beginnen kort iets vertellen over uw situatie?**

2. **Ter voorbereiding heeft u een document met enkele vragen over intimiteit gekregen. Was u in de gelegenheid om hier over na te denken?**
   - Indien ja: Heeft u dit document bij de hand? En zou u hier wat over willen delen? Bijv. over de eerste vraag: wat betekent intimiteit voor u?
     - De andere vraag was of u een herinnering zou kunnen beschrijven, die voor u te maken heeft met intimiteit sinds de diagnose. Kunt u hier wat over delen? Dan vullen we deze samen op de tijdlijn in.
     - Hebt u toevallig foto's gemaakt? Hoe was dit om te doen? Zou u ze kunnen laten zien en vertellen waarom u juist die foto's hebt gemaakt?
   - Indien nee: dat is geen probleem.
     - Een van de vragen was om na te denken over wat intimiteit voor u betekent. Zou u daar anders nu wat over kunnen delen?
     - De andere vraag was of u een positieve of negatieve herinnering zou kunnen omschrijven, die voor u te maken heeft met intimiteit sinds de diagnose.
       - Zou u daar nu wat over kunnen delen? Dan vullen we deze samen op de tijdlijn in.

3. **Hoe ervaart u op dit moment uw intimiteit en seksualiteit?**
   - Emotionele intimiteit (bijv. zelfbeeld, schuldgevoel, kinderwens)
   - Lichamelijke intimiteit (bijv. erectie/pijn/zin/opwinding/orgasme)
   - Indien relatie: en hoe ervaren jullie intimiteit en seksualiteit onderling?
   - **Vraag door naar emoties:** hoe voel(de) u zich hierbij/wat ging er in u om?

4. **Is uw intimiteit en seksualiteit veranderd? En zo ja, hoe?**
   - Emotionele / lichamelijke intimiteit
     - Is uw behoefte naar intimiteit of seksualiteit veranderd?
     - Is wat u onder intimiteit of seksualiteit verstaat in de loop van de tijd veranderd?
   - Indien relatie:
     - Zijn er belangrijke gesprekken, gevoelens of gedachten die jullie samen hebben gedeeld?
     - Is er ooit een situatie geweest waarin jullie andere wensen of verwachtingen hadden over intimiteit? Hoe gingen jullie daarmee om?
     - Soloseks vs. seksualiteit samen

5. **Kijkend naar de tijdlijn, wat zijn de belangrijkste gebeurtenissen, gevolgen of problemen?**
   - Wat heeft indruk gemaakt?
   - Op het gebied van intimiteit / seksualiteit / relatie
   - Kunt u deze gebeurtenissen ook in periodes opsplitsen?
   - Wie waren er voor u belangrijk?

Kort een samenvatting geven van wat er is besproken
- Wat valt op bij de tijdlijn (bv. pijnpunten)
- Zo is het nu + zo is het gegaan

6. **Hoe bent u met deze gevolgen omgegaan?**
   - Hebt u op bepaalde momenten behoefte gehad aan ondersteuning?
   - Wat hebt u zelf al geprobeerd?
   - Welke rol kunnen naasten/zorgverleners/anderen spelen?

7. **Stel dat alles mogelijk was, is er dan iets wat u/jullie zou kunnen helpen op het gebied van intimiteit of seksualiteit?**
   - Welke specifieke ondersteuning zou behulpzaam kunnen zijn?
   - Praathulp, informatie, seksspeeltjes
   - Nu, maar ook vroeger

8. **Stel dat u advies geeft aan iemand anders in dezelfde situatie. Welke tips of bemoedigende woorden over intimiteit of seksualiteit zou u geven?**

Afronding

9. We zijn nu aan het einde van het gesprek gekomen. Zijn er nog belangrijke dingen die we nog niet hebben besproken en u wel graag zou willen delen?

10. Tenslotte zou ik graag nog willen weten hoe het voor u was om dit gesprek te voeren?

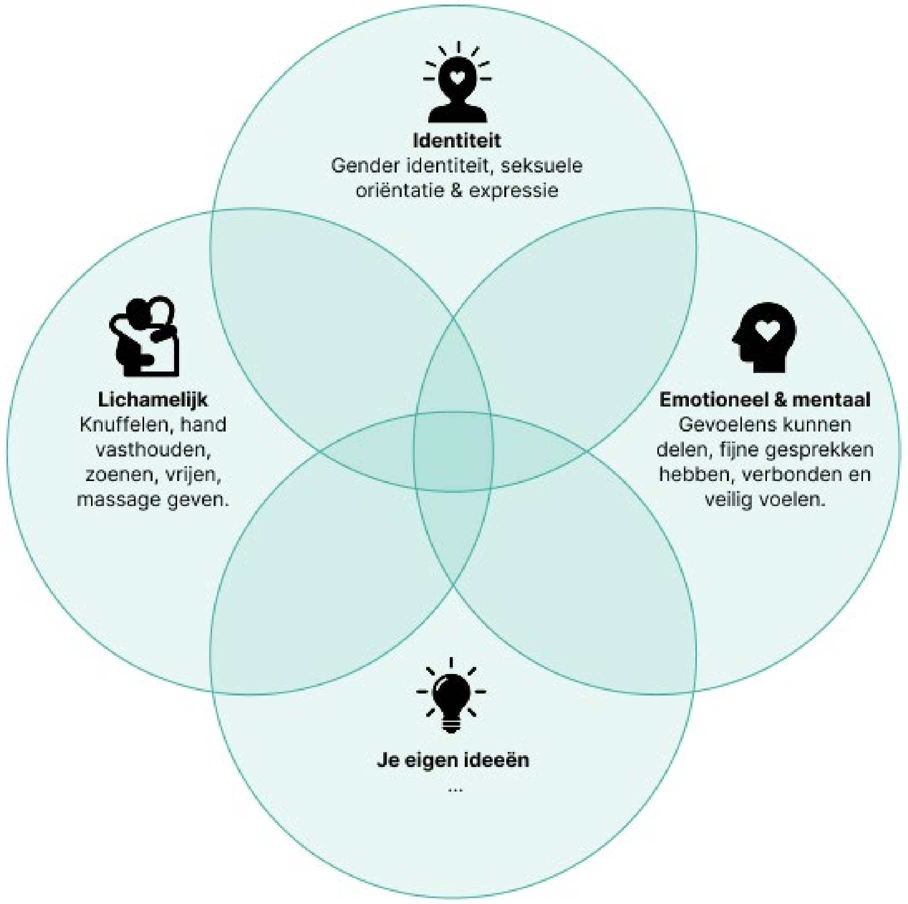
Voicerecorder uitzetten

Nogmaals dank dat u mee wilde doen aan dit onderzoek en uw openhartigheid.
Wij gaan de komende periode nog met anderen in gesprek en de gesprekken analyseren.
Wilt u bij dit onderzoek betrokken blijven? Bijvoorbeeld middels een vervolggesprek?
En wilt u op de hoogte gehouden worden van de uiteindelijke resultaten?

Vragen om materiaal mee te nemen/door te sturen

C. INTERVIEWS - DEFINTIONS & MAP

Intimiteit & seksualiteit



Identiteit
Gender identiteit, seksuele oriëntatie & expressie

Lichamelijk
Knuffelen, hand vasthouden, zoenen, vrijen, massage geven.

Emotioneel & mentaal
Gevoelens kunnen delen, fijne gesprekken hebben, verbonden en veilig voelen.

Je eigen ideeën
...

D. ALL 7 DESIGN DIRECTIONS

1. Support Open Communication: Overcoming Taboos and Communication Barriers

Designing interventions focused on reducing the taboos surrounding sensitive topics like sexuality and death, and fostering open dialogue in relational, social and healthcare settings. This direction emphasizes tools that promote communication between partners, but also with friends, family and healthcare providers, aiming to reduce isolation. It should be nuanced however that this design direction does not aim to completely eliminate taboos surrounding sexuality and death. This direction moreso aims to provide individuals that need to communicate and connect, the appropriate tools to do so.

2. Supporting Sexual and Relational Autonomy: Addressing the Loss of Equality in the Relationship

This design direction focuses on supporting partners and couples in situations where incurable cancer has disrupted relational balance and reduced the autonomy of one or both partners. It addresses the shift from partner to caregiver and the feeling that life begins to revolve around the ill person. A particular emphasis is placed on the loss of autonomy over sexual and intimate needs, which are often suppressed out of fear of burdening the ill partner or causing guilt.

3. Acknowledge the Role of caregiving partners : Recognizing Unseen Needs

Designing solutions that ensure the emotional, relational, and sexual needs of the partner are acknowledged within relationships, social situations and healthcare. This direction focuses on creating inclusive systems and tools that recognize the significance of the partner’s role, ensuring that both the ill person and caregiving partner receive appropriate recognition.

4. Supporting Transitions in Sexuality: Adapting to Shifts in Needs

This direction focuses on supporting couples in navigating the changes in sexuality brought on by incurable cancer. It advocates solutions that help couples adapt to new forms of intimacy and redefine sexuality beyond stigmas. This could include designing resources that guide couples through the transition to non-penetrative forms of sexuality.

5. Integrating Sexuality into Holistic Care: Standardizing Sexual Support in Healthcare

Aimed at addressing the underrecognition of sexuality in palliative care and healthcare in general, this design direction advocates for the integration of sexual well-being into the holistic model of care. It emphasizes the need for standardized sexual care guidelines that are sensitive to the specific needs of the ill person and their partner, ensuring that sexual health is not sidelined in the treatment process.

6. Shifting the Focus: Moving Beyond Penetration in Sexuality

This design direction challenges the dominant focus on penetrative sex in both healthcare and societal discussions of sexuality. It advocates for a broader, more inclusive definition of sexuality that values non-penetrative forms of intimacy, such as kissing, cuddling, and sensual touch. Solutions could include creating educational tools, resources, and support systems that encourage couples to explore these alternative forms of sexual expression.

7. Personalizing Sexuality: Embracing the Individualistic Nature of Sexual Care

Given the individualistic nature of sexuality, this design direction advocates for highly personalized approaches to sexual care. It stresses the importance of flexible, adaptable solutions that cater to the diverse needs and desires of ill person and their partner. This could involve designing systems that offer tailored advice and support, recognizing that each individual’s experience of sexuality is unique, particularly in the context of illness and palliative care.

E. SWOT ANALYSIS - RESULTS

1. Support Open Communication: Overcoming Taboos and Communication Barriers

The first direction shows strong potential because it directly addresses one of the most recurrent themes identified across the literature, market research, and interviews. Its strength lies in its broad applicability across relational, social, and healthcare settings. However, its openness also presents a weakness: the direction can easily become diffuse, as communication can be approached in many ways. Opportunities include the growing societal acceptance of conversations about intimacy and mental well-being, while threats stem from the sensitivity and cultural taboos surrounding sexuality and death, which may limit user acceptance.

2. Supporting Sexual and Relational Autonomy: Addressing the Loss of Equality in the Relationship

The second direction builds directly on the strong theme of relational imbalance identified in the interviews, where partners described a loss of autonomy over their own emotional, intimate, and sexual needs. Its main strength lies in its focus on supporting partners in expressing these needs without guilt, while also acknowledging the constraints imposed by illness. However, the structural inequality created by incurable cancer makes full relational equality unattainable, which forms an inherent weakness of this direction. Opportunities arise from a growing awareness of the emotional burden experienced by partners in palliative contexts, creating room for tools that help couples navigate changing roles and desires. At the same time, threats relate to the risk that such tools may unintentionally increase pressure on either partner, particularly if discussions about unmet needs feel confronting or emotionally overwhelming in an already vulnerable situation.

3. Acknowledge the Role of caregiving partners : Recognizing Unseen Needs

The third direction, strongly aligns with the research finding that partners feel overlooked in both relational and healthcare contexts. Its strength lies in explicitly validating their emotional and sexual needs. However, this direction requires sensitivity, as designs must avoid overshadowing the experiences of the ill partner. Opportunities include a growing awareness in healthcare of the emotional and relational impact on partners, while threats concern potential resistance within medical contexts that remain patient-focused rather than relationship-focused.

4. Supporting Transitions in Sexuality: Adapting to Shifts in Needs

The fourth direction directly addresses the shifts in sexual needs and capacities that accompany incurable cancer. It offers strong design potential through guidance, reframing, and alternative forms of intimacy. Its main weakness is that such transitions often require slow, gradual processes (such as sensate-focus based approaches), which may be difficult to implement in a context of limited time and declining health. Opportunities lie in improving couples' ability to navigate change, while threats include the emotional difficulty of accepting a new sexual identity and the time-pressure inherent in palliative care.

5. Integrating Sexuality into Holistic Care: Standardizing Sexual Support in Healthcare

The fifth direction, is powerful in its systemic ambition. Its strength is the potential for large-scale, long-term impact if sexuality is embedded structurally in palliative care. However, this direction requires cultural and institutional change across healthcare systems, an unrealistic goal within the timeframe and scope of this design project. Opportunities include for example alignment with holistic care frameworks, whereas threats involve slow adoption, institutional barriers, and variation between care settings.

6. Shifting the Focus: Moving Beyond Penetration in Sexuality

The sixth direction challenges normative definitions of sexuality and aligns with expert recommendations for broader sexual exploration. Its strength is its conceptual clarity and its alignment with both medical and psychological sexological approaches. However, such cultural reframing is difficult to achieve at scale. Opportunities in acceptance arise from the increasing visibility of sex-positive movements, while threats include cultural resistance and the risk that users may feel their personal definitions of sexuality are being challenged or replaced.

7. Personalizing Sexuality: Embracing the Individualistic Nature of Sexual Care

The seventh direction acknowledges the highly individual nature of sexual needs and offers strong potential for tailored support. Its main strength is its sensitivity to personal variation; however, personalization can be resource-intensive and may be difficult to implement within an already strained healthcare system. Opportunities exist in the broader societal shift toward individualized care, while threats include feasibility constraints, privacy concerns, and the risk of over-complexity for users or care providers.

Taken together, the SWOT analysis provides a structured understanding of the potential and limitations of each design direction. This overview forms the basis for selecting one direction that is both meaningful in relation to the research insights and feasible within the scope of this project.

F. CONCEPT REFINEMENT

- 1st iteration

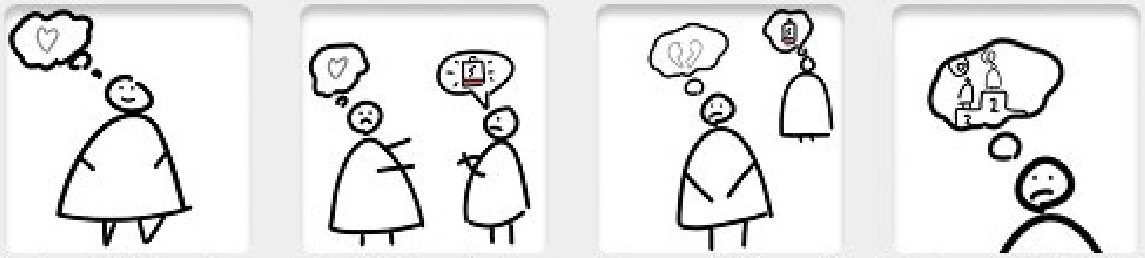
Design Brief

Relaties waar een ernstige ziekte zoals ongeneeslijke kanker speelt, hebben vaak te maken met een verschuiving in rollen. Zo verschuift de rol van de ene partner naar een zorg vragende rol en die van de andere partner naar een meer verzorgende rol. Deze transitie zorgt over het algemeen voor een grotere focus op de behoeften van de partner met ongeneeslijke kanker.

De verschuiving in focus reflecteert bovendien op de seksualiteit en intimiteit in een relatie. Aangezien ongeneeslijke kanker en behandelingen veel negatieve invloed hebben op de seksuele en intieme behoeften van een individu, is de verzorgende partner vaak opgezadeld met onvervulde behoeften en verlies van autonomie over deze gevoelens.

Communicatie over het probleem kan een remedie zijn door mensen verbonden te laten voelen. Echter, taboes rondom seksualiteit en een naderend levenseinde voorkomen dit vaak.

Probleem Scenario 1



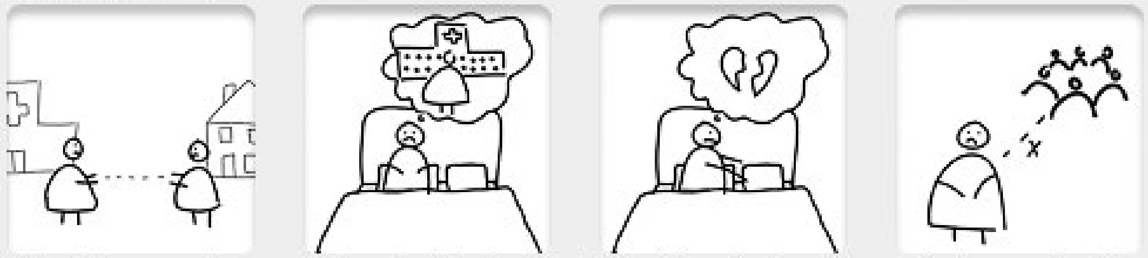
Partner voelt spontane liefde

De ander heeft geen energie om erop in te gaan

Uiting van liefde wordt afgewezen

Partner voelt alsof het leven van de ander leidend is

Probleem Scenario 2



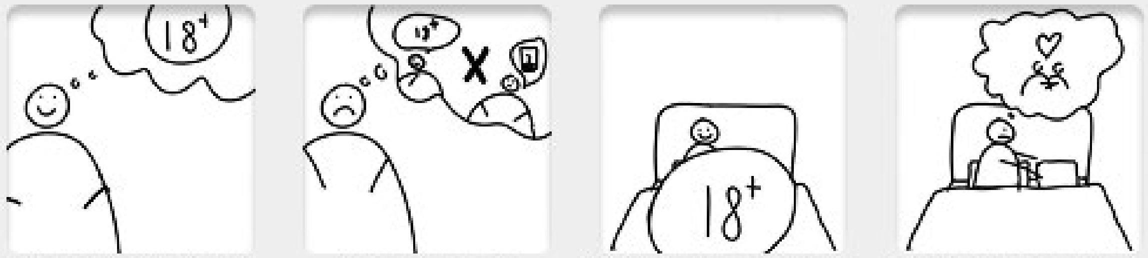
Afstand tussen partners (ziekenhuis & thuis)

Partner heeft behoefte aan de ander

Deze behoefte kan niet worden vervuld

Partner voelt zich eenzaam

Probleem Scenario 3



Partner heeft seksuele behoeften

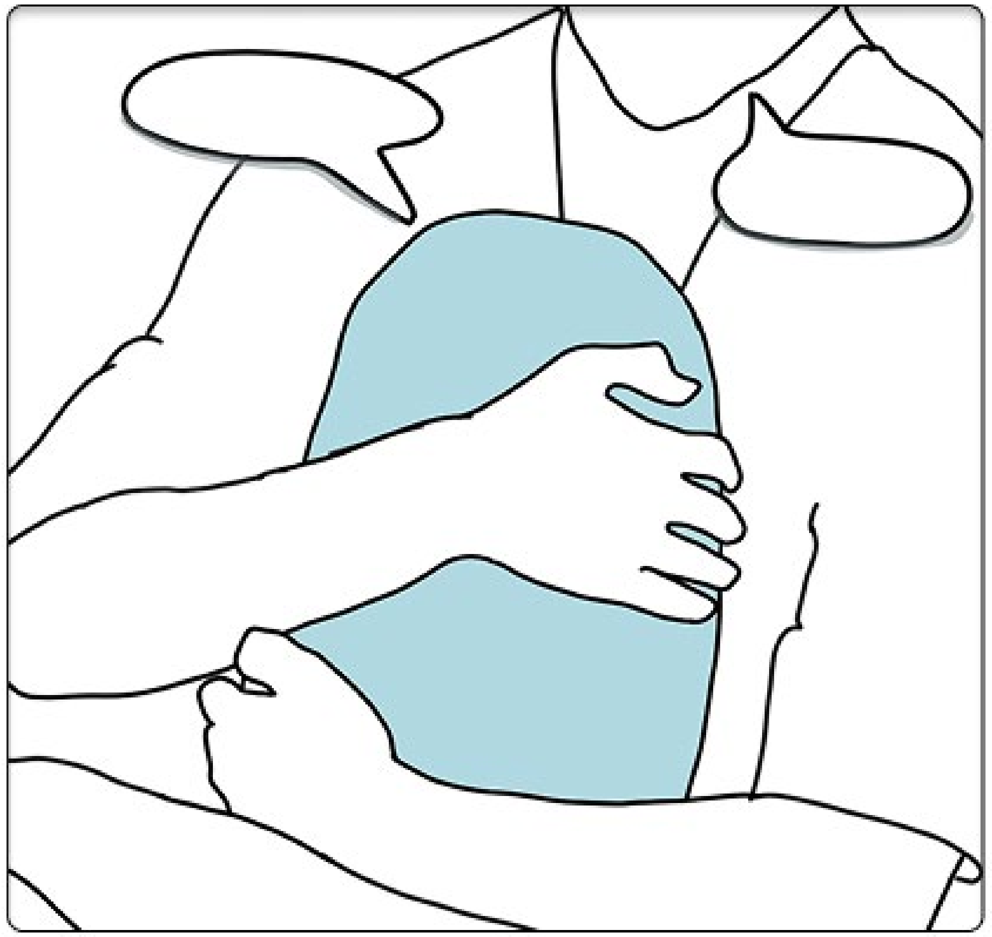
Is bang voor de afwijzing van de ander

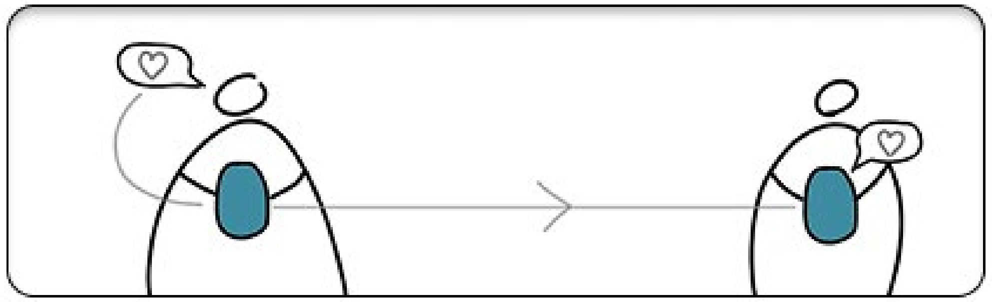
Solo masturberen is een fijne uitlaatklep

Voelt zich eenzaam en schuldig na de tijd

1st iteration - Step 2

Pillow Partner

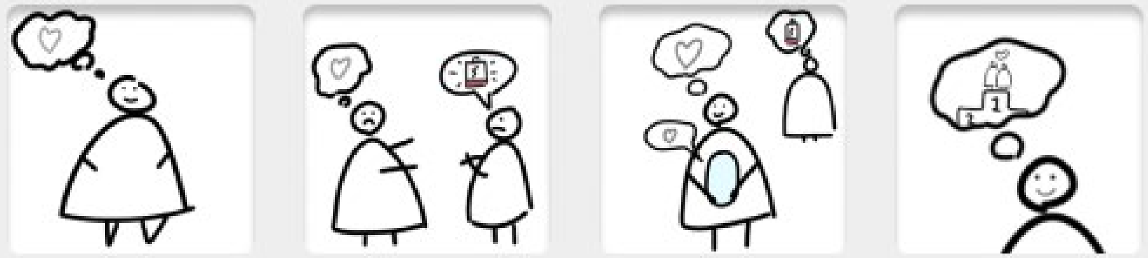




Eigenschappen concept

1st iteration - step 3

Oplossing Scenario 1



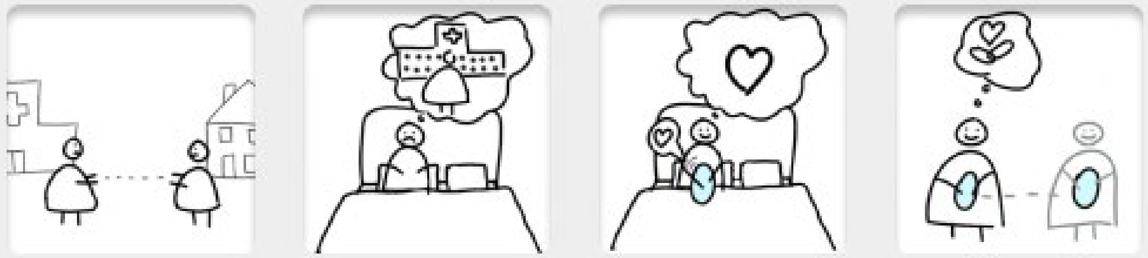
Partner voelt spontane liefde

De ander heeft geen energie om erop in te gaan

Kan authentieke liefdesuitingen geven en ontvangen uit kussen

Voelt zich een beetje in controle over intieme behoeften

Oplossing Scenario 2



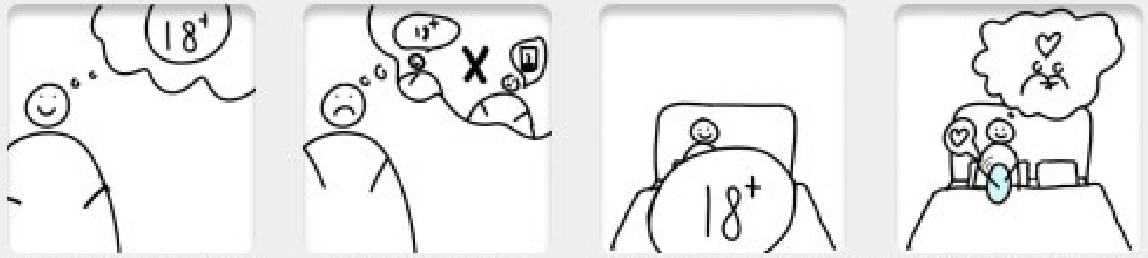
Afstand tussen partners (ziekenhuis & thuis)

Partner heeft behoefte aan de ander

Knuffelen met kussen is wel een optie

Voelt zich toch een beetje verbonden

Oplossing scenario 3



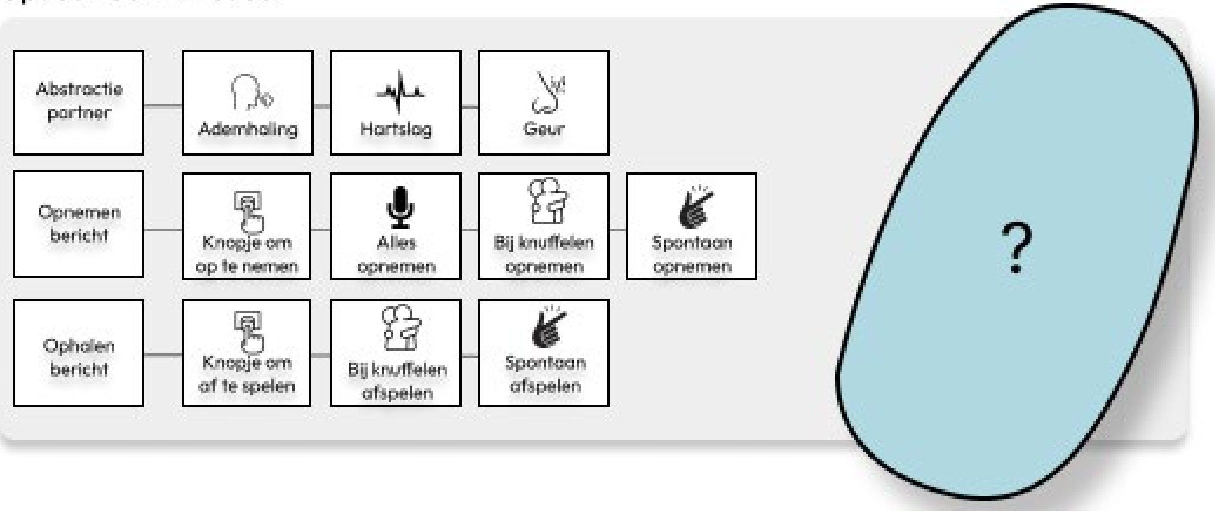
Partner heeft seksuele behoeften

Is bang voor de afwijzing van de ander

Solo masturberen is een fijne uitlaatklep

aftercare en een gevoel van connectie

Opties voor Functies



Abstractie partner — Ademhaling — Hartslag — Geur

Opnemen bericht — Knopje om op te nemen — Alles opnemen — Bij knuffelen opnemen — Spontaan opnemen

Ophalen bericht — Knopje om af te spelen — Bij knuffelen afspelen — Spontaan afspelen

G. CONCEPT REFINEMENT - 2ND ITERATION - TOPIC LIST

Introductie (voorlezen aan participant)

Wat fijn dat u tijd heeft gemaakt voor dit gesprek. Voor mijn afstudeerproject aan de TUDelft doe ik onderzoek naar relaties en **intimiteit, verbinding en emotionele ondersteuning binnen relaties**. Een doel van dit project is om hiervoor een ondersteunend product te maken. Vandaag bekijken we een vroeg concept. Het gaat om een object dat partners kunnen gebruiken om persoonlijke of warme berichten met elkaar te delen.

Het interview bestaat uit drie delen:

1. eerst bespreken we uw **eerste indrukken** van het concept,
2. daarna bekijken we **hoe u het in uw eigen relatie zou gebruiken**,
3. en tot slot bespreken we **wat het concept volgens u zou moeten kunnen of ondersteunen**.

Vertrouwelijkheid van gesprek
Het gaat om uw ervaring en beleving. Er zijn geen goede of foute antwoorden.
U kunt het altijd aangeven als u het gesprek wilt pauzeren of stoppen.
Alles wat u zegt, wordt vertrouwelijk behandeld en anoniem verwerkt.

Tekenen van IC formulier:
Voordat we beginnen wil ik u vragen om het toestemmingsformulier even door te lezen.
Als u akkoord bent met deelname, kunt u het hier meteen ondertekenen.
Laat het gerust weten als u vragen heeft.

Informed consent form laten tekenen.

Korte vragenlijst:

Om uw situatie iets beter te begrijpen, zou ik graag samen met u een paar korte vragen doornemen. Het kost maar een paar minuten. Is dat goed?

Vragenlijst samen invullen.

Toestemming
Vindt u het goed dat ik het gesprek opneem met een audiorecorder?

- Dan kan ik mij beter concentreren op het gesprek, zonder dat ik alles op hoef te schrijven.
- Als ik zo de audiorecorder aanzet, zal ik uw deelnemersnummer noemen en u nog een keer vragen om uw toestemming voor de opname.

Heeft u nog vragen voordat we beginnen?

Audiorecorder aanzetten
Dit is een opname voor een gesprek met respondent [X].
Geeft u toestemming om dit gesprek op te nemen en om uw antwoorden te gebruiken voor onderzoeksdoeleinden, nu en in de toekomst?

Dank u wel. Dan gaan we nu door met het gesprek.

STAP 1 — EERSTE REACTIES OP HET CONCEPT

(Met.twee.dummy_kussens.>.functioneel.testkussen.- .alleen.basis.uitleg?.geen.doelen.noemen)

Introductie.van.het.concept

- »Dit.is.een.eerste.prototype.van.de.Pillow.Partner¿een.set.kussens.waarmee.partners. korte.intieme.of.steunende.berichtjes.kunnen.opnemen.en.afspelen¡.Wat.zijn.uw.eerste. gedachten.hierbij?‹

Vragen

1. **Eerste indrukken**
- Wat valt u als eerste op?
- Wat vindt u prettig / minder prettig?
- Welke gevoelens of associaties roept dit op?

2. **Interpretatie van gebruik**
- Hoe denkt u dat dit werkt?
- Waarvoor zou dit volgens u bedoeld kunnen zijn?

3. **Uiterlijk en vormgeving**
- Wat vindt u van de vorm / uitstraling?
- Wat zou u veranderen?

4. **Emotionele reactie**
- Hoe voelt het om zo'n kussen vast te houden?
- Voelt het warm, neutraal, ongemakkelijk…? Waarom?

STAP 2 — RELATIONELE TOEPASSING & ERVARINGSOEFENING

(Hier.vooral.de.functionaliteit.laten.zien¿opnemen–afspelen)

Functionele.test

- »Dit.kussen.kan.een.kort.bericht.opnemen.en.afspelen¡.Ik.wil.u.vragen.om.een.kort?. testberichtje.op.te.nemen._.alsof.het.bedoeld.zou.zijn.voor.uw.partner¡‹
- Daarna: »Nu.kunt.u.het.bericht.afspelen?.zodat.u.het.ontvangen.ook.kunt.ervaren¡‹

Vragen.over.gebruik.in.de.relatie

1. **Gebruikssituaties**
- In welke situaties zou u dit gebruiken?
- Wat zou u opnemen?
- Wanneer zou u iets terug willen horen?

2. **Emotionele betekenis**
- Hoe voelde het om iets in te spreken?
- Hoe voelde het om een bericht af te spelen?

3. **Ruimte voor eigen behoeften (autonomie – maar nog niet benoemen)**
- Zou u dit ook gebruiken op momenten dat uw partner er niet voor u kan zijn?
- Wat zou dit voor u kunnen betekenen?

4. **Indirecte communicatie (maar nog niet benoemen)**
- Denkt u dat dit zou helpen bij dingen die u lastig vindt om direct te zeggen?

5. **Relatie-context**
- Hoe zou het concept in jullie relatie gebruikt worden? Waarom?
- Ziet u verschillen tussen hoe u en uw partner dit zouden gebruiken?

STAP 3 — INTRODUCTIE VAN DE ONDERLIGGENDE DOELEN (AUTONOMIE & COMMUNICATIE)

(Pas.nu.de.design.intenties.uitleggen)

Uitleg.twee.ontwerpdoelen

1. De Pillow Partner is bedoeld **om autonomie over intieme en emotionele behoeften te** ondersteunen.
2. De Pillow Partner is bedoeld om **communicatie over moeilijke of gevoelige onderwerpen** te vergemakkelijken.

Reflectievragen

1. **Herkenning**
- Herkent u deze twee doelen in het concept?
- Waarom wel/niet?

2. **Autonomie**
- Denkt u dat dit product u zou helpen om eigen gevoelens of behoeften te uiten zonder afhankelijk te zijn van de stemming of beschikbaarheid van uw partner?
- Wat zou helpen om dit nog beter te ondersteunen?

3. **Communicatie**
- Denkt u dat het kussen een ingang zou kunnen zijn voor moeilijke gesprekken?
- Hoe zou dit veiliger of prettiger kunnen worden gemaakt?

4. **Aanpassingen**
- Wat zou u veranderen aan het kussen om deze doelen beter te bereiken?
- Zijn er functies die ontbreken?
- Zijn er dingen die juist weg zouden moeten?

AFSLUITING

- “Is er nog iets dat u belangrijk vindt om te noemen over het concept of uw ervaring?”
- Bedanken voor deelname.
- Optioneel: vragen of ze later opnieuw betrokken willen worden.