Master Thesis

Supporting nurses to discuss intimacy and sexuality with patients with incurable cancer

by Shannon Caladrin Walraven

MASTER THESIS BY
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Preface

This graduation project has been a memorable journey with several touchpoints with people who guided and helped me throughout the project. I feel grateful and would like to thank everybody who supported me during the last six months.

Marieke, thank you so much for giving me the opportunity to do a project on the topic of the end of life and introducing me to the GPS Project. You were always very patient with me and did not mind repeating something several times until I received the message. Your feedback was honest which I really appreciate and your enthusiasm for my project was contagious at times I felt unsure about a certain direction.

Gert, I remember our first meeting when you asked me: “what do you look for in a coach”. I said that I was looking for someone direct and would say things as “what do you think you are doing”. During our coaching sessions it never came to that point. You always liked to think along with my considerations and asked the right questions to help me further. We laughed, I cried, I have experienced our meetings as very pleasant, from person to person. Thank you Gert!

Irene, every official meeting we had you asked exactly the right question. As if you saw right through me. I would like to thank you for sharing your experience with me and encouraging me to do activities outside the project to get familiar with Amsterdam UMC.

Susanne, you were always there to have a pleasant conversation. If it was not about the project, then we talked about other things to relax and unwind. Thank you for always willing to help me, your good advice and the nice collaboration we had.

Infinite thanks to **all nurses and CNS** who participated in the project and shared their inner thoughts with me. It means a lot to me and it was the key element in the project.

Christiaan, thank you for being there and supporting me. You gave me the surprise visits and warmth that I needed sometimes.

Rins, my third coach as you name yourself. I totally agree. Thank you for your thorough feedback on my report which brought it to the next level. Hopefully we will find a nice project to work on in the future because I really like working with you!

Janneke, you were the one calling me at night asking how I have been. Always there to help, give feedback, pushing me over a threshold even though it was for a swim in the sea. I can learn a lot from your approach. Thank you Janneke.

Yinte, I really enjoyed our time studying together, your feedback and interest for my project. I see a new career for you in acting, thank you for participating in my video.

Faey, you where there at the beginning of the project when I needed it the most and made me laugh about silly jokes. Merci.

Nimuë and **Bram,** thank you so much for sharing your time and voice with me. It really helped me in making the final concept.

Abstract

For many people, experiencing intimacy and sexuality is an important aspect of the quality of life. People who are suffering from incurable cancer are no exception (Wang et al., 2018). Often patients encounter a shift from focus on diagnosis and treatment, to emphasis on psychosocial support when cancer treatment is no longer effective. When it comes to intimacy and sexuality, these topics are experienced as difficult to discuss for both patient and healthcare specialist.
To improve the quality of life of patients with incurable cancer, the GPS project, which stands for Conversations About Psychosocial Needs, Intimacy and Sexuality (Gesprekken over Psychosociale behoeften, intimiteit en Seksualiteit) was founded by the Amsterdam UMC.
Their goal is to help and support nurses and clinical nurse specialists (CNS) improve their knowledge and skills about signaling and discussing psycho-social needs, intimacy and sexuality with patients with incurable cancer by putting together a training program.This graduation project focuses on designing for the online learning environment the GPS project set up, to effectuate awareness among nurses and contribute to a better understanding of the patient's needs and questions about intimacy and sexuality in this important phase of the end-of-life. The aim is to make the online learning environment the base of their training in order to develop conversation skills and be engaging, inspiring and effective. To achieve this goal, extensive research has been done on the needs of nurses and CNS. By using the method Context Mapping interviews are conducted which have led to uncovering their barriers and enablers towards discussing intimacy and sexuality with patients with incurable cancer. Supported by literature and multiple Co-creation sessions with stakeholders, this has led to a design for a preparatory exercise within the online learning environment which is called: "The sea of experiences" (figure 1). In an empathetic way, the exercise encourages the participants to think about their own abilities when it comes to discussing this topic, complemented by showing different perspectives on barriers and enablers. An evaluation of the concept with the target group showed that the exercise helped them to have a better understanding of the patients' needs, feel supported and have the right mindset by feeling inspired to go through the rest of the online learning environment. As a result of the evaluation, recommendations are formulated with regard to the form and content of the concept. After complying with the recommendations, the concept should be ready to be implemented in the online learning environment of the GPS project. To conclude, the concept is a valuable step towards improving communication about intimacy and sexuality between healthcare specialists and patients, and therefore contributes to improving the quality of life of patients with incurable cancer.

Figure 1, A screen from "The sea of experiences"

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INTRODUCTION

In the following chapters the graduation project will be explained, to begin with its origin, the problem definition. Next to that, the project approach will be presented along with a clarification of the different phases it consists of.

1.1 A need for discussing intimacy and sexuality

For many people, experiencing intimacy and sexuality is an important aspect of the quality of life. People who are suffering from a disease are no exception (Wang et al., 2018). In 2021, in the Netherlands, 123.672 (Wat is er nodig om het onderwerp seksualiteit bespreekbaar te maken?, 2021) people were diagnosed with cancer. Cancer knows all sorts of forms and appearances, sometimes curable. However, in many cases it is not. Due to this disease and its treatment, people are often faced with physical and psychological changes. A shift in needs and wishes can occur, some becoming more important than others meaning that the need for intimacy and sexuality may change as well. Expressing this shift in needs and wants to their loved-ones and healthcare professionals is important. The ability to get answers to questions concerning these changes is important in improving the quality of life. Especially in a hospital environment which is often experienced as distant, good communication is key. However, this is not always the case, since healthcare specialists and patients have a certain uncertainty about who they can approach, talk to and what they can and cannot discuss when it comes to this sensitive and personal topic.

"The aim of palliative care is to provide a holistic approach, which encompasses all aspects of a person's wellbeing, including intimacy and sexuality." - Wang et al. 2018

Because intimacy and sexuality are such personal and sensitive topics, it is hard to address, for both the patients as well as for the healthcare professionals. Moreover, healthcare professionals are not always aware of the need of patients to talk about intimacy and sexuality. Therefore it is not surprising that these needs are often neglected in conversations between patients and healthcare professionals. When healthcare professionals become aware of this, they acknowledge the importance of discussing and providing support for sexual wellbeing needs (O'Connor et al., 2019; Traa et al., 2014).

1.2 Introduction GPS Project

The GPS project, which stands for Conversations About Psychosocial Needs, Intimacy and Sexuality (Gesprekken over Psychosociale behoeften, intimiteit en Seksualiteit) was founded by the Amsterdam UMC with the goal to help and support nurses and clinical nurse specialists (CNS) improve their knowledge and skills about signaling and discussing psycho-social needs, intimacy and sexuality with patients with incurable cancer. The GPS project aims to accomplish this by a training program that is currently in development. This program consists of three parts: 1) a physical training day to practice conversation skills, 2) an online learning environment which provides the necessary information and preparation to follow this physical training day and 3) intervision.

1.3 Introduction graduation project

The Amsterdam UMC aims to establish an inspirational and encouraging learning environment for nurses and CNS to improve their knowledge and abilities. Finding out how to reach the target group and how to effectuate this inspiring interaction with the online learning environment is central. The main goal of this graduation project for the Technical University of Delft is to create a part of the online learning environment which enhances this desired interaction. To specify the project goal, the topics of the GPS project which comprises psychosocial needs, intimacy and sexuality has been narrowed down to the topics of intimacy and sexuality. For this project, the following goal is formulated:

The content for the online environment is composed by the conducted research done within the GPS project. Still, the exact content should be specified. Finding out the needs of the nurses and CNS could be a way to deliver a successful concept. Looking at what makes an inspiring online learning environment and finding out what can cause sensitivity for this topic is important within this research.

The aim of the project is to deliver a 'product' that is co-created and tested by nurses and CNS, which could be immediately implemented if desired by the GPS project team.

Within the GPS project, a large group of other healthcare institutions next to the Amsterdam UMC are working together to contribute to the development of the training. This existing and valuable collaboration will be used in the different steps of this graduation project. Therefore the project finds its base in Co-creation and a qualitative approach.

"To effectuate ***awareness*** among nurses and contribute to a ***better understanding*** of the patient's needs and questions about ***intimacy*** and ***sexuality*** in this important phase of the end-of-life. The online learning environment forms the base of their training in order to develop ***conversation skills*** and should be ***engaging***, ***inspiring*** and ***effective.***"

1.4 Project approach

The overall structure of this project is defined by the Double Diamond Approach (see figure 1.4.1). This is an approach that is divided into four parts where the different phases diverge and converge. In this chapter they will be explained along with the corresponding research and design steps.

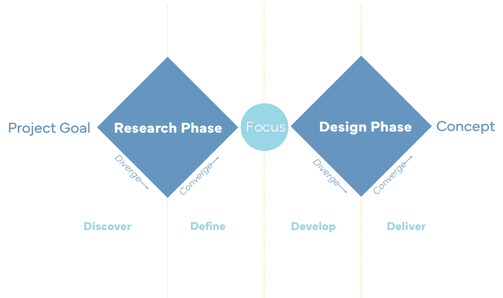


Figure 1.4.1, The Double Diamond Approach

1. Orientation
In the orientation phase the goal is to get a better understanding of the project. Therefore multiple aspects will be elaborated on. This includes more information about the GPS project, the terms intimacy and sexuality, the target group and online learning environments.

2. Discover
In the discover-phase, research is conducted to come to an overview of the existing information on the topic and to find out what desired information is still missing. This starts with exploring existing (online) materials, websites, flyers, videos, etc. about intimacy and sexuality to get an idea of what is already out there. Secondly, literature has been consulted on the topic discussing intimacy and sexuality in cancer care and healthcare facilities. Multiple perspectives are taken into account. Next to this online research, semi-structured interviews are conducted with nurses and CNS to investigate their view on the topic of discussing intimacy and sexuality with patients in cancer care. The method Context Mapping is used, in which the user is central. Lastly a Co-creation is presented in chapter 3.4, showing the preferences of nurses and CNS concerning the online learning environment.

3. Define
This second phase gives an overview of the insights gathered in the discover phase. A focus is formulated based on the insights and together with the project goal this is the starting point of the second diamond, the design phase.

4. Develop
In the development phase it is time to diverge again and explore all the possible solution directions that fit the chosen focus. This is done by conducting a Creative session with designers. A second Co-creation with the panelists is used to test and evaluate interaction principles that were derived from the Creative session. During this phase, one solution direction is chosen and evaluated with a third Co-creation session with two nurses. This has led to a concept that is further developed.

5. Deliver
In the last phase of the Double Diamond, the concept as it was at the end of the development phase is further defined and detailed. Also the coherence with the rest of the online environment will be covered in this phase. The final concept is presented in chapter 6.2 and consists of a working prototype in the chosen online learning environment of the training "Gesprekken over Psychosociale behoeften, intimiteit en Seksualiteit".

6. Concept evaluation
In this chapter the evaluation of the concept and outcomes are discussed.

7. Discussion
For the completion of the project, in the discussion the conclusion and limitations will be presented. Furthermore, recommendations will be given concerning the concept and the project. Lastly, a personal reflection on the project, process and concept are presented.

2 ORIENTATION

In the orientation phase the GPS project is discussed in more detail. Next to that, an elaboration on the concepts of intimacy and sexuality is done. In addition, the target group is highlighted. Finally, the last chapter is devoted to online learning environments and the online learning environment used for the project.

2.1 GPS Project in depth

In this chapter a more detailed description of the GPS project will be presented since the background of this project is of great importance for understanding the scope of the project and this research phase.

2.1.1 Motive for starting the project

Gesprekken over Psychosociale behoeften, intimiteit en Seksualiteit bij patiënten met ongeneeslijke kanker, also known as the GPS project has its origin in the program of ZonMw: ' Palliantie. Meer dan zorg'. It is a granted project being carried out by the Public and Occupational Health department of Amsterdam UMC, location VUmc. As mentioned in the introduction they experienced that discussions about psychosocial care needs in general and about problems with intimacy and sexuality in particular are not yet sufficiently discussed with patients in the last phase of their life. This applies to hospital and home care settings (De Vocht, 2012). Insight into these problems is therefore often lacking, as are targeted follow-up actions. As a result, patients do not receive the care they might need and want. Discussing problems surrounding intimacy and sexuality is often experienced by nurses as difficult and is therefore not done often. The demand for support remains, even when we look at teaching materials. Currently, there are various tip sheets, e-learnings and information on this topic, but nevertheless they turn out to be unsuitable for this particular training. In chapter 3.1 these materials will be more elaborated. The wish to improve the palliative care next to supporting nurses and CNS in their work plus the scarce suitable training materials form the base to start this project.

2.1.2 Target groep of the GPS project

Because there is still confusion about who is responsible for discussing intimacy and sexuality in healthcare settings (see chapter 3.2.2) the GPS project chose to focus on nurses and the CNS who provide care to patients with incurable cancer. They form the target group in this project. The reason to focus on this group of healthcare specialists is because of their close contact with the patients and the close relation to other topics they discuss during care.

Implementation of the combined intervention as mentioned in chapter 1.2 which is also visualized in figure 2.1.1 focuses on structural conversations about the needs concerning psychosocial care and questions about intimacy and sexuality by nurses and CNS.

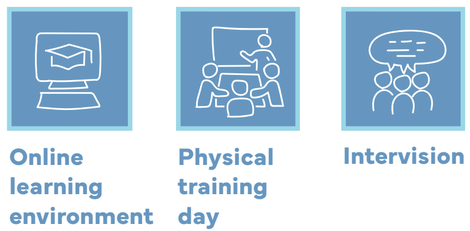


Figure 2.1.1, The three steps of the GPS Training

2.1.3 The tools Lastmeter and PLISSIT

For the application for the subsidy it was necessary to offer various tools as supporting material. These tools together with the theory form the base of the online part of the training. These tools consist of the Lastmeter and the PLISSIT.

The Lastmeter was originally developed by NCCN as the "Distress Thermometer and Problem List", a list where patients can give an indication of distress and problems concerning physical, but more important for this project, psychosocial needs. The Lastmeter can be seen in figure 2.1.2. Healthcare specialists can ask specific questions based on the patients filled out Lastmeter. This can contribute to a better understanding of the patients needs and therefore the healthcare specialist can provide better care.

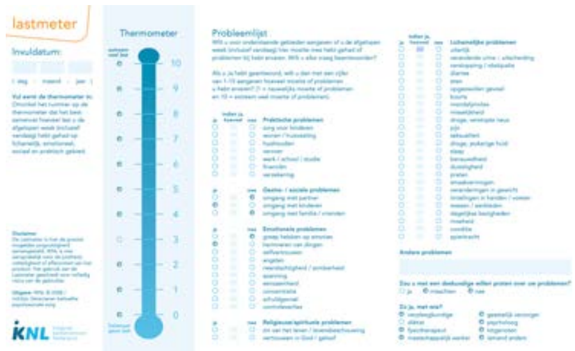


Figure 2.1.2, Lastmeter (Lastmeter, 2022)

The PLISSIT conversation model is freely available through various manuals and websites, and is included in the IKNL Palliative Care Guideline. PLISSIT stands for 'Permission, Limited instruction, Specific Suggestion and Intensive Therapy'. The PLISSIT can be seen in figure 2.1.3. It is a roadmap to support healthcare specialists during conversations with patients. In short: 1) The healthcare specialist should ask the patient for permission to talk about intimacy and sexuality, 2) When the patient gives permission, the healthcare specialist can provide limited information on the subject, 3) when the patient indicates having any concerns the healthcare specialist can give a specific suggestion and 4) when the patient has a more complex problem, the healthcare specialist can refer to a specialist on the topic for intensive therapy. After each step more patients will be helped, this means that fewer patients reach the step where intensive therapy is required.

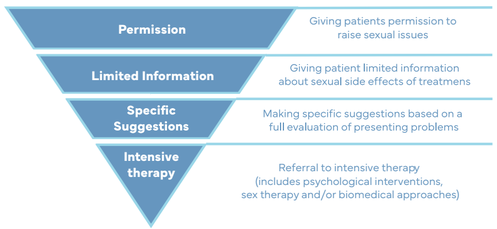


Figure 2.1.3, PLISSIT Model

2.1.4 Co-creation as the fundament of the project

As mentioned in the introduction (chapter 1.2), the GPS project was created for and by various healthcare institutions. The idea is that together they will provide the necessary input to realize the training and to be able to teach and support their own people afterwards with this training. This means that several Co-creation sessions are organized where topics concerning the training are discussed. In this graduation project two of these sessions were used to collect input for the focus and concept. Next to that the broad network of people involved in the project was consulted to find participants for the interviews and the final evaluation of the concept.

"Not all healthcare providers need to have conversations about intimacy and sexuality, but every patient needs to be seen."

- a quote from one of the panelists

This quote became the slogan of the GPS project. Its origin lies in the willingness to help patients but not at the expense of the nurses and CNS. It is important that they can see and help the patient but this does not have to mean they need to have this conversation at all times. There are other options to appeal to, for example by referring to a colleague.

2.2 Intimacy, sexuality and where it is intertwined

In this project the terms intimacy and sexuality are widely used. To give meaning to these terms they will be discussed and defined in this chapter.

2.2.1 A Theoretical definition of intimacy

Intimacy is a term that encompasses many things and is hard to define because the variety of the definition is great. Gayle (1991) stated that the theoretical definition for intimacy is: a quality of a relationship in which the individuals have reciprocal feelings of trust and emotional closeness towards each other. Furthermore they openly communicate thoughts and feelings with each other, which shows their ability for self disclosure. Notable is that physical closeness is not incorporated into this definition and therefore not a necessary condition for experiencing intimacy.

2.2.2 Sexuality according to the dictionary and from a patient perspective

What defines sexuality? The Cambridge Dictionary (2022) describes it as the attitudes and activities relating to sex. A more elaborate but still concise definition of sexuality is given by the NCI Dictionary of Cancer Terms (2022): A person's behaviors, desires, and attitudes related to sex and physical intimacy with others.

Southard and Keller (2009), did research on the importance of sexuality from a patient perspective and they found out that sexuality includes passion, feeling desirable, sharing, and the ability to be sexy. The themes that were most significant for male participants included maintaining normal relationships, physical touch, and arousal. Sexuality themes for women were based on body image, remaining appealing to their partners, the ability to be a woman, maintaining femininity, love, sex, and intimacy.

2.2.3 A project definition where intimacy and sexuality are intertwined

From the interviews, described in chapter 3.3 it emerged that there are several views on intimacy and sexuality and how they are related. An argument for seeing both concepts as one and the same is that sexuality is not just about sex but is more than that and therefore highly related to intimacy. Another opinion from the interviews is that intimacy and sexuality are two different things because intimacy is something between friends and family, while sexuality is between sexual partners.

However, these different definitions do not have to contradict each other. Intimacy does not necessarily include this physical aspect sexuality has and sexuality in turn does not need to be physical and without intimacy. Although the different views and definitions make it sometimes appear otherwise, there is an overlap which is visualized in figure 2.2.1. Since the interpretation of the two terms is widely varied, it suits the project to not define them into one sentence. When talking about intimacy and sexuality it is important that all views can be seen and understood so that the patient can be seen and understood by the healthcare specialist. Therefore, intimacy and sexuality will be seen as multi-interpretable and with greater or lesser overlap.

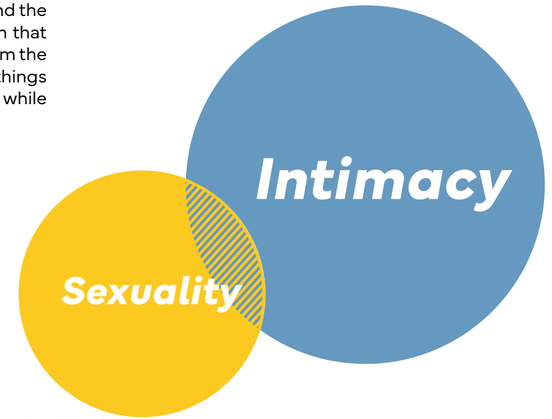


Figure 2.2.1, Intimacy and sexuality overlap

2.3 The target group

As discussed in paragraph 2.1.2, the target group of the project consists of nurses and clinical nurse specialists (CNS). In this chapter a brief description of this group is given.

2.3.1 The tasks and qualities nurses and CNS have

Nurses and CNS are in close contact with the patient. They evaluate and monitor the state of the patient and coordinate with multiple specialists when considered necessary. Next to physical care they also provide mental support to the patients. Therefore they often are highly skilled in social interaction and are verbally well equipped. Furthermore, they are adaptive and broadly oriented. A nurse must hold an associates degree, a CNS works with patients in a variety of specialties in an advanced setting and must hold a masters degree. Contact with the target group showed that they often have a practical approach and perform tasks under high work pressure. Next to that, they like to be involved with the patient, are super helpful and will always hold the door for anyone.

The main takeaway is that the target group is often occupied and can not permit themselves to fill their time with unnecessary activities. Therefore, it must be taken into account that they do not lose an unnecessary amount of time in the context of the research. Considering the design, it is important to address nurses and CNS personally to make them feel involved.

2.4 Online learning environments

As the implementation of the concept will take place in an online learning environment, this chapter will discuss multiple aspects: 1) What is an online learning environment, why is it used and by whom, 2) what aspects are important when making an online learning and 3) “Moodle”, the online platform chosen by the GPS project.

2.4.1 What is an online learning environment, why is it used and by whom?

Online learning is described as having access to learning experiences via the use of some technology (Benson, 2002, Carliner, 2004, Conrad, 2002). An online learning environment therefore is the place facilitated by that particular technology and where education is shared. What can be seen is that together with digitalisation, education and training are moving to online learning environments. This is not surprising since it is known that online learning can enhance an educational experience, support development, ease time constraints, overcome geographic limitations and can offer greater flexibility (Reeves et al., 2017). Using online learning environments happens within all kinds of disciplines, including those of health care. Because of this increasing demand for online learning courses, it is important to examine more interactive and creative ways in which learners can be motivated and make the online experience more realistic and effective (Monahan, McArdle, & Bertolotto, 2008).

2.4.2 Important aspects of making an online learning course

Kellam et al. (2012) conducted a study including quantitative and qualitative data where the majority of the participants which were working in health care indicated that digital videos were a valuable addition to the online learning environment. Recommendations concerning the future design of digital videos in pedagogical settings included: the use of personal testimonials and stories; the use of problem-solving scenarios involving modeling and demonstrations; and tailoring modeling scenarios to the specific needs of learners. Additionally, Aitken (2012) noted that the pedagogical approaches required to realize the potential value of these online learning courses, should be based not on the online delivery or the technologies used, but on the specific needs of the student group. Teaching is delivered online, but learning occurs as the students move through the various contexts they inhabit. Recognizable scenarios and examining personal experiences can help students prepare for those contexts.

Another aspect of online learning environments that could be viewed as a strength is the need for communication and collaboration. Online forums and discussion boards have become an invaluable resource (Monahan, McArdle, & Bertolotto, 2008). They allow students to communicate with their peers and tutors thus empowering them to socialize and learn more effectively together online. The value of this cannot be neglected since online learning environments tend to contribute to isolations of the learners and can make them feel unsupported (Reeves et al., 2017).

During the project, other important specifications the online learning must meet were also determined by the target group and can be found in chapter FIXME.

2.4.3 Moodle

Moodle (Moodle - Open-source learning platform | Moodle.org, 2022) is the selected platform by the GPS project. It is an online learning environment that is also used by the Amsterdam UMC for several courses. To give an impression of what Moodle looks like, an image of the course in Moodle can be seen in figure 2.4.1. This online learning environment offers the possibility to share all kinds of media such as videos, games, questionnaires, slides, etc. The teachers have the option to hide or share different parts of the course at any time. It has the option to communicate with each other and to embed more complex learning experiences such as interactive scenarios. For these more complex components the creator platform for workplace learning Articulate 360 (Articulate 360 — One Subscription That Simplifies Every Aspect of Course Development, 2022) can be used. This is a program in which a design can be made and later embedded in the Moodle environment. Articulate 360 is also used for the final concept which can be found in chapter 6.2.

2.4.4 GPS course in Moodle

During the project, the GPS course for the online learning environment was also in development. This was done by multiple iterations. A block diagram of the different parts can be seen in figure 2.4.1. Courses in Moodle are most of the time made up of different tiles per subject; this also applies to the moodle environment of the gps project. It is structured as follows: 1) a general introduction of the course to inform the participants, 2) a tile about psychosocial needs including a short lecture and a casus, 3) a similar tile about Intimacy and sexuality, 4) a knowledge quiz, 5) a summary, 6) an exercise and 7) additional materials.

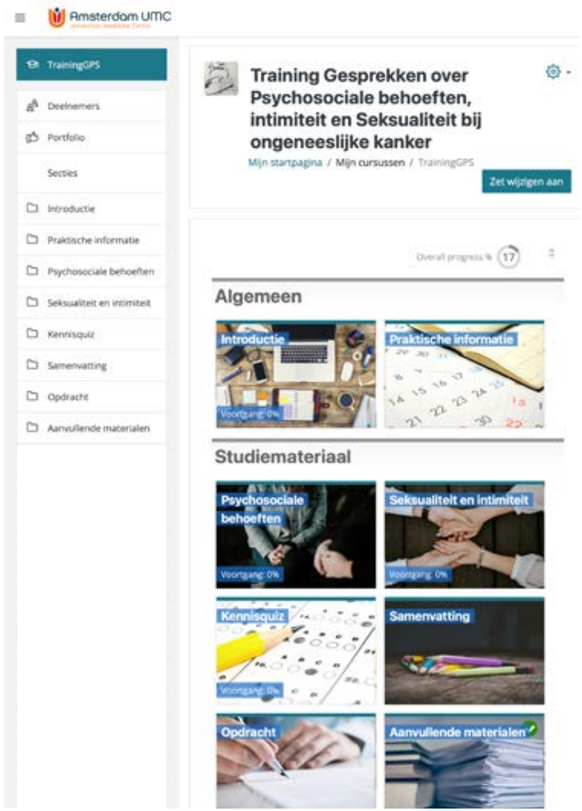


Figure 2.4.1, Tiles GPS course in Model environment

RESEARCH PHASE - discover

This chapter investigates what knowledge exists on the topic discussing intimacy and sexuality in cancer care. This will be presented in four data streams, consisting of: 1) An overview of information and training materials on this subject, 2) findings from literature on the different perspectives and stakeholders, 3) interviews with the target group and 4) a Co-creation with panelists of the GPS project to determine their needs and wishes concerning the online environment . Investigating the existing knowledge and different points of view will lead to insights in order to formulate the focus of the project.

3.1 Overview patient information and training materials

To improve education and training about awareness on and discussing intimacy and sexuality with patients with incurable cancer, existing materials on this topic are being mapped out. To get an idea of what is already there, and what can contribute to the online learning environment, both patient information as well as the information provided for caregivers has been considered in this research. Next to that, not all materials are specifically focused on cancer patients, but all include intimacy and sexuality during sickness. A few of the most common or outstanding materials are high-lighted in this report, the total overview can be found in appendix A. Next to that, an analysis of the several tools is executed to determine the relationship to and desired location of the concept. In this chapter a distinction is made between information for patients, information for healthcare professionals and information for both.

INFORMATION PROVIDED FOR HEALTHCARE SPECIALISTS

Name: De roze olifant
By: Pfizer
Includes: A toolbox that consists of 3 training exercises for healthcare specialists concerning intimacy and sexuality among breast cancer patients

(De Roze Olifant, 2022)

Name: Changed sexual health
By: Rutgers, Seksindepraktijk
Includes: Animation video with voiceover addressing how to use the PLISSIT model


(Seks in de praktijk - Informatie voor zorgprofessionals, 2022)

Name: Richtlijn veranderende seksuele gezondheid bij chronisch zieken, mensen met een lichamelijke beperking en ouderen
By: V&VN, ZonMW, Trimbos instituut en Rutgers
Includes: Written guidelines on how to interact with patients who are dealing with changed sexual health


(Richtlijn Veranderende Seksuele Gezondheid Bij Chronisch Zieken, Mensen Met Een Lichamelijke Beperking En Ouderen, 2021)

Name: Intimiteit en seksualiteit bij kanker
By: Noordhoff Health
Includes: E-Learning

(Noordhoff Health, 2022)

INFORMATION PROVIDED FOR HEALTHCARE SPECIALISTS AND PATIENTS

Name: Sick and sex
By: Sickandsex.nl
Includes: Website with news, blogs, and the influence of the clinical picture on intimacy and sexuality

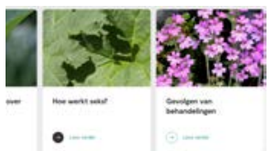
(Seksualiteit en intimiteit ten tijde van ziekte, 2022)

Name: Seksualiteit en intimiteit bij kanker
By: nfk
Includes: Fact sheet presenting findings from research in order to provide an overview of what is needed in order to discuss intimacy and sexuality

(Wat is er nodig om het onderwerp seksualiteit bespreekbaar te maken?, 2021)

INFORMATION PROVIDED FOR PATIENTS

Name: Olijf
By: Olijf, netwerk voor vrouwen met gynaecologische kanker
Includes: A website addressing all sorts of topics concerning gynecological cancer to answer questions from patients. They use photographs of flowers and plants in order to reach the rightful audience.



(Seksualiteit, 2021)

Name: Seksualiteit en intimiteit bij prostaatkanker
By: Prostaatkankerstichting.nl
Includes: Guidebook for patients with personal quotes concerning the changed sexual health during prostate cancer


(Seksualiteit En Intimiteit Bij Prostaatkanker, 2022)

Name: De bespreekkamer
By: aya zorgnetwerk
Includes: Podcast presenting interviews with young people suffering from cancer and how they deal with their changed intimate and sexual health

(De Bespreekkamer, 2022)

3.1.1 Analysis of the online information

The analysis is done by plotting the different sources of information on two axes: 1) From alienating to a personal approach and 2) from a passive to an active way of consuming the information provided. This coordinate system can be seen in figure 3.1.1.

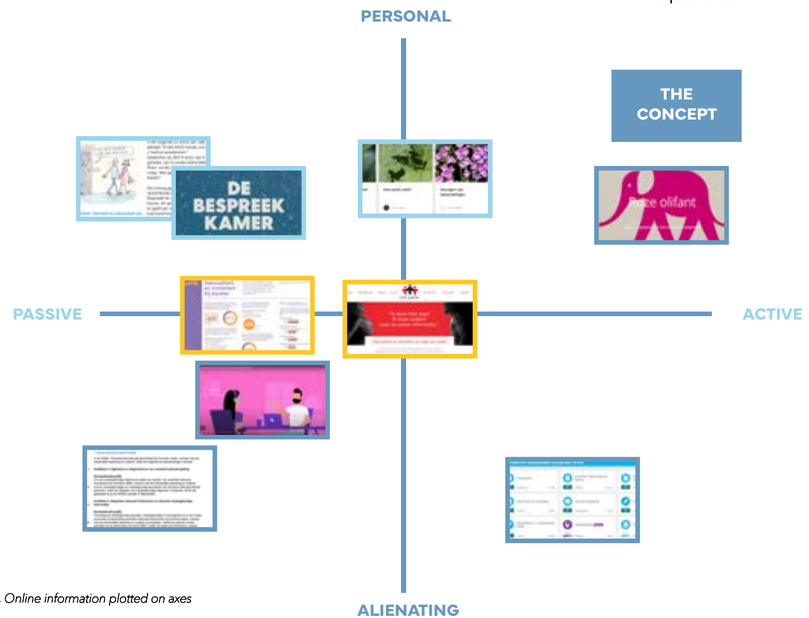


Figure 3.1.1, Online information plotted on axes

As can be seen in figure 3.1.1, most of the information available is on the passive side of the axis. Next to that, the more personal information sources are meant for patients instead of healthcare specialists. In return, the information for healthcare specialists is generally more alienating. The information meant for both groups are neither alienating or personal. One source that stands out is "De roze olifant", which is also activating and personal. It consists of a box with "prepared lectures" and assignment booklets. This enables the participants to get started with the provided material. As indicated in the coordinate system, this is also a desired place for the concept. A personal approach in order to activate the participants.

3.1.2 Conclusion

Variety

To conclude, much information can be found on the topic: awareness on and discussing intimacy and sexuality in healthcare. There is a great variety in materials, ranging from infographics to interactive training boxes to manuals and videos. The style and design of these tools differ as well, ranging from the use of exuberant color schemes to gray areas with text.

Accessibility

The different information is widely spread over the internet and sometimes hard to find. Effort must be put in the research to receive the desired information. Next to that, knowing what to look for is important to find the desired information. There is only one online training on this topic that cannot be accessed without a paid account. From the perspective of healthcare professionals, it is not likely that they will follow this training on their own initiative considering an absence of a direct cause.

An opportunity

Although the information provided for patients could be valuable for healthcare professionals, often it is not presented as such, which is a missed opportunity because much of that information is more applicable and personal than the information provided for healthcare specialists. This information stream makes use of personal stories used in podcast format, video and quotes. This in comparison with more theoretical web pages including text and schemes. Next to that, much of the information is provided in a passive way. Activating the healthcare specialist could be a new and effective approach in order to transfer information.

3.2 Findings from literature

To find out more and form a comprehensive understanding of discussing intimacy and sexuality in healthcare, literature has been consulted. Researching existing literature makes it possible to make an overview of the available knowledge on the topic; Finding out the doings, experiences and needs of healthcare specialists, patients and relatives but also identifying their context. The following research questions are formulated and will be answered in this chapter.

Research questions:

- *What role do intimacy and sexuality have in living with cancer?*
- *Who has the responsibility of bringing up the subject of intimacy and sexuality within the healthcare system/hospital area?*
- *What is the status of awareness and assumptions from healthcare professionals concerning the topic?*
- *What are obstacles healthcare professionals encounter when discussing intimacy and sexuality with patients? (and even before and afterwards as well)*
- *How do patients experience the care they receive, regarding intimacy and sexuality?*
- *How do partners of patients experience healthcare regarding intimacy and sexuality?*
- *What is known about online learning environments in healthcare?*

3.2.1 Role of intimacy and sexuality in cancer

One thing that is clear is that intimacy and sexuality are important aspects of human life. Not only when you are young and healthy, but also when you are suffering from a disease and are getting closer to the end of life. Nevertheless, chronic illness and associated treatment related side-effects can have a major impact on and affects the wellbeing in many ways (Hordern and Street, 2007; Verschuren et al., 2010). Having cancer is no different to that and can impact the sexuality of the patients and their partners regardless of the type of cancer or the type of treatment (Hordern and Street, 2007).

In 2017, the Nederlandse Federatie van Kankerpatiënten organisatie (NFK) conducted research on sexuality and intimacy in cancer. 67% of 2657 (reference FIXME) participants pointed out that their intimacy and sexuality has deteriorated since they were diagnosed with cancer. However, many patients in the terminal phase of their illness continue to value and maintain intimate relationships which has many positive implications for both the physical and psychosocial wellbeing (Wang et al., 2018). An important aspect to keep in mind is that sexuality can be described as focused on relationships and 'closeness' as opposed to just intercourse (Lavin et al., 2006). These terminally ill patients who value their sexuality, want open communication and the opportunity to discuss the impact of treatment (Hawkins et al., 2009). (Hordern & Street, 2007). This is not surprising since they often stay behind with unanswered questions. These questions include the influence of treatment on sexual functioning, how to cope with feeling alienated from your body or wondering if it harmful to touch your loved ones after chemo. Next to that, treatment can cause functional and emotional problems concerning sexuality as patients may be disadvantaged if they are not informed and not offered sexual health care (Krouwel., 2019). Luckily, awareness concerning the impact of intimacy and sexuality on well-being in cancer care has been increasing among healthcare specialists (Walker et al., 2017).

3.2.2Addressing intimacy and sexuality, the role as healthcare specialist

Despite sexual concerns being prominent among cancer patients, such issues are often left unaddressed by health care providers during clinical assessment (Wiggins et al., 2007). Literature points out that even among patients who indicated concerns about intimacy and sexuality, that their problems are rarely addressed (Walker et al., 2017). Healthcare professionals often reported lacking confidence and skills to proactively engage with patients but recognized this can lead to unmet needs and sub-optimal patient management. This is not surprising looking at the findings of Hautamäki et al. (2007) that mentioned that, while 98% of health care providers say that addressing sexual health is part of their job, only 2% of providers report routinely asking their patients about sexual health. Important to be aware of is that these numbers are purely based on routinely asking their patients about sexual health, which does not mean the topic is never addressed. However, a survey revealed that Dutch oncologists do not routinely bring up the subject of sexuality during treatment and follow-up (Krouwel., 2019). The question about who is responsible for bringing up this subject remained when de Vocht et al. (2011) found out that not all healthcare professionals consider it their task to discuss the subject.

Understanding what cancer patients need to know but especially from whom they receive information during care is essential to ensuring quality care (Rutten et al., 2005). Nevertheless, not all healthcare facilities have a clear division of tasks between the oncologist, nurse and clinical nurse specialist. This leads to assumptions other professionals will talk about sexuality and can result in it not being discussed by anyone (Butler et al., 2001).

Evcili. (2018) states that within the multidisciplinary team, especially nurses play a key role in the presentation of sexual health counseling which is also an important part of the holistic care. Additionally the study of Krouwel et al. (2015) revealed that oncology nurses consider counselling on sexual issues to be an important responsibility, which is in line with discussing other side-effects caused by the disease or its treatment.

3.2.3 Awareness and assumptions

All cancer patients should be asked whether they feel that the illness or treatment causes problems in their relationship or sexuality. And oncology nurses should be also encouraged to discuss sexuality issues with patients (Hautamäki-Lamminen et al., 2013). To do so, there needs to be awareness concerning intimacy and sexuality being a quality-of-life concern. Nevertheless, due to several assumptions, healthcare specialists are not always aware of intimacy and sexuality being important topics to discuss. For example, adolescent or elderly patients are commonly perceived as groups that are not sexually active (Krouwel., 2019) (Marks et al., 2014). But age is not a defining factor since sexual activity continues to an old age. Therefore, not addressing this topic with older patients can not be neglected (Ben Charif., 2016). Other assumptions are caused by the patient's sex, diagnosis, cultural background, and partnership status (Hordern & Street, 2007).

These assumptions also influence to what extend healthcare specialists counsel patients and inform them about potential sexual side effects of planned cancer treatment. In addition, their view on the patient's prognosis and whether they stated they had more knowledge about sexual function has influence on the quantity of information healthcare specialists provide (Krouwel., 2019).

3.2.4 Obstacles for healthcare professional

Even when the healthcare specialist is aware of their role and does not have any assumptions, it does not mean that everything is solved. As mentioned before, discussing sexual health issues in routine practice is challenging, and there are several barriers to these conversations (Dyer et al., 2013). Some are more prominent than others, but all will be addressed in this paragraph.

Lack of knowledge
Firstly, the lack of knowledge stands out because of its occurrence in many forms. To begin with, health care providers commonly report feeling unprepared to address patients' sexual concerns (Wiggins et al., 2007) (Levin et al., 2010). Next to that they feel vulnerable to the attitudes of their patients and colleagues, including fear of patient litigation, as well as reluctance to open "Pandora's box" (Hordern & Street, 2007). Which origin lies in the lack of knowledge. Formalized education and the availability of accurate information regarding sexuality can provide them the desired knowledge (L. Albers et al., 2020) (Wang et al.,2018). This missing knowledge can also exist due to the absence of life experiences, which helps others to communicate with patients about intimacy and sexuality (Hordern & Street, 2007). Nurses who have undergone further training, are more experienced, older, possess an academic degree and work in a department with a strict policy concerning sexual functioning provide significantly more sexual counselling (Krouwel et al., 2015) (O'Connor et al., 2019). Another factor concerning the lack of knowledge is that when healthcare specialists do identify problems, they are hesitant to address them. They feel that they have no resources to offer (Gleeson et al., 2017). In a similar manner, lack of onward referral option was also considered to be a reason to not engage with patients (Lavin et al., 2006). On top of that, some suggested that they would not address sexual issues with single or widowed patients (Ussher et al., 2013).

Too personal
Secondly, healthcare professionals report that they regard patients' sexual lives as too personal to ask about and not wishing to cause offense (O'Connor et al., 2019). (Richards et al., 2016). Some healthcare professionals therefore focus on physical function. O'Conner (2019) points out that this 'objective' approach of clinical factors as sexual function or biomedical aspects of care can feel more comfortable for healthcare specialists to have this conversation. The downside of this is that they fail to address the psychological or sociological aspects of intimacy and sexuality. Even though healthcare specialists are used to discussing personal topics, sexuality can still be experienced as a taboo. Evicii (2018) concluded that in a conservative society like Turkey this is a major factor in not discussing the topic by nurses. Due to the rearing styles, cultural, social and religious factors "sexuality" is neglected and ignored. In varying degrees, this is the case in many other countries and places.

The patient being too ill
Thirdly, another aspect found is 'the patient being too ill' (Krouwel., 2019; Lavin et al., 2006). The healthcare specialists do not see an opening to talk about intimacy and sexuality while the patient is in such a state. Also, frequency of bringing up sexual health declined when treatment had a palliative intent compared to a curative intent (Krouwel., 2019). Although this is the case, this does not mean the patient is not in need of support on this matter.

Other barriers
Other barriers named in literature were, heavy workload, lack of time, presence of a third party and no angle or motive for asking, factors that healthcare specialists have little influence on. However, personal discomfort and lack of knowledge can be improved upon and are achievable by providing adequate knowledge and appropriate practice training (Krouwel et al., 2015; Moore et al., 2013).

Assuming the problem cannot be solved because healthcare specialists are not aware of their ability to help is also a severe obstacle. Wang et al. (2018) found that bringing up the subject of sexuality by a healthcare specialist improves quality of life and reduces stress of patients and partners. This suggests that the care patients need does not have to be complex and that listening to the patients' concerns might be sufficient in order to take away pain or stress. Being aware of the small things healthcare specialists can do in order to make a big difference could be of influence in overcoming barriers.

3.2.5 Patient experience

Although intimacy and sexuality are rarely addressed as named above, many patients expect that providers will or should address sexual problems with them and facilitate resources that can help them ameliorate their suffering (Sanchez Varela et al., 2013). Especially patients who feel their relationship weakening during their disease, value access to sexuality-related information (Hautamäki-Lamminen et al., 2013). While some patients wish to discuss this topic, they do not always dare to ask their questions. This can be caused by embarrassment or the feeling that it has no priority to talk about intimacy and sexuality along with all the other complications. Another obstacle for patients is when the topic has been addressed once and along with other information, they do not recall in a later stage of treatment that intimacy and sexuality are topics that can be discussed. Therefore, they feel health care providers do not provide an opportunity to talk about sexual function or even ignore their sexual needs (Krouwel et al., 2019).

Considering the sexual side effects (figure 3.3.1) of treatment and the possible additional burden rises the question, should this be a part of the informed consent? Nevertheless, according to Krouwel et al. (2019), Dutch oncologists rarely bring up these side effects during the informed consent conversation before starting a treatment. Which is remarkable since informed consent is seen as a crucial component of medical practice and authenticates patients' autonomy.

Patients encounter a variety of physical issues:
36% - Erectile dysfunction
31% - Fatigue
29% - Suffering from vaginal dryness
25% - Difficulty climaxing
25% - Difficulty ejaculating

In addition to:
38% - No sexual desire
35% - No sexual arousal
32% - Do not feel like having sex
29% - Nature of sexual relationship has changed
27% - Image of self has changed

Figure 3.2.1, Sexual side effects (Wat is er nodig om het onderwerp seksualiteit bespreekbaar te maken?, 2021a)

3.2.6 The partner

Not only patients and healthcare professionals play a part in this matter, also the partners should not be forgotten. Literature shows that the disease can have long-term effects on relationships and the way partners feel about each other. Communication and participation in sexual activities can provide a sense of normalcy and offer couples mutual enjoyment and foster a sense of closeness (Taylor., 2014) (Redelman., 2008). Changes in sexuality can also weaken or worsen relationships if partners are reluctant to discuss problems openly (Badr., Taylor, 2009). Practical advice including experiences from others and emotional support could help them to cope with intimate sexual changes, altered self-image, and the disease itself (Rasmusson and Thome, 2008; Sheppard and Ely, 2008; Hawkins et al., 2009; Albers et al., 2020).

However, not all partners are as involved or open to talk about intimacy and sexuality with the healthcare professional. Albers et al. (2020) found out that the limited majority of partners find it important and prefer to receive information from a healthcare specialist as routine care regarding this topic. It is preferable to adjust the information to the partner's social and cognitive condition when trying to let partners and patients cope with the changed intimacy and sexuality. An important aspect to be aware of as partner, patient and healthcare specialist, although expressions of sexuality may be impacted by changes to physical capability, physical expression can be replaced by validation of the emotional connection between patients and their partners (Taylor., 2014). Therefore, it is of great importance that this approach of intimacy and sexuality is shared by the healthcare specialist.

3.3 Interviews with the target group

After conducting the online literature research, it is time to get a better understanding of the wants and needs of the target group and to empathize with them. Interviews were conducted with nurses and clinical nurse specialists (CNS). In this chapter the research questions, interview method, set-up and outcomes will be addressed.

3.3.1 Research questions

In search of choosing and formulating the focus, multiple questions arose regarding discussing intimacy and sexuality with patients with incurable cancer. The interview was set up in order to answer the following questions:

- *What does intimacy and sexuality mean for the individual and how does it manifest itself in the care of patients with incurable cancer?*
- *What different factors are encountered prior to / during / after a (potential) conversation about intimacy and sexuality?*
- *How does cultural diversity play a role in their work and how is it dealt with?*
- *What conversation tools are being used?*
- *Are nurses and CNS informed about the Lastmeter and the PLISSIT and to what extent are they being used and experienced?*

Within the coming process of this project, the first three research questions were proven to be most valuable, as they delivered the main insights on how to proceed. The insights derived from the last two research questions, although valuable for the overall picture, will not be discussed in this chapter (see appendix I).

3.3.2 Method

For conducting the interviews, Context Mapping was used (Contextmapping – A Design Approach to Learn from Everyday People and Use the Insights for Innovation, 2022). The most important step during the interviews is to go along in the story of the participant. By looking at the present and reflecting on that, the step to the past can be made which enables the participant to also look at the future (see figure 3.3.1). It is often hard for people to

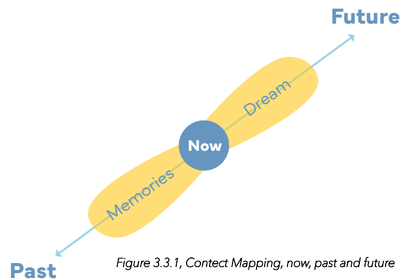


Figure 3.3.1, Contect Mapping, now, past and future

immediately express their needs and wishes for the future, since some might never have thought of it before Asking people right away what they need in the future will result in shallow answers, which are not a representation of their latent needs. People can easily express what they think and say at the moment, a researcher can observe what people do and use, but latent needs, which are subconscious needs that drive people, are more difficult to express. With this method an attempt has been made to deepen the conversation and therefore a greater understanding of the participants' needs, wishes, struggles etc. (see figure 3.3.2).

The conducted interviews were semi structured and accompanied by an exercise. Normally, sensitizing the participants is done before the interview. Due to the logistical reason of the target group having little time, the exercise is filled out during the interview. The exercise was used as a generative tool including a timeline (see figure 3.3.3) which has common ground with the steps named above, looking at the now, the past and the future.

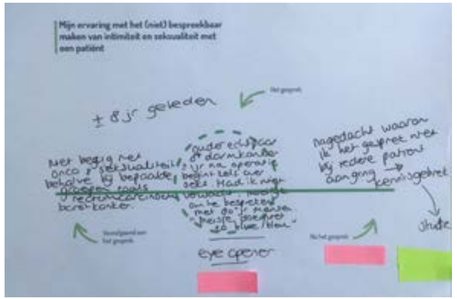


Figure 3.3.3, Filled out timeline of one of the interviews

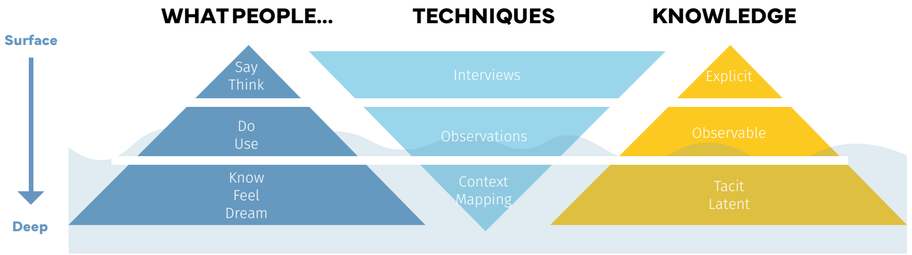


Figure 3.3.2, Contect Mapping, surface, deep

The exercise

"Think of a moment where you were having or about to have a conversation with a patient about intimacy and/or sexuality. What was the situation? Who was there with you? What preceded it and what happened afterwards?"

Next to that, the specific interview questions (see appendix B) were also intertwined with these steps, more focused on their memories and their future dreams concerning conversations with patients about intimacy and sexuality.

3.3.3 Participants

Six people participated in the interviews, five panelists of the Co-creation and one person who is a colleague of a panelist. Their function ranged from nurse, CNS and providing sexual counseling. All were working in the oncology department in a hospital. Since male and female interpret intimacy and sexuality differently (see chapter 2.2), the results of the interview may be imbalanced because only female participants took part (see figure3.3.4).

Participant	Function	Sexual councelling	Years of experience	Gender
P1	Nurse	V	10	Female
P2	CNS	V	15	Female
P3	Nurse	X	18	Female
P4	Nurse	X	9	Female
P5	CNS	X	10	Female
P6	CNS	V	22	Female

Figure 3.3.4, Participant specifications

3.3.4 Interview set up

Upfront to the interviews, the participants received an invitation (see appendix C) with the exercise as mentioned above to give an impression of what to expect in the interview. All interviews were conducted individually, except for one. Due to practical reasons this interview was partly conducted with two participants and partly separate.

An audio recording was made in order to make transcripts of the interviews. The consent form which gives permission to make this recording can be found in appendix D. A Photograph of the set up can be seen in figure 3.3.5.

Figure 3.3.5, Photograph of set up interview

3.3.5 Pilot

Prior to the interviews, a pilot test was conducted. This was done with a nurse from outside the GPS project, working in home care who had no specific affinity with patients with incurable cancer. From the pilottest was learned that a few adjustments had to be made concerning the order of the questions to make the interview more consistent.

3.3.6 Analysis of the interviews

To give answers to the research questions, an analysis of the interviews has been executed, using quotes from the transcripts as input for concept cards (see figure 3.3.6). These cards were provided with an interpretation and clustered by subject. The total overview of the 108 concept cards in clusters can be found in appendix E. With these clusters the individual research questions are answered.

Figure 3.3.6, Concept card

Inconsistency in meaning of sexuality and intimacy - *What does intimacy and sexuality mean for the individual and how does this manifest itself in their work?*

What became clear from the interview was that not every nurse and CNS give the same definition to intimacy and sexuality. Also the ease of discussing one of the two varied. To elaborate on this, one participant mentioned considering intimacy and sexuality as one because sexuality does not only include sex. Whereas others mentioned that intimacy and sexuality encompass completely different things. This difference is again split into people who indicate that they prefer discussing sexuality because it stems from the disease and its treatment and is a more clinical approach. On the other hand, there are the people who find intimacy easier to discuss because it connects to personal conversations that are already held and is not directly about sexual acts which embarrassment entails.

"I wouldn't really see it as two different things. Maybe if you only see sexuality as penetration, but I think sexuality is more." - a nurse

When it comes to sexuality, I somehow find it more difficult, I really think it's a separate topic, for example intimacy, then you might go over it a lot easier while talking. - a CNS

Culture is not the problem, assumptions are - *How does cultural diversity play a role in their work and how is it dealt with?*

The nurses and CNS that participated in the interviews indicate that they have no problems if a patient has a different cultural background. Nevertheless, three participants who followed an additional training concerning the topic discussing intimacy and sexuality indicate that they have learned a lot in the field of diversity awareness. Not the cultural differences are a problem but the assumptions that go along with it can cause patients to be hurt or not seen by the healthcare specialist. Therefore, informing the healthcare specialists about these assumptions and making them aware of everything it can include could help in order to fill the gap of cultural differences. When it comes to a language barrier, conversations are often experienced as difficult. Due to the discomfort of all parties when an interpreter is present, the conversations cannot easily go into depth and the patient cannot optimally be supported with their care question.

A division between barriers and enablers - *What different factors are encountered prior to / during / after a (potential) conversation about intimacy and sexuality?*

To answer this question the majority of clusters could be divided into two groups: 'Enablers' and 'Barriers'. Among these enablers and barriers there are several different topics that can cause the conversation between healthcare specialist and patient about intimacy and/or sexuality will or will not take place.

In the following paragraphs the different factors encountered divided into ***enablers*** and ***barriers*** are listed along with an explanation.

ENABLERS

Knowing the boundaries of your job description
To open the conversation it can be helpful to know as a healthcare specialist where your profession stops and when you can refer to a specialist in case the need of the patient becomes too complex. Knowing you do not have to answer all questions or find solutions to problems patients address can feel reassuring. This also works the other way around, knowing what you can do as a nurse and CNS is motivating for having this conversation.

Having the option to refer to a professional
Having this option for referral and especially knowing where to find specialists as a sexologist or psychologist makes healthcare specialists less hesitant to start the conversation. From the interviews it became clear that people who do not have this option in their hospital find it way harder to ask the patients about their intimacy and sexuality.

Seeing the human behind the patient
Being aware of the patient also being a person with feelings next to the disease and its treatment could lead to more personal and humane conversations including the subject of intimacy and sexuality. Half of the participants emphasized how important it is to have a personal relationship with the patient and not see them as only the disease they carry.

"I wouldn't really see it as two different things. Maybe if you only see sexuality as penetration, but I think sexuality is more." - a nurse

Realizing you have to make time to discuss this subject
There is not much time during daily care, knowing that a conversation about intimacy and sexuality does not come naturally helps in order to actively start one. One of the participants noted she had not been taught about this during her study.

Taking responsibility for the start of the conversation
The interviews showed that not many patients will start this conversation by themselves, two participants emphasized the importance of taking responsibility for this start as a healthcare specialist. Otherwise the conversation will probably not take place at all.

"And of course that should also start ringing some bells, like wait a minute, the rest of the patients aren't talking about it. I can't imagine it is not an important topic to them." - a CNS

Listening can be enough
Four from the six interviewees mentioned that being willing to just listen to patients can already contribute and that therefore the conversation does not have to be complicated. Most of the time it is about understanding and normalizing the patient's concerns.

Being able to spar with colleagues
Issues are easier to solve together, four of the participants mentioned that they find support with their colleagues. Situations that are experienced as difficult can be discussed and a solution can be found together. Next to that also a more humoristic and lightweight vibe can be created among eachother and the topic of intimacy and sexuaality.

"We, the case managers at urology have agreed that we will always discuss this point." - a CNS

BARRIERS

Experiencing lack of knowledge
The lack of knowledge is mentioned by every participant. Some of them followed this additional training about intimacy and sexuality, the lack of knowledge is not a problem to them anymore but they all experienced this insecurity of not knowing what to do or say. The participants mentioned that the feeling of lacking knowledge can occur when patients bring up questions they do not know how to answer. Or that they do not want to ask questions that bring up other questions from patients they do not have an answer to.

"I remember one time when a patient asked, "Why aren't you asking about how the sex is going" and I wasn't ready for that question at all." - a CNS

Missing a routine and the experience that comes along
When healthcare specialists never ask patients about intimacy or sexuality it is likely that they will continue not addressing this topic. Three of the participants brought up that the more they practice and start conversations, the easier it gets.

"In the end it's just about gaining experience, then it gets easier". - a CNS

Seeing no immediate cause
Two participants experienced it being difficult to ask the patient about their intimacy and sexuality in the absence of a direct cause. Sometimes they also think there is no need for the patient to discuss this.

"I also get the feeling that patients don't really need it". - a nurse

Driven by assumptions
As mentioned before in the answer to the question, "How does cultural diversity play a role in their work and how is it dealt with?", assumptions can withhold healthcare specialists from providing the patient with the desired care. These assumptions can relate to all sorts of things, age, culture, gender, etc. Three from the participants mentioned explicitly that their assumptions have been or still are an obstacle in discussing intimacy and sexuality with patients.

3.3.7 Conclusion

The timeline exercise has only been filled in completely by half of the participants, nonetheless, it was of good support in telling their story. During the interview the participants were very open and willing to answer all the questions asked, even if the given answer did not plead for themselves. This openness gave good insight into their doings, which have led to the distinguishment between the barriers and enablers. These barriers and enablers will later be used in the formulation of the focus (see chapter FIXME) and as input for the concept (see chapter FIXME).

3.4 Co-creation session one

Within the GPS project, Co-creation sessions are used as the main input for the development of the entire training program. By exchanging information between all involved parties, multiple perspectives are considered which is important to get the most out of the project. The panel consists of patient representatives, caregivers, network coordinators, researchers, educators, policy officers and trainers.

In this chapter the first Co-creation session is described which was used to gather input for the focus of the project.

3.4.1 Objectives for the session

Finding out the needs of the panelists concerning the run-up to the training and setting boundaries for making the online learning environment stood central. Therefore, prior to the session the following questions were prepared to ask to the panelists:

- *How do you get your colleagues motivated for the training, and therefore;*
- *What is the need of nurses in relation to the (online) training*

Next to that, a more specific question was asked to find out their needs concerning the online learning environment:

- *What is important for the online learning environment to make it user friendly and appealing to follow*

The questions were answered in the form of a discussion between all twelve panelists that were present at the session. Notes were taken to provide an overview at the end of the discussion. The most valuable outcomes of this session are presented below. The total overview of the notes (see figure 3.4.1) and accompanying explanation of the session can be found in appendix F.

Needs of nurses to motivate **Important for online environment**

Figure 3.4.1, Overview notes Co-creation session

3.4.2 Outcomes of the session

Derived from the discussion, multiple points emerged. They are noted down per question, including an interpretation. Next to being input for the focus, these points are also of use for the concept.

The need of nurses and CNS in relation to the (online) training is to:

- *See the goal: quality of life comes first*
- *Let real examples from practice speak for themselves*
- *See the effect of 'just' listening to the patients, which shows that also doing little things can contribute to the quality of life*
- *See the reaction of the patient which speaks volumes, in combination with the question asked by healthcare spe cialist*
- *See the contrast, which questions are not appropriate*
- *Keep it light weighted and fun, it is a beautiful human subject*

What can be seen from these answers is that there is a need for the **WHY** do we do this, the **WHAT** do we do and the **HOW** do we do it. This manifests itself in wanting to see the underlying reason for having the conversation about intimacy and sexuality with patients along with concrete examples of situations and the cause and effect of it. Taking these needs into consideration, they can be used as **input** for the final design.

Online learning specific needs of nurses:

- *Keep it short*
- *An overview at a glance*
- *Time estimation for the individual parts*
- *Videos not longer than ± 4 minutes*
- *Intuitive structure*
- *Information divided per subject*

As can be seen, these needs are more practical and can be used for the whole online training. Nevertheless, they are also important to keep in mind when it comes to the conceptualization within this project. They can be of good use as **guidelines** in the way the final design is structured and presented.

3.5 Conclusion research phase - discover

Now that the four streams of data have been investigated it can be concluded that much information can be found on discussing intimacy and sexuality with patients with incurable cancer. It is not an unknown subject in literature and also the online information provided is abundant. In literature, online information, Co-creation and the interviews it was found that many of the issues concerning discussing this topic are similar. However, no unequivocal solution has been found for these issues. Therefore, it is crucial to exploit these challenges in the exploration for a solution.

FOCUS AS OUTCOME OF THE RESEARCH PHASE - define

In this phase of defining, all gathered insights from the GPS project, online information/teaching materials, literature, the conducted interviews and Co-creation, is combined to formulate the focus of this project.

4.1 Focus

The focus of this project that will be presented in this chapter is the common thread for the remaining process of the project. It is the starting point for the second diamond from 'the design phase' and all further steps taken.

4.1.1 Three streams of insights towards the focus

In the research phase four steps were taken to get the full picture of the project and everything that comes along with it. This included doing research on online information/teaching materials, literature, the conducted interviews and a Co-creation session. The first steps was on an exploratory basis to gather insights about the online information streams that relate to this topic. The following steps regarding literature, the interview and the Co-creation session provided specific insights that were used to formulate the focus. To jog the memory, an overview of the insights from all three steps are presented in the following overview.

INTERVIEW INSIGHTS
Nurses and CNS indicate:

Enablers
Knowing the boundaries of your job description
The option to refer to a professional
Seeing the human behind the patient
Realizing you have to make time to discuss this subject
Taking responsibility for the start of the conversation
Listening can be enough
Being able to spar with colleagues

Barriers
Lack of knowledge
Lack of routine and the experience that comes along
No immediate cause
Lack of awareness

LITERATURE INSIGHTS
Nurses and CNS encounter:

A lack of awareness
Having assumptions
A lack of knowledge
Feeling unprepared
Feeling vulnerable
Not feeling responsible
Not knowing/having referral options
Lack of time
No direct cause
Doubting own abilities

INSIGHTS CO-CREATION ONE
The need of nurses and CNS:

See the goal
Real examples
See the effect of listening
See the reaction
See the contrast
Keeping it light and fun

As described in chapter 3.3, the analysis of the interviews showed that there was an emphasis on two principles: Enablers, that make it easier to start a conversation about intimacy and sexuality and Barriers, which withhold nurses and CNS. Based on these finding, the focus of the project is formulated. The focus will be elaborated by explaining the presented keywords, complemented by the insights from the three data streams named above.

As can be seen, engage and inspire was already adopted in the project goal. Those are important aspects when it comes to retention in a positive way. Therefore, they have been preserved in the formulation of the focus. Also the insights from the Co-creation have led to adopting these elements, the panelists indicated that they want to engage by seeing the goal and want to be inspired by, for example, keeping it light and fun.

FOCUS

*"**Engage** and **inspire** nurses for the online training about discussing **intimacy** and **sexuality** with patients by creating **awareness** on **existing barriers** and **empowering** them through their **individual enablers.**"*

Engage and inspire

To understand Engage and Inspire, the project goal presented in chapter (FIXME) should be revisited:

*"To effectuate **awareness** among nurses and contribute to a **better understanding** of the patient's needs and questions about **intimacy** and **sexuality** in this important phase of the end-of-life. The online learning environment forms the base of their training in order to develop **conversation skills** and should be **engaging**, **inspiring** and **effective.**"*

Awareness

From literature and the interviews it became clear that the lack of awareness concerning the topic of discussing intimacy and sexuality as mentioned in the description of the GPS project is a prominent factor. Therefore, awareness is also adapted in the focus of this graduation project. In this case it will concentrate on making the nurses and CNS aware of the barriers encountered.

Existing barriers

In literature multiple barriers were found for starting a conversation about intimacy and sexuality with patients with incurable cancer. Not only in literature but also in the interviews many barriers came forward. These encountered barriers do not apply to every healthcare specialist, a barrier for one does not have to be a barrier for the other. Next to that there are also barriers that are encountered by patients, therefore it is called, existing barriers.

Empowering

From the interviews it could be abstracted that there is a great willingness to take care of this topic but what is also found in literature, insecurity and doubt stands between. With this focus the aim is to empower nurses and CNS by showing examples of a possible approach as insight from the Co-creation.

Individual enablers

The examples used to empower nurses and CNS are called enablers. These enablers come forth from the interviews and reviewed literature. What applies to the barriers also applies to the enablers, not every enabler suits everyone. The nurses and the CNS need to find what suits them and gives them support. It is what touches them personally, and that is why it is called, individual enablers.

DESIGN PHASE - develop

The design phase is the beginning of the second diamond, develop. In this phase the formulated focus will be used to execute a Creative session and explore solutions towards a concept. Next to this Creative session, two Co-creation sessions are held and explained in chapters (FIXME).

5.1 Creative session

In this part of the project where the research phase has been completed and the focus is formulated, it is time to broaden the view for all the possible solutions for the concept. To explore possible solution directions, a Creative session was conducted.

5.1.1 Goal of the session

The goal of this session was to explore possible solution directions for the concept. Doing this with people from outside the project made it possible to take a step back and look at it from another perspective.

Finding out different manners in which **barriers** and **enablers** can be presented stood central during this Creative session.

5.1.2 Structure of the session

The session consisted of three parts: 1) First an introduction to the project was given to inform the participants about the project. Sharing the formulated focus and discussing this was an important part of the session to fully understand the desired outcome. 2) To come up with new and broad ideas, an icebreaker, and multiple exercises to stretch the mind were undertaken. 3) In this last part the way in which the barriers and enablers can be presented was explored. Using cards from the game DIXIT, displaying random scenes were used to build ideas on. The different idea directions were shortly presented and discussed at the end of the session. An impression of the setup can be seen in figure 5.1.1.

5.1.3 Participants

The session was conducted with two participants, a former Industrial Design Engineering student and a junior designer at social design studio MUZUS.

Figure 5.1.1, Impression setup creative session

5.1.4 The most inspirational directions

The most inspirational ideas and idea directions accompanied with the associated interaction qualities can be seen in figure 5.1.2.

Figure 5.1.2, Ideas used from the Creative session

5.1.5 Chosen direction

Exploring different solution directions have led to multiple ideas. Combining a few of these ideas and the accompanying qualities have led to a promising direction for the concept. An overview of all the ideas can be found in appendix G.

“The pond of experiences” which can be seen in figure 5.1.2, has been taken as the starting point for the solution direction. The idea is to fish for experiences in order to learn from each other. The interaction qualities sharing, reflecting and activating fit the target group and the focus.

Think about **sharing barriers** and **enablers** together with a moment of **reflection** to create **awareness** and make it **engaging** and **inspiring** by activating them with a little task.

Adding the idea of making a token (see figure 5.1.2) of your own experience adds up to the reflection part of the pond. Share reflections and make the pond richer in its knowledge. These reflections also allow nurses and CNS to put their barriers in the spotlight (see figure 5.1.2) to overcome them. Looking at these experiences makes you also a fly on the wall (see figure 5.1.2) which could give an intimate and valuable insight into the lives of others.

5.2 The early concept

The idea retrieved from the Creative session was developed into an early concept. In this chapter the concept will be explained in more detail. The position of the concept within the online learning environment will be discussed as well.

5.2.1 From a nascent idea to an early concept

To turn the idea of the "pond of experiences", (described in chapter 5.1) into an early concept, the idea has been further developed. An overview of the steps defining the concept are visualized in figure 5.2.1.

The pond of experiences is meant to serve as a warmup exercise to assist in bringing the participants in the right mindset for going through the online learning environment. The goal is to let them think about their own situation, barriers and enablers in order to intrigue and motivate them to learn about the topic.

For sharing the existing **barriers** and individual **enablers** it is chosen to use audio fragments. The way in which audio leaves room for people's own interpretation and the possibility to adapt to their personal circumstances suits the project. The use of audio will be further discussed in chapter 6.1.

"The moment of reflection" will be accomplished by asking the participants reflective questions. These questions are there to make them think about their own approach and whether they feel good and empowered by it. In addition, these questions should support them to think about other possibilities in case they are not satisfied with the way they currently handle conversations about intimacy and sexuality. By sharing these reflections with others, possibly on the online platform or on the training day the participants get the chance to put their barriers in the "spotlight" and overcome them.

Figure 5.2.1, Overview defining steps concept

Lastly, abstracted from the idea "fly on the wall" the participants can read the reflections of others to see how they deal with or perceive certain situations. The intention is to help them place their view in perspective and to learn from each other. This is partly in line with the findings of the literature in chapter 2.4, indicating a need to be in contact with other participants.

5.2.2 The position in the online environment

At this point in the project the idea was to let the concept be a part of the introduction of the tile about intimacy and sexuality (see chapter 2.4 for the whole overview of tiles within Moodle). The exercise should serve as a warming up to create awareness about the subject before starting with the theoretical part. With the development of the concept this position in the online learning environment is changed to the general introduction. An elaboration on this choice can be found in chapter 6.1.

5.3 Co-creation session two

The aim of this second Co-creation session with the panelists of the GPS project is to collect feedback on the chosen focus (see chapter 4.1) and the promising direction for the concept (see chapter 5.2).

5.3.1 Goal and set up

Nine panel members were present at this session. The session consisted of a presentation, an exercise and a discussion. The aim of the presentation was to inform the panel on the path chosen and present a more explicit example of the focus to make it concrete and possible to respond. The example showed a short audio fragment of one of the conducted interviews. In the fragment, multiple barriers that can be encountered and withhold nurses and CNS from discussing intimacy and sexuality were mentioned. These barriers included, having limited time and not feeling in charge when a doctor is present.

Based on this audio fragment, an exercise was given. Three questions were asked to identify their reaction and test a part of the focus and the chosen direction.

The panel was asked to first write their answers down on post-it's (see figure 5.3.1) to let them all have their own experience. Later, the discussion started by sharing what the panel members had written down.

The given questions and accompanying goal:

Q1. What does this fragment do to you? – *Getting a grasp of their first feeling / impression of hearing such barrier*

Q2. How would you act in this situation? – *See how they would respond on a given situation*

Q3. What is it like to reflect on this? – *Letting them think about what their own abilities and skills are and identify how they feel about this*

Figure 5.3.1, Answers from panel on post-its

5.3.2 Feedback from the panel + Interpretation

Question 1. First impression: All answers about the fragment were focused on the context of the outlined situation. Therefore, feeling what this fragment did to them personally was not addressed. Mentioning what in this situation was lacking for them and naming the barriers stood central in their answers. Next to that many questions arose concerning the specifics of the context and the behavior of the people mentioned in the audio fragment. Recognition

Question 2. How to act: They all responded with a plan of action. This shows that they all actively searched for a solution to help the patient and that they have no problems relating to a described situation. Action

Question 3. Reflect on: A part of the participants mentioned that they had too little information about the context to properly reflect. Nevertheless, others mentioned that they became more aware of the situation and signals of the patient and therefore saw more chances to provide support. They also valued having this realization of being more aware. This awareness consists of the realization that they are already doing a good job, have the right knowledge, courage and/or do not want to leave the patient behind with unanswered questions. Realization

5.3.3 To conclude

What became clear, as well as in the discussion as from the answers written on the post-it's, the panel members could **extract the multiple barriers**. Nevertheless, answering the first question as stated above did not lead to describing their own feelings towards the situation on the audio fragment. The panel members **dive directly into the context** and have many questions to make it more specific. Attention should be given in formulating questions when this is not the desired outcome. From the second question it appears that they have no difficulties in **formulating a plan of action.** This is an interesting quality that could be used for the concept. Next to that, letting the panelists realize and formulate what they could do in a similar situation led to a **positive experience of their own capabilities.**

5.4 Co-creation session three

This Co-creation session had a different set up than the two prior to this chapter. Where the others were in a live setting with multiple panelists and organized by the GPS project, this one was online, with one nurse and one CNS and it was organized for this project. The input of the target group is of great importance, therefore the idea for the concept has been presented to them. Their feedback and thoughts concerning this concept direction will be presented in this chapter.

5.4.1 Goal of the session

The goal of the session is to gather feedback from the target group on the concept direction. Next to that, the aim is to collect their thoughts and discuss multiple possibilities solutions/ideas to allign the concept along with their values to make sure it best fits their wishes and needs.

5.4.2 Set up

The session was executed online via Zoom (Video Conferencing, Cloud Phone, Webinars, Chat, Virtual Events | Zoom, 2022) and use have been made of a miro board (The Visual Collaboration Platform for Every Team | Miro, 2022) in order to show the idea in a schematic overview (see figure 5.4.1) and to collect notes.

The following questions were used to start the evaluation:

- *What tips the balance within the interaction?*
- *What interaction would you like to have with it? (Think about interactions like: active, passive, layback, game element / competition etc.)*
- *Which form suits the idea?*
- *How is the idea of sharing reflections?*
- *What questions to reflect would be suitable?*
- *What is the impression of listening to an audio fragment?*

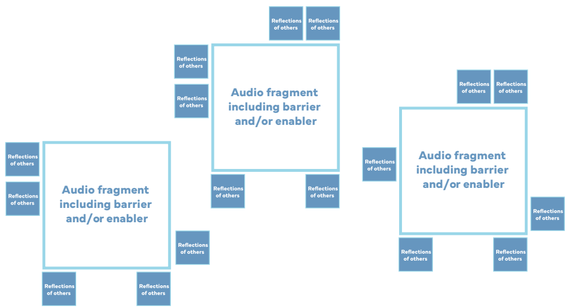


Figure 5.4.1, Schematic overview of the idea presented to the participants

5.4.3 Outcomes

When the concept direction was discussed, it became clear that in this introduction the reason for following this training must stand out. Moreover, the participants mentioned that for them the purpose of the steps to be followed must be clear. It will be more likely for them to finish this introduction completely. Next to that, mentioning that its purpose is to create awareness and addressing that the reflection of the participants is valuable to others and that no answer is wrong could contribute to let them feel at ease and motivated.
For the reflections they indicated that it should be accessible, the idea of writing a reflection made them wary of assignments that take a lot of time and where they feel that they have to write an entire essay. For the questions themselves they advised to formulate them properly, it should not make them feel hurtful, even with the best of intentions.

For the questions, the participants made suggestions: “Do you recognize yourself in this”, “What is my perspective on this”, “Do I want this to change or is it oke like this”. Showing multiple fragments with experiences could help to see with whom you can identify. It would also be a good addition to let the fragments connect to the theory that will be addressed in the course. To create the right mindset, the audio fragments with experiences need to have a proper introduction that explains the context. The participants also mentioned that they would like to have the overview of how far they are in the experience.

Their feedback for the audio fragment included that when they are staged, it is important to make it as real as possible, they got the creeps of obviously fake fragments. They liked the form of the fragment being audio, they mentioned that it is easier to draw it to your own setting.

Lastly, they advised to make the visualization appealing by using humor, which came also forward during the interviews. During the conversation the idea of showing little people swimming naked in the sea of experiences was born. Showing the diversity of all these different people could also be a way to take cultural diversity more into account.

DESIGN PHASE - deliver

Deliver, this is the last phase of the second diamond where all the ideas and input from the development phase is converged into a concept. The development of the concept in all its details will be described in chapter 6.1 accompanied with the presentation of the final concept in chapter 6.2.

6.1 Development of the concept

The idea direction chosen in chapter 5.1 is gradually developed through the input of the Co-creation sessions. In this chapter the developed idea will be explained and elaborated on each aspect.

6.1.1 The idea

The concept is based on the idea that the participants can learn from each other's experiences, relate it to their own life and reflect on that. The several steps make the experience richer. They share their reflections with others to learn from each other but they are also taking time to stand still and look at what this means to them professionally or even personally. This idea that has been abstracted from "the pond of experiences" of the Creative session (see chapter 5.1) still takes place underwater and is called: "The Sea of Experiences".

To understand all the steps of the concept, figure 6.1.1 can be seen to support the following paragraphs in their explanation.

Overview steps
In figure 6.1.1, a schematic overview can be seen of all the different steps of the concept, to begin with the introduction.

1. The introduction explains the purpose of this concept and introduces the user to the "The sea of experiences".

2. "The sea of experiences" is shown and the user can click one of five experiences.

3. The context of the experience is presented to introduce the experience fragment.

4. The user can play the fragment and the experience will close again.

5. A pop-up will show a question to reflect on the fragment and the users own experience.

6. After filling out the question the reflection of others will appear

7. Reading the reflections of others will provide insights for the rest of the training

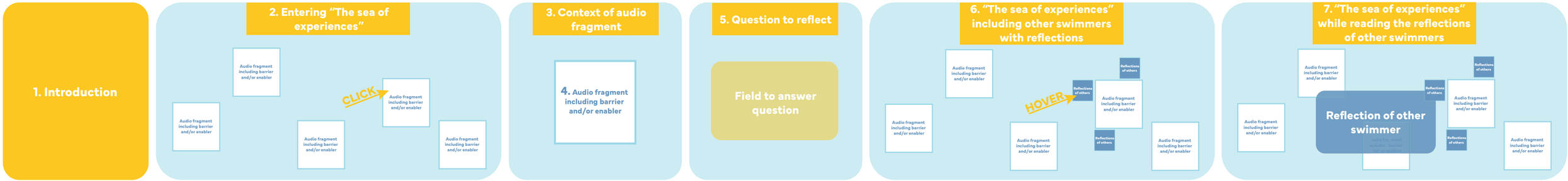


Figure 6.1.1, Overview steps in concept

6.1.2 Placement of the concept

First, the concept was meant as the introduction of the tile of Intimacy and sexuality (see chapter 3.4). However, sensitizing the participants with this exercise suits the general introduction better as it is beneficial for the participants to go through the whole training with this particular mindset. Together with the GPS project team it is decided to generalize certain texts and fragments so that they can also be applied to psychosocial needs as well as for intimacy and sexuality. As the project is merely based on intimacy and sexuality, four out of five audio fragments (see paragraph 6.1.5) will be based on these subjects and one is specifically focused on psychosocial needs.

6.1.3 Introduction text

With the introduction text, the user will be introduced to the "sea of experiences" and informed about the goal of the exercise. This is done in a direct and personal style of writing to address the users personally. During Co-creation three the participants explicitly mentioned that they want to be informed about the purpose and what is done with their input. The Introduction text can be found in appendix H.

"Dive into the sea of experiences"

6.1.4 Context text

During Co-creation session two and three, it became clear that many questions arose after listening to the audio fragment. Therefore, an introduction for the audio fragment is added which explains the context. Together with two members of the GPS project, iterations are made to find the right words to introduce the different experience stories. The context text can be found in appendix H. Attention has been paid to the accessibility of the text. Words such as hospital or oncology department have been deliberately avoided to ensure that healthcare specialists who work in a different field can also relate and feel addressed.

6.1.5 Experience audio fragments

The form of an audio fragment is chosen for sharing the experience stories. During Co-creation three was found that audio makes it possible to relate to the speaker and that it is easier to adapt it to your own situation, easier that seeing a video which takes away the imagination. When going through the online learning environment, participants have to watch lectures which also include audio. Therefore no problems are foreseen when using this media since the participants already have to be in a setting where it is possible to listen to sound.

Choosing the fragments is done by picking parts of the conducted interviews (see chapter 3.3) and composing them into experience stories that relate to the theory of the online learning environment. Another criteria was that the questions asked based on this story need to be suitable for reflection. Five fragments are chosen to use in this concept. The text of the fragments can be found in appendix H together with an elaboration on the topics that they address.

The fragments come forth from the interviews. Nevertheless, it is counterfeit. To make it sound as real as possible, the fragments are recorded with three actors. To bring in some diversity, one male and two female voices are used to record the five fragments.

6.1.6 Reflection questions

Based on the feedback from Co-creation three and iterations made with the GPS project members, the reflection questions are formulated and can be found in appendix H. The aim is to let the users think about their position towards discussing intimacy and sexuality with patients and whether or not this is their desired position.

During Co-creation three, it was indicated that answering the questions should be easy accessible. This will make it more likely that the participants will answer them. In a time where we constantly react to each other online, with placing comments on social media, typing seems the right choice for the form of the reflection. During the process of developing the concept other possibilities have been put forward. For example, making an audio recording. However, recording is a whole other interaction, where a silent room is preferrable, anonymity is partly lost and a microphone is needed.

There were several options to give substance to what will be done with the answers. Initially, they would be added to the total overview of reflections to complement the "sea" and give a full picture of all the ideas and thoughts on the different topics brought up in the audio fragments. However, this can not be done automatically by the program in which it is made, Articulate 360. Therefore a member of the GPS project needs to add them by hand. The question is whether this will also happen in practice. The advantage is that the reflections that add the most insights can be selected by a "gatekeeper", so that the sea will not have a repetition of similar reflections. In addition, a plan has been made that the trainer of the physical training day will use the answers as input for the training day. Formulating the questions has also been into consultation with the trainer to ensure the questions are suitable for this purpose. Therefore, the answers need to be saved in Moodle. The concept will benefit from users being informed of the purpose of their responses because this will encourage them to complete the entire exercise and they will be aware of how their responses affect the physical training day.

6.1.7 Reflections to broaden the perspective

After answering the questions, the participants can read the reflections of other people to see how they deal with certain situations and learn from each other. Another point of the reflections is to show the users that there is no "one-way" to solve a problem or act upon a situation. In the first place it is chosen to put these general reflections together based on the research of the project, literature and the gathered knowledge of the GPS project. The writing style should resemble how an individual would write a reflection or answer the question themself. As mentioned in the last paragraph (6.1.1), these reflections can also be manually replaced by real answers of participants to make them more diverse and complete. An overview of the composite reflections can be found in appendix H.

6.1.8 Form and style

For the form has been decided to stay close to the idea of fishing in a pond. Nevertheless, it is chosen to shape it a little bit more to the subject, intimacy and sexuality. Therefore, the pond changed into a sea and the experiences were given the shape of an oyster. It is like listening to a shell, but this shell can open up for you and will show its pearl. The pearl stands for the experience of someone which is valuable for others. For the reflections is chosen to visualize them with a diverse pallet of naked people swimming around the oysters. They are searching for oysters but also for each other inorder to exchange insights. As mentioned in chapter 5.4 the naked human figures came forth from Co-creation three, with the desire to make it more fun and break the ice. Next to that they stand for literally exposing yourself. The sea therefore has to be a serene place in which the users feel at ease and open up.

The GPS project team had an illustration made (see figure 6.1.2) to use for the online learning environment. In this illustration an older couple can be seen, they are holding each other in a loving and intimate way. The illustration is based on an existing couple from which the male suffered from cancer and his wife was supporting him till the end of his life. They found a way to maintain their intimate relationship by good support of the healthcare professionals.

The style suits the topic and the concept and to keep coherence in the whole online learning environment this illustration will be the main input for the illustrations of the sea, oyster with pearl and the swimming human figures.

Ingena Visser, MSc Educational Advisor & Art Educator works for the Amsterdam UMC. She will make all illustrations needed for the online learning environment and therefore also the illustrations for the concept. A moodboard (see figure 6.1.6) was made to help her in making the desired illustration.

The Illustrations Visser made for the concept can be seen in the next chapter where the final design is presented (chapter 6.2).

Figure 6.1.2, Theme illustration GPS Project

Figure 6.1.3, Moodboard for illustrations

6.1.9 Building the concept

As mentioned in chapter 2.4, it was chosen to make use of Moodle as the online learning environment platform, meaning that the concept needs to be implemented in this program. The technical possibilities in Moodle are not sufficient to build the concept. Therefore, Articulate 360 - Storyline is used to build “The sea of experiences”. This program makes use of different layers to which interactions can be added.

Anika Willemsen, MA MSc. Educational advisor, at Amsterdam UMC is involved in the development of the online learning environment. She was closely involved in exploring the possibilities of Moodle and Articulate 360 – Storyline to verify if the concept could be built. Multiple iterations are made which have led to the concept in chapter 6.2. However, not all technical applications of the concept have been applied yet. The option to save the answers of the participants and several use cues are still missing. The possibility is there. However, the application requires more time than the project allows. Adding these last iterations will be part of the recommendations (see chapter 8.3).

6.2 Dive into “The sea of experiences”

In this chapter the final concept will be shown in all its details, the appearance but also the interaction in the online environment. Or click on “Start” at the previous page.

The start of the experience
“The sea of experiences” starts with an introduction which explains the purpose of the exercise to the user and finishes by clicking on the oyster which says “Start”.

Arriving in the sea with oysters
Secondly the user arrives in a serene environment of a sea with five closed oysters.

Opening an oyster
By clicking on one of the oysters, the oyster will open up and show a pearl. By clicking on the pearl, an audio fragment will play. Next to the opened oyster, a text appears, which gives an explanation of the context of the audio fragment to prepare the user for what is coming before listening to the pearl. The audio fragment tells an experience of a healthcare specialist addressing multiple barriers and/or enablers concerning discussing intimacy and sexuality with patients. After listening to the audio fragment the user can click on the cross and will return to the sea.

Swimmer
By returning to the sea the user will see the opened oyster and a little swimmer will appear which swims towards the oyster.

Reflective question
Clicking on the swimmer will open another pop-up, which shows a question based on the audio fragment. The user can answer this question in the designated text field and can close the assignment by clicking on the button which says “verder”.

Other swimmers
When the pop-up closes, other swimmers will appear and gather around the oyster.

Reflections of other swimmers
When hovering over the other swimmers, their answers to the question asked will appear in a textbox to inspire and support the thoughts of the user.

Explore
As the journey continues the user can open all oysters with their different experiences and questions to reflect, until every oyster is open. Then they can continue with the online learning.

CONCEPT EVALUATION

In the following chapter the concept will be verified based on an evaluation with the target group to find out to what extent the concept succeeded in its initial goal.

7.1 Evaluation of the concept with the target group

An evaluation with the target group is conducted, to find out to what extent the concept connects to the target group, is clear in use and reaches the initial goal.

7.1.1 Set up

Since the concept is in an online environment, the evaluation of the concept is executed online. Via Zoom the evaluation is hosted. The link to the concept is shared by using the chat function so that the participants can go through the concept.The screen sharing option gives the opportunity to follow the participants' doings. Next to that, they are asked to 'think aloud', a method that supports gaining insight into the thoughts of participants. A brief overview of the GPS project, training, and learning environment is provided so that participants can understand in which context the concept is placed. After experiencing the concept, multiple questions are asked. Unlike the previous Co-creation sessions, this evaluation is done individually, so that the participants can not influence each other's answers.

The questions that will be asked are formulated in order to verify the concept connects to the target group, is clear in use and if the project goal and accompanying focus is reached.

PROJECT GOAL

*"To effectuate **awareness** among nurses and contribute to a **better understanding** of the patient's needs and questions about **intimacy** and **sexuality** in this important phase of the end-of-life. The online learning environment forms the base of their training in order to develop **conversation skills** and should be **engaging**, **inspiring** and **effective.**"*

FOCUS

"Engage** and **inspire** nurses for the online training about discussing **intimacy** and **sexuality** with patients by creating **awareness** on **existing barriers** and **empowering** them through their **individual enablers."

The following questions are formulated:

- *What is your first impression of the sea of experiences?*
- *How did you experience navigating through the concept?*
- *How did you experience listening to the audio fragments?*
- *How did you experience answering the reflection questions?*
- *How did you experience reading the reflections of others?*
- *How has this affected your approach for the rest of the training?*

7.1.2 Participants

Evaluation of the concept is done with three participants. The participants are selected on the criteria that they are working as a nurse or CNS, that they have no prior knowledge of this project and are going to follow the GPS training. Subsequently, the participants were all working in a hospital that is affiliated with the GPS project.

7.1.3 Outcomes evaluation

What is your first impression of the sea of experiences?
The first impression of the participants was good. They all reacted enthusiastically and mentioned that the appearance of the sea really appealed to them because of its accessibility and balance between playfulness and beauty. Next to that, they found the introduction text inviting and fun. One participant indicated that the introduction triggered to discover more.

"I'm a visual thinker so I think it's nice that these little people swim by."

How did you experience navigating through the concept?
As expected, due to the missing use cues, two out of three participants had difficulties with navigating through the sea. It was not clear to them they had to click on the oysters and the pink swimmer to go to the next screen. Once they knew where to start, they experienced it as intuitive. One participant mentioned that it is actually appropriate that not everything is totally explained because that also fits with the subject of discussing intimacy and sexuality. Nonetheless, it is important that everyone understands and can navigate through the environment. Discovered is that on many fixed work computers the sound of the fragments was not loud enough. This made it hard to listen to the fragments. Furthermore, hovering over the diverse swimmers is possible on an Ipad but does not works intuitive since a finger has to touch the screen.

How did you experience listening to the audio fragments?
All participants found it interesting to listen to the audio fragments. Two participants mentioned that the fragments help as preparation for the questions. One participant mentioned that one fragment raised questions that differed from the question asked.

"Listening to this fragment made me realize there is also a need for intimacy in palliative care."

How did you experience answering the reflection questions?
All participants stated that answering the questions encouraged them to think carefully about how talking about intimacy and sexuality works for them. Next to that they realized that they never thought of this before. They mentioned finding it valuable to think about. Nevertheless, one participant mentioned that describing feelings was difficult. The other two had no trouble formulating an answer right away.

"I'd never thought of it that way before. It's strange that you know the answer right away."

How did you experience reading the reflections of others?
One participant immediately noted that the text of the other swimmers were answers of other people. Also the other two participants figured it out after reading the text. A participant pointed out finding it very pleasant to read them. Reading them after answering the reflective question made the participant think about their own position even more. Another participant mentioned that one text of a swimmer did not seamlessly connect to the question asked. Overall the reflections were considered a valuable addition in the step towards awareness.

"It does give a good feeling. Noticing you are not the only one who finds it difficult to discuss or keep a conversation going makes it a bit easier."

How has this affected your approach for the rest of the training?
The three participants agreed that the exercise made them aware of the importance of the topic which helped them to understand the patients needs. Already going over the several topics is beneficial because this no longer has to be done during the theory. Next to that, they mentioned that they would be more receptive to certain topics addressed in the theory of the course.

"This struck me as being significant! Consequently, that also alters the way I perceive the theory."

Other comments from the evaluation
Two of the participants agreed upon informing the users on what is done with their answers. Telling the answers will be used as input for the training day would contribute as they know they have influence and the training will meet their needs. Furthermore, the environment was well received as it turns the participants right on. The alternation between the various components was experienced as innovative, pleasant and dynamic. They felt engaged and inspired for the rest of the training.

"The environment gave me a safe feeling and I think it is a beautiful idea of oysters opening up, just like people."

"I think this assignment is good to get myself an overview of what I need."

DISCUSSION

In this part, attention will be given to the following topics for the completion of the project: 1) Conclusion, 2) limitations of the research, 3) recommendations concerning the concept and process and 4) a personal reflection on the project, process and concept.

8.1 Conclusion

By designing an online experience an attempt has been made to create awareness among nurses and CNS for the topic: discussing intimacy and sexuality with patients with incurable cancer. "The sea of experiences" is the result of the project "Supporting nurses to discuss intimacy and sexuality with patients with incurable cancer".

As the project tries to reach the project goal and focus, research is conducted. Literature and online information on the topic has been consulted which showed that discussing intimacy and sexuality with patients with incurable cancer is not an unknown subject in literature and online information is abundant. Nevertheless, there are still many barriers to overcome for healthcare specialists. Co-creation sessions and interviews with the target group showed that many of the issues addressed in literature concerning discussing this topic are similar. However, no unequivocal solution has been found for these issues.

In search for a solution to overcome these barriers multiple Co-creations and a Creative session have been held. Putting these barriers in the spotlight and simultaneously highlighting the enablers which help healthcare professionals in having these conversations is the chosen concept direction. This direction has led to "The sea of experiences" an exercise based on the individual, a quest for one's own path. "The sea of experiences" has been evaluated by the target group on how well the concept matches with the design goal and focus and to point out further recommendations.

As a result of the evaluation, the participants indicated, becoming more aware of the importance of discussing **intimacy** and **sexuality** and the **needs of patients**. In addition, they felt more **engaged** towards the rest of the online learning environment and were **inspired** to be more thoughtful about the topic. As the participants did not go through the actual online learning environ-

PROJECT GOAL

*"To effectuate **awareness** among nurses and contribute to a **better understanding** of the patient's needs and questions about **intimacy** and **sexuality** in this important phase of the end-of-life. The online learning environment forms the base of their training in order to develop **conversation skills** and should be **engaging**, **inspiring** and **effective.**"*

FOCUS

"Engage** and **inspire** nurses for the online training about discussing **intimacy** and **sexuality** with patients by creating **awareness** on **existing barriers** and **empowering** them through their **individual enablers."

ment it can not be determined whether the concept is **effective.** However, the prospects look good as all of the participants stated they were more motivated to go through the rest of the training. The **individual enablers** in the audio fragments were used to empower the users. The participants mentioned to be supported by reading the reflections of the other swimmers. Nevertheless, whether the participants felt **empowered** stays unclear.

Concluding, “The sea of experiences” reached its goal partly, as the essence of the project goal and accompanying focus corresponds to the experience of the participants. Further research should indicate if next to being **aware**, feeling **engaged** and **inspired**, the users will also feel empowered to have conversations about intimacy and sexuality with patients with incurable cancer.

8.2 Limitations

A few limitations are encountered during the research which may have influenced the outcome of the project. They will be addressed in this chapter.

8.2.1 Participants interview

Five out of six people who participated in the interviews were involved in the GPS project. This indicates that they are engaged and most likely find the topic important. However, it should be considered that not all nurses and CNS are interested or willing to discuss this topic. It could be that interviewing people outside the project lead to different outcomes and thus to a different design.

Next to that, the people who took part in the GPS Co-creation sessions during the project and were available to approach for an interview happened to be all women. Male participants may have a different perspective on the subject. It would be valuable to let this group participate when further research is done.

8.2.2 Testing in online learning environment

Through the use of the try-out website, the concept was tested for review. A greater understanding of the location and purpose of the concept, and consequently different outcomes, could result from having the overview and testing it in the context of the rest of the online learning environment.

8.3 Recommendations

Since there is always potential for improvement, in this chapter recommendations will be given concerning the concept, the coherence with rest of training and process.

8.3.1 The concept

The current concept does not yet inform the users that they are starting an exercise of approximately ten minutes. It is recommended that this information will be added as the panelists and interviewees have indicated that they appreciate it to be informed on what is coming and how much time it is going to cost. A suitable place for this information would be on the Moodle page right before the user will see the start screen of the "The sea of experiences". Additionally, the user should also be informed about the destination and purpose of the answers given in the exercise, as they are used as input for the physical training day. The option to save the answers must still be applied to the concept when it will be used in the online learning environment. Furthermore, the concept can also be used on a tablet or smartphone. Nevertheless this works not ideal as the hover function is not entirely straightforward and the text will be small. Therefore, it is recommended that the users will be informed to do the exercise on a PC or laptop.

For the current concept is chosen to use audio to transfer the experience stories. Although this choice is substantiated and also came out well in the evaluation, this could not be the ideal option for people with poor auditory memory. Other options should be explored and tested to see if there is a better way of transferring the message.

The evaluation showed that the different participants had different ideas about what question they found logical after one of the audio fragments. Therefore, it is recommended to do another evaluation focused on the audio fragments, reflective question and answers of other swimmers with more people to filter out the ambiguities and see how different people interpret them.

Furthermore, there are a few practical things that need to be adjusted or added. This includes, 1) replacing the images with more diverse swimmers, 2) replacing the standard text boxes with images in the same style as the sea, 3) adding a button with which the user can pause the audio fragments, 4) adding usecues when the user needs to press on the oyster and swimmer for the first time and 5) adjusting the standard volume of the audio fragments to a higher level.

8.3.2 Coherence with rest of training

The style of the concept which is based on the course image (see chapter FIXME) has been well received by the target group. As the concept is part of the online learning environment, the advice would be to use images in the same style for all the different parts of the training to create a unified totality. This includes the images on the slides of the mini lectures, the case descriptions and other images used in the online environment.

8.3.3 Process

Next to hospitals, the GPS project works together with homecare facilities. Despite the fact that contact has been made with the homecare facility, they did not participate in any of the research activities. Their view on the topic would have been a great addition to the concept. It would be beneficial to take their vision into account while the concept is optimized.

As it was not entirely clear if the participants felt **empowered** as stated in the focus, after going through "The sea of experiences", it is wise to conduct another evaluation. Also, the predictions about their approach for the rest of the training should be verified. It is recommended to do this second evaluation by going through the whole online learning environment so that they have the complete experience.

8.4 Personal reflection

In this chapter a personal reflection on the project, process and concept will be given. Since it is my own reflection, this section will be written from the first perspective.

8.4.1 Reflection on project

When I first heard about the project I was immediately intrigued. Besides the subject matched my interests for healthcare, intimate relations, and the end of life, it also had something very vulnerable and valuable. Paying attention to a subject that is so underexposed really appealed to me.

The GPS project is in my eyes a beautiful collaboration between all involved parties. Working together to advance each other is a great concept and contributing to this is of great value to me. At first, I thought everything was already done and set concerning the training. In practice, I noticed that everybody was still searching for a way in which they could contribute. This gave me more room to take my space as designer and contribute to a pleasant online learning environment.

At the start of the project the directions for designing a concept were still very broad. During the research phase I choose to focus on one part of the online learning environment instead of a concept / learning path that encompasses the entire online learning environment. I kept the bigger picture in mind by preparing the users for the online training with the current concept. Formulating a vision helped me personally to keep seeing the online learning environment as a whole. However, this vision did not directly contribute to the concept and therefore cannot be found in the report.

A reason for the project being so broad is that it has multiple stakeholders / target groups. Discussing intimacy and sexuality with patients with incurable cancer is in the first place the most important for the patients. However, placing this subject in a training program, askes for a completely different target group, nurses and CNS. The project being so broad gave me the freedom to choose and explore different angles. I choose to find out more about this last target group. I am glad I choose this group as main input for the concept and speaking to them was of great value to me personally. If I would redo the project, I would also be very interested to get in contact with the people it is all about, the patients.

8.4.2 Reflection on process

My intention was to emphasize on the conceptualization. In the end, however, much more time was spent on research. I am still amazed at how this could have happened. In retrospect, I do not mind, because I had the idea that I first had to gather more of information before I could get started with the conceptualization. Even though the time spend, I could have made the research more specific. In the project, there is not always a dividing line between patients, patients with cancer and patients with incurable cancer. Considering the time for the project I am not disappointed in the result, but I am aware that some aspects of the project could be specified or elaborated on even more. The same applies for the chapter about intimacy and sexuality, which deserved much more attention since those are the main concepts of the project.

Furthermore, the planned activities always turned out well, with recruiting participants in time to let it all fit together. Also, the two Co-creation sessions were, not totally coincidental, at a right moment during my project.

To conclude, the process went well, and I am content with the with the milestones that have been reached. Having more time during the defining phase of the concept would have been even more pleasant since one of my goals for this project was to learn and explore more about programs like Adobe and in this particular case, Articulate 360 – Storyline.

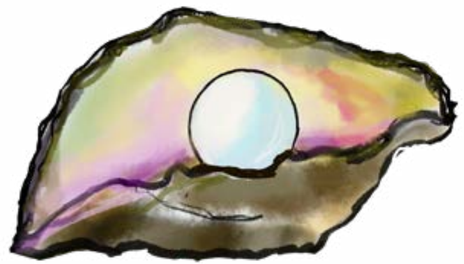
8.4.3 Reflection on concept

During my last day in Amsterdam at the medical faculty, before rounding of the project I spoke to one of the members of the GPS project which had been on a sabbatical for a few months. This were exactly the moths in which I joined the GPS project. When I showed her the concept, she said that this was exactly covering the message she had in mind when attending the Co-creation sessions. This was a great compliment for me and makes me prouder and more certain about what I made. Also, for the concept is still room for improvement, as well for the content as the appearance. Nevertheless, the idea of a personal approach is good and innovative and might be a new direction for other online learning environments.

8.4.4 Personal reflection

I had to get used to being an expert in my own field. I learned a lot during this project, especially about how to interact with other people. This applies to communicating with my coaches as with a group. Although it was very easy for me to create a pleasant and safe atmosphere during the interviews, this was more difficult while standing in front of a group. I encountered this during Co-creation session two. I can work on letting my expectations be and just be in the moment so that a change of outcome will not influence my appearance for the participants. In this way I can give people the feeling their input is good (which it was) instead making them feel confused.

It was great to work in a team like the GPS project, where I had all contacts at my disposal. Maybe because of that I have the feeling the project went quite smooth. In addition, bringing the technical people from the Amsterdam UMC together to work on the concept was a great experience.



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APPENDIX

10

A : Overview online information
B : List interview questions
C : Interview invitation
D : Concent form
E : Concept cards
F : Notes Co-creation session one
G : Creative session ideas
H : Text concept
I : Answers research questions interview
J : Design brief

Appendix A : Overview online information

Zorg voor beter	*https://www.zorgvoorbeter.nl/seksualiteit*
Seks in de praktijk - Rutgers	*https://seksindepraktijk.nl/*
Pfizer - Roze olifant	*https://www.pfizer.nl/roze-olifant*
Seksualiteit - Rutgers	*https://seksualiteit.nl/onderwerpen/ziekten-en-beperking/lichamelijke-ongemakken/*
Seksualiteit en intimiteit ten tijde van ziekte	*https://sickandsex.nl/*
nfk nedelandse federatie van kankerpatienten organisaties	*https://nfk.nl/themas/kanker-en-seks*
er is iets groots, iets wilds en rustigs gaande	*https://www.adwindekluyver.nl/erisietsgroots*
Nederlandse wetenschappelijke vereniging voor seksuologie	*https://www.nvvs.info*
Nederlands Huisartsen Genootschap	*https://www.thuisarts.nl*
Platform over seksualiteit bij gynaecologische kanker	*https://olijf.nl/leven-met-kanker/seksualiteit*
venvn	*https://www.venvn.nl/media/tmeewxjl/richtlijn-veranderende-seksuele-gezondheid-def.pdf*
Pfizer - Prostaatkanker stichting	*https://prostaatkankerstichting.nl/wp-content/uploads/2020/08/Web_Folder_Seksualiteit_PKS-1.pdf*
kanker .nl	*https://www.kanker.nl/gevolgen-van-kanker/seksualiteit-bij-kanker/algemeen/in-gesprek-met-je-arts-over-seksualiteit*

kwf	*https://www.kwf.nl/kanker/gevolgen-van-kanker/kanker-en-je-relatie*
hogeschool utrecht	*https://www.hu.nl/onderzoek/projecten/praten-over-intimiteit-en-seksualiteit-met-oncologiepatienten*
radboud umc	*https://www.radboudumc.nl/centrum-voor-oncologie/gps*
medische oncologie	*https://medischeoncologie.nl/jaargangen/2021/6-aug/elke-kankerpatient-ervaart-problemen-bij-seksualiteit-en-intimiteit.html*
Nursing	*https://www.nursing.nl/zo-ga-je-het-gesprek-aan-over-seksualiteit-stepped-skills-model-1439376w/*
OOK optimale ondersteuning bij kanker	*https://netwerkpalliatievezorg.nl/Portals/64/documenten/2019/kanker%20en%20seksualiteit%20januari%202019%20palliatieve%20zorg.pdf*
kennislink	*https://www.nemokennislink.nl/publicaties/artsen-praten-niet-graag-over-seks/*
borstkanker vereniging	*https://www.borstkanker.nl/leven-met-borstkanker/late-gevolgen/seksualiteit-en-intimiteit*
Podcast de herontdekking van haarzelf	*https://soundcloud.com/herontdekkingvanhaarzelf*
Gycon - intimiteit en seksualiteit bij borstkanker	*https://www.zgt.nl/media/20048/presentatie-intimiteit-en-seksualiteit-bij-borstkanker.pdf*
Medisch centrum leeuwarden	*https://www.mcl.nl/aandoeningen-en-behandelingen/aandoeningen/borstkanker/seksualiteit-en-intimiteit*

Imeldaziekenhuis	*https://www.imelda.be/sites/default/files/uploads/Flipbooks/GK5/kanker-seksualiteit/files/assets/common/downloads/Kanker%20en%20seksualiteit.pdf?uni=7a9a54c06c978f8e09c2b1ce06118db6*
NET-groep podcast	*https://www.net-kanker.nl/seksualiteit_intimiteit_en_kanker.html*
NTVO kanker en seksualiteit	*https://www.ariez.nl/wp-content/uploads/2018/12/NTVO8_2018_Art._Segeren-2.pdf*
Thema-avond 'Omgaan met kanker: (sociale) relaties en seksualiteit' voor AYA's	*https://www.umcg.nl/NL/UMCG/Agenda/Evenementen/Paginas/aya-omgaan-met-kanker.aspx*
Isala patient informatie, lezing praten over seksualiteit en intimiteit	*https://www.youtube.com/watch?v=sK6--Qe2zsQ*
Elkerliek ziekenhuis - mens tot mens	*https://www.elkerliek.nl/elkerliek/documenten/patientenfolders-vanuit-brochuremaker/50949.pdf*
mens-en-gezondheid-infonu	*https://mens-en-gezondheid.infonu.nl/relatie-en-huwelijk/182021-kanker-en-seksualiteit-het-taboe-doorbreken.html*
AYA zorgnetwerk	*https://ayazorgnetwerk.nl/nieuws/praten-over-seksualiteit-en-intimiteit-met-ayas-hoe-doe-je-dat/*
Hematon	*https://www.hematon.nl/thema-s/kanker-en-seksualiteit*
etz buitengewoon	*https://www.etz.nl/ETZWebsite/files/91/910347c4-aacf-42f4-9fc8-9f96fffa4b02.pdf*
Boek over seksualiteit en kanker	*http://www.kankerenseksualiteit.nl/index.html*

KWF kankerbestrijding	*https://stichtingnooitalleen.nl/wp-content/uploads/2016/10/brochure-kanker-seksualiteit.pdf*
Noordwest oncologisch centrum	*https://oncologie.nwz.nl/Voor-pati%C3%ABnten/Medische-informatie/Behandelingen/Behandeling/tid/649*
tergooimc	*https://www.tergooi.nl/tergooiers-petri-oost/*
KWF	*https://www.kwf.nl/help-mee/fietsen/alpe-dhuzes/seksuele-revalidatie-na-gynaecologische-kanker*
De bespreekkamer podcast	*spotify*
Sick&Sex - Kanker en intimiteit	*https://player.hihaho.com/81D27369-528F-4C84-A976-16DE-7DE4F4EA*
de herontdekking van haarzelf	*https://www.deherontdekkingvanhaarzelf.nl/*
hartelust sick and sex	*https://open.spotify.com/show/4Ihgp5DkqS8Svru0arPOnR?si=G3eMs-77QPOxu822mxkl6A&utm_source=copy-link&nd=1*

Appendix B : List interview questions

Richtlijn interview vragen:

Waar gaan we het over hebben: Achtergrond, tijdlijn positieve en negatieve ervaring, ervaring scholing tools

Deel 1:
- Kun je vertellen over je achtergrond, opleiding, leeftijd, hoeveel jaar al aan het werk als verpleegkundige?
- Wat betekent intimiteit en seksualiteit voor jou?
- Waar zitten voor jou de verschillen (voor het bespreekbaar maken)?

Deel 2:
Aan de hand van tijdlijn - emotie stickers plakken
- Hoe zag het er uit, context?
- Wie waren er bij? Hoe was dit?
- Wat is jouw ervaring met familieleden of partner van de patiënt bij het gesprek betrekken?
- Hoe reageerde de patiënt op dit gesprek?

- Wat ging eraan vooraf? Timing / moment ziekte
- Hoe signaleerde jij het problemen / de behoefte aan een gesprek / opheldering bij de patiënt?
- Wat zou jou weerhouden / aansporen om een gesprek over intimiteit en seksualiteit te openen?
- Wat was voor jou het belang om dit gesprek te voeren?

- Hoe ga jij om met patiënten die moeite hebben met het bespreken van IS?
- Welke handvatten mis je in zo'n situatie?
- Elke patient is anders. Hoe ga je om met grote verschillen tussen mensen? Culturele diversiteit. (Waarden & normen, overtuigingen en gedrag)

- Wat gebeurde er daarna?
- Wat heeft dit voor uitwerking op jou?
- Wat denk je dat dit voor uitwerking heeft gehad op de patiënt (en naasten)?

- Hoe heb je vertrouwen gekregen in IS bespreekbaar maken? Of waar zitten de knelpunten?
- Bepaalde manier of gewoonte ontwikkeld gaandeweg?
- Hoe zou je het graag willen zien? Droams

Emotie stickers bespreken gedurende alle vragen

Deel 3:

Gebruik je bepaalde tools als gesprekssstarter?
- Welke is/zijn dit?
- Hoe ben je bij deze tool gekomen?

Ken je de lastmeter?
Hoe is de lastmeter geïntroduceerd?
Gebruik je de Lastmeter?
- Kun je vertellen waarom niet waarom wel?
- Wat doe je als iemand een laag cijfer geeft aan IS?
- Wat doe je als iemand een hoog cijfer geeft aan IS?
- Hoe is de Lastmeter aan jou geïntroduceerd?

Ken je de PLISSIT
Hoe is de PLISSIT geïntroduceerd?
Gebruik je PLISSIT?
Permission - Toestemming geven om over IS te praten
Limited Information - Informatie geven over (mogelijke) veranderingen
Specific Suggestion - Adviezen geven om hiermee om te gaan
Intensive Therapy - Indien nodig verwijzen naar een gespecialiseerde zorgverlener

Gebruik je de PLISSIT?
- Kun je vertellen waarom niet waarom wel?
- Wat is jouw ervaring hiermee?
- Tot welke laag kom jij meestal met de patiënten?
- Hoe is de PLISSIT aan jou geïntroduceerd?

- Is er tijdens je scholing en/of bijscholing aandacht besteed aan IS?
- Welke scholing heb je tot nu toe gehad over IS?
- Kun je een voorbeeld geven van lesmaterialen die je wel/niet aanspreken?
- Heb je wel eens met acteurs geoefend? Hoe was deze ervaring?
- Heb je het idee dat je genoeg feedback hebt gekregen tijdens deze scholing?
- Ken je Moodle, een online leeromgeving? Wat is je ervaring hier mee?

Heb je zelf nog ideeën tips, wat mag niet missen, wat maakt je enthousiast?

Appendix C : Interview invitation

Uitnodiging

Graag nodig ik je uit voor een interview. Jouw ervaring omtrent het bespreekbaar maken van intimiteit en seksualiteit met patiënten is heel waardevol. Mijn vraag is dan ook of je dit met mij zou willen delen. Vind je dit een lastig onderwerp om te bespreken of gaat het je juist gemakkelijk af? Ik hoor het graag tijdens het interview.

Waarom:

Voor het project Gesprekken over Psychosociale behoeften, intimiteit en Seksualiteit (GPS project) vanuit het Amsterdam UMC, ben ik bezig met het ontwerpen van een online leeromgeving. Deze leeromgeving maakt deel uit van een training die bedoeld is om verpleegkundigen te ondersteunen bij het voeren van gesprekken met patiënten over intimiteit en seksualiteit. Jouw input is hierbij van groot belang.

Duur: +- 40 min
Waar: Bij jou op je werk
Wanneer: Tussen 14 en 23 maart

Voorbereiding:

Ter voorbereiding van het interview zou het fijn zijn als je alvast terugdenkt aan een moment waarop je met een patiënt hebt gesproken over intimiteit en seksualiteit of een moment waarop je dit juist niet hebt gedaan. Dit mogen zowel negatieve als positieve ervaringen zijn.

Hartelijke groeten,

Shannon Walraven - Student Design for Interaction
s.c.walraven@student.tudelft.nl

Appendix D : Concent form

Toestemmingsformulier audio-opname en foto's

- ☐ Ik neem vrijwillig deel aan dit interview dat wordt uitgevoerd door Shannon Walraven voor het GPS project van het Amsterdam UMC. Tevens is dit onderzoek onderdeel van een afstudeerproject aan de TU Delft. Ik begrijp dat mijn participatie zal worden vastgelegd op een audio-opname.
- ☐ Ik begrijp en ga ermee akkoord dat de gegevens en informatie die ik vandaag deel, vertrouwelijk worden behandeld.
- ☐ Ik begrijp dat de opnamen voor geen enkel commercieel doeleinde zal worden gebruikt en dat de opname zes maanden na afloop van het onderzoek wordt vernietigd. De opname kan onderdeel uitmaken van de informatie die aan de universiteit wordt aangeboden voor educatieve doeleinden.
- ☐ Ik sta toe dat foto's van dit interview, mits geanonimiseerd, mogen worden gebruikt voor rapportage.
- ☐ Ik begrijp dat ik mij op elk moment kan terugtrekken uit het onderzoek, zonder consequenties, en dat ik geen reden hoef op te geven voor mijn terugtrekking.
- ☐ Ik doe afstand van elk recht dat ik heb om de definitieve opnames en het rapport te inspecteren of goed te keuren. Ik ontdoe Shannon Walraven van elke aansprakelijkheid voor het maken, bewerken of gebruiken van de opnamen van dit onderzoek volgens het hierboven beschreven gebruik.

Naam participant: .....

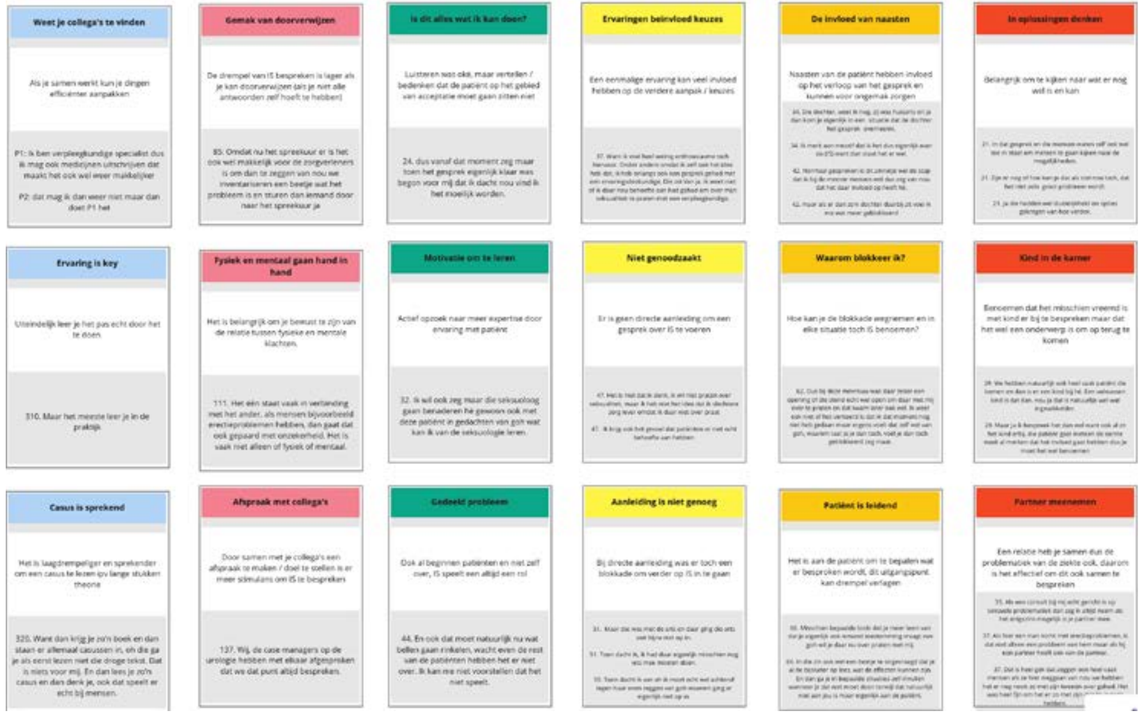
Handtekening participant: .....

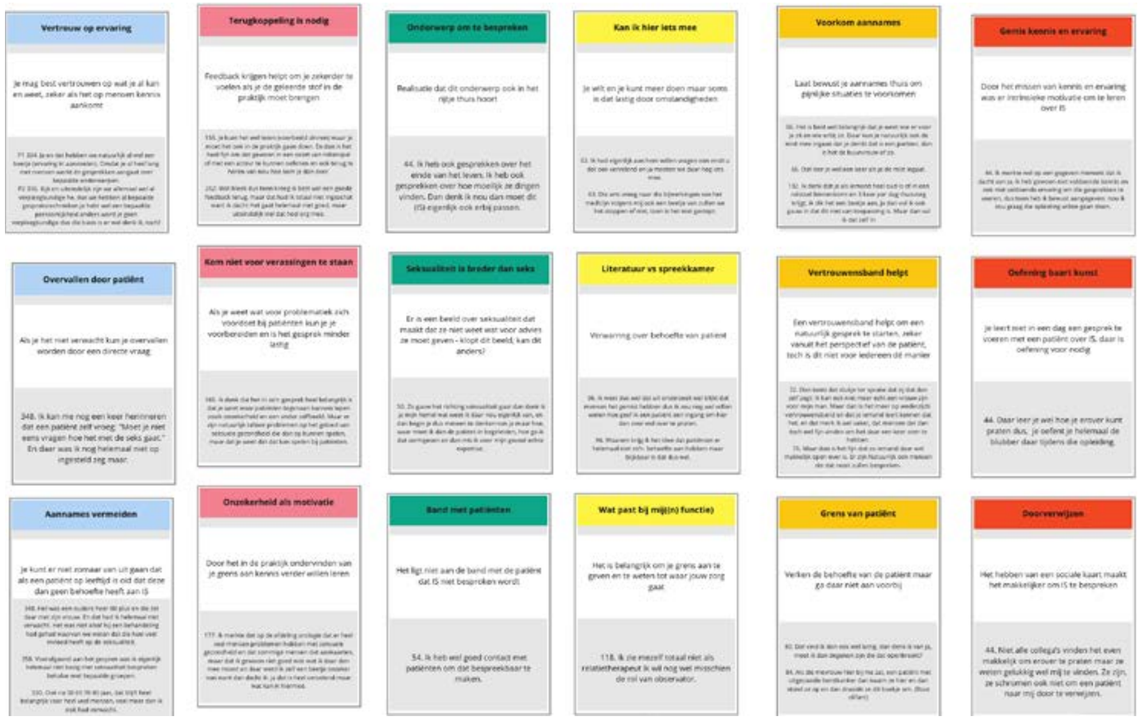
Naam onderzoeker: .....

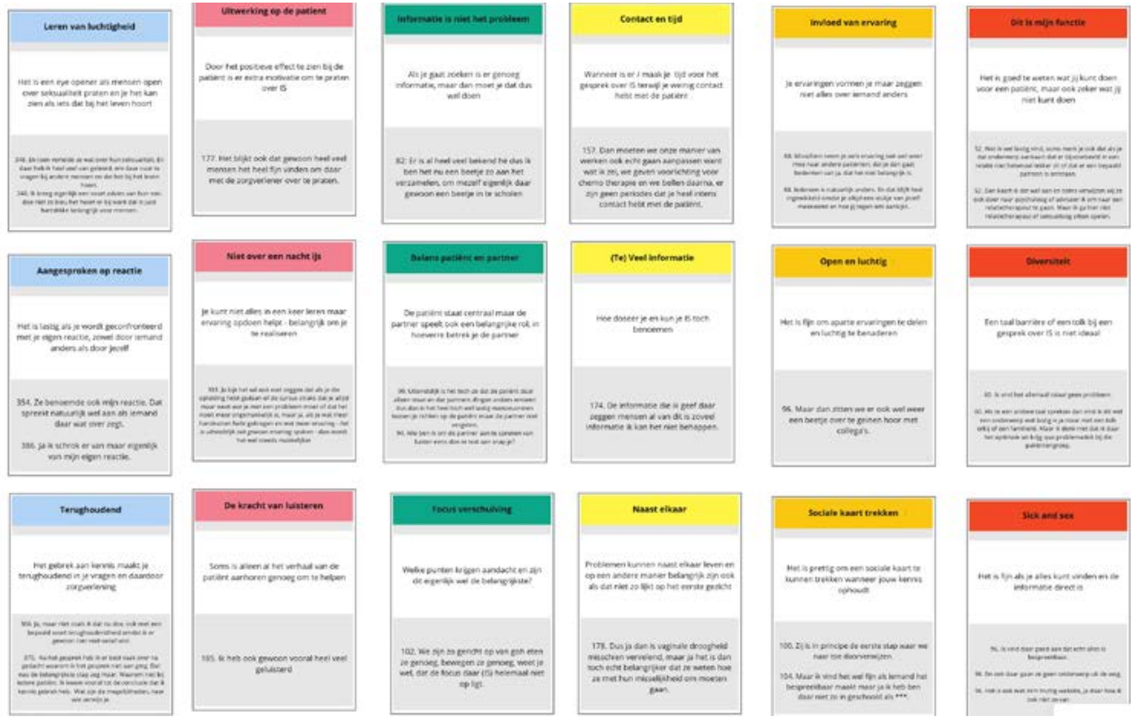
Handtekening onderzoeker: .....

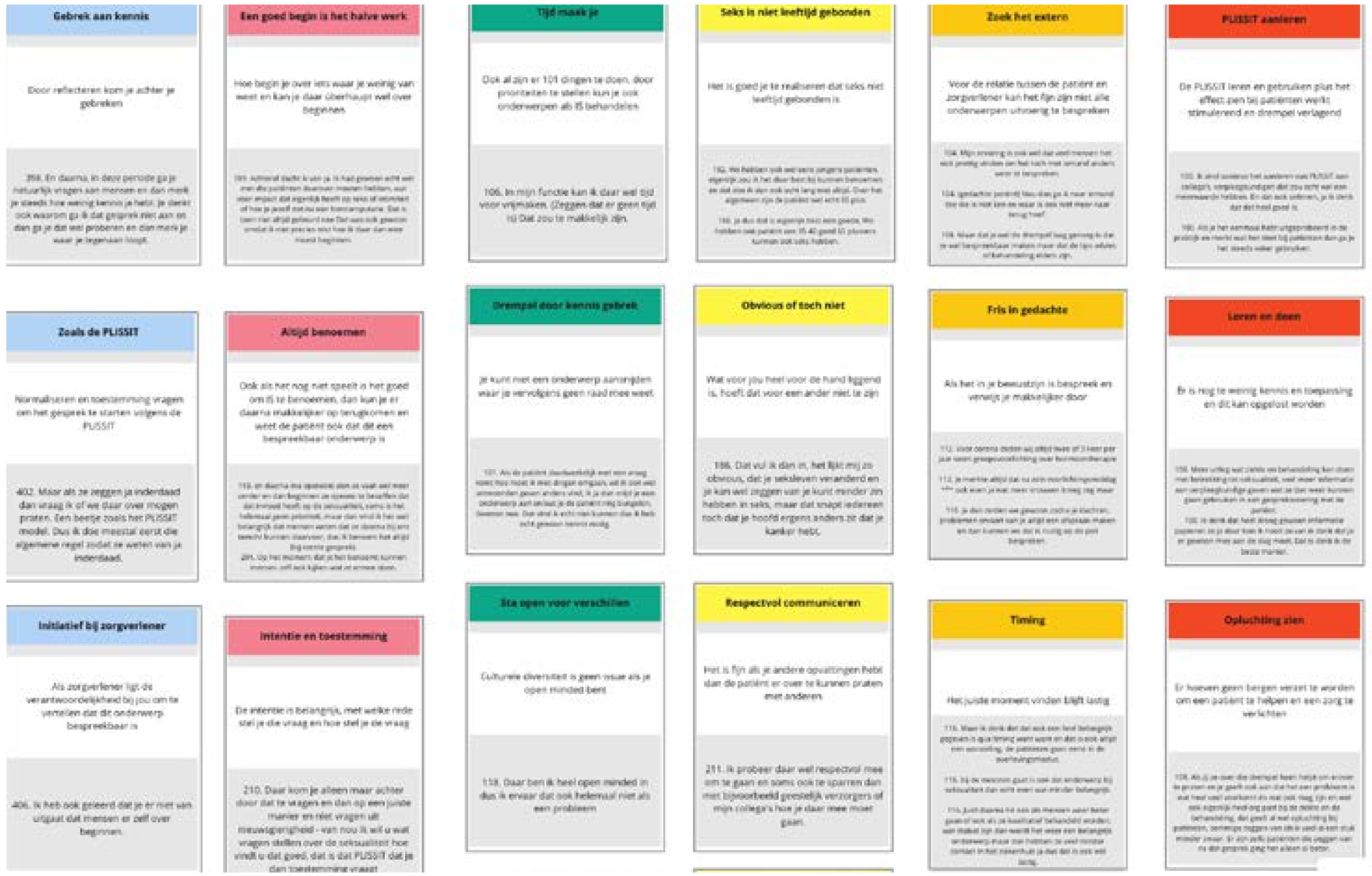
Datum: .....

Appendix E : Concept cards

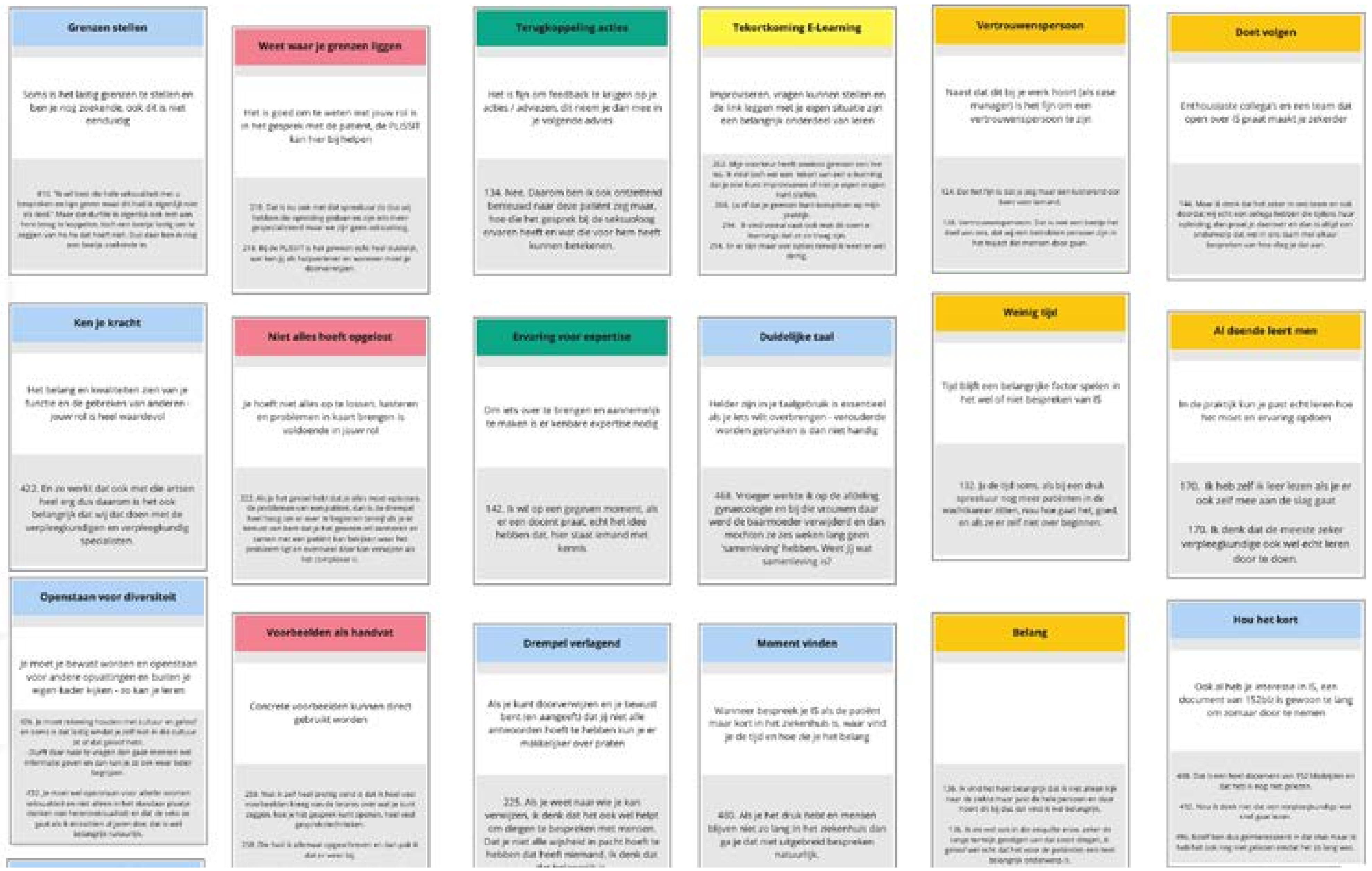



Vertrouw op ervaring
Je mag best vertrouwen op wat je al kan en weet, zeker als het op mensen kennis aankomt
Terugkoppeling is nodig
Feedback krijgen helpt om je zekerder te voelen als je de geleerde stof in de praktijk moet brengen
Onderwerp om te bespreken
Realisatie dat dit onderwerp ook in het rijtje thuis hoort
44. Ik heb ook gesprekken over het einde van het leven. Ik heb ook gesprekken over hoe moeilijk ze dingen vinden. Dan denk ik nou dan moet dic (S)i eigenlijk ook erbij passen.
Kan ik hier iets mee
Je wilt en je kunt meer doen maar soms is dat lastig door omstandigheden
Voorkom aannames
Laat bewust je aannames thuis om gelijkjke situaties te voorkomen
Gemis kennis en ervaring
Deze het missen van kennis en ervaring was er inntrinsieke motivatie om te leren over IS
Overvallen door patiënt
Als je het niet verwacht kun je overvallen worden door een directe vraag.
248. Ik kan me nog een keer herinneren dat een patiënt zelf vraag: "Sinet je niet eens vragen hoe het met de seks gaat." En daar was ik nog helemaal niet op ingesteld zeg maar.
Kom niet voor verassingen te staan
Als je weet wat voor problematiek zich voordoet bij patiënten kun je je voorbereiden en is het gesprek minder lastig
Seksualiteit is breder dan seks
Er is een beeld over seksualiteit dat maakt dat ze niet weet wat voor advies ze moet geven - klopt dit beeld, kan dit anders?
Literatuur vs spreekkamer
Verwarring over behoefte van patiënt
Vertrouwensband helpt
Een vertrouwensband helpt om een natuurlijk gesprek te starten, zeker vanuit het perspectief van de patiënt, toch is dit niet voor iedereen dé manier
Oefening baart kunst
je leert snel in een dag een gesprek te voeren met een patiënt over IS, daar is oefening voor nodig
44. Daar leer je wel hoe je ervver kunt praten dus, je oefent je helemaal de blubber daar tijdens die oplleiding.
Aannames vermeiden
Je kunt er niet zomaar van uit gaan dat als een patiënt op leeftijd is dat dat deze dan geen behoefte heeft aan IS
Onzekerheid als motivatie
Door het in de praktijk ondervinden van je grens aan kennis verder willen leren
Band met patiënten
Het ligt niet aan de band met de patiënt dat IS niet besproken wordt.
54. Ik heb wel goed contact met patiënten om dat bespreekbaar te maken.
Wat past bij mij(n) functie)
Het is belangrijk om je grens aan te geven en te weten tot waar jouw zorg gaat.
Grens van patiënt
Verkies de behoefte van de patiënt maar ga daar niet aan voorbij
Doorverwijzen
Het hebben van een sociale kaart maakt het makkelijker om IS te bespreken
44. Niet alle collega's vinden het even makkelijk ons erover te praten maar ze weten gelukkig wel mij te vinden. Ze zijn, ze schrijmen ook niet om een patiënt naar mij door te verwijzen.


Leren van luchtigheid
Het is een eye opener als mensen open over seksualiteit praten en je het kan zien als iets dat bij het leven hoort
Uitwerking op de patient
Door het positieve effect te zien bij de patiënt is er extra motivatie om te praten over IS
177. Het blijkt ook dat gewoon heel veel mensen het heel fijn vinden om daar met de zorgverlener over te praten.
Informatie is niet het probleem
Als je gaat zoeken is er genoeg informatie, maar dan moet je dat dus wel doen
Contact en tijd
Wanneer is er / maak je tijd voor het gesprek over IS terwijl je weinig contact hebt met de patiënt
Invloed van ervaring
Je ervaringen vormen je maar zeggen niet alles over iemand anders
Dit is mijn functie
Het is goed te weten wat jij kunt doen voor een patiënt, maar ook zeker wat jij niet kunt doen
Aangesproken op reactie
Het is lastig als je wordt geconfronteerd met je eigen reactie, zowel door iemand anders als door jezelf
354. Ze benoemde ook mijn reactie. Dat sprreekt natuurlijk wel aan als iemand daar wat over zegt.
386. ja ik schrok er van maar eigenlijk von mijn eigen reactie.
Niet over een nacht ijs
Je kunt niet alles in een keer leren maar ervaring opdoen helpt - belangrijk om je te realiseren
Balans patiënt en partner
De patiënt staat centraal maar de partner speelt ook een belangrijke rol, in hoeverre betrek je de partner
(Te) Veel informatie
Hoe doseer je en kun je IS toch binnenen
174. De informatie die ik geef daar zeggen mensen al van dit is zoveel informatie ik kan het niet behappen.
Open en luchtig
Het is fijn om sparte ervaringen te delen en luchtig te benaderen
96. Maar dan zitten we er ook wel weer een beetje over te geinen hoor met collega's.
Diversiteit
Een taal barriere of een tolk bij een gesprek over IS is niet ideaal
Terughoudend
Het gebrek aan kennis maakt je terughoudend in je vragen en daardoor zorgverlening
De kracht van luisteren
Soms is alleen al het verhaal van de patiënt aarhoren genoeg om te helpen
105. Ik heb ook gewoon vooral heel veel geluisterd
Focus verschuiving
Welke punten krijgen aandacht en zijn dit eigenlijk wel de belangrijkste?
102. We zijn zo gericht op van gon eten ze genoeg, bewegen ze genoeg, weet je wel, dat de focus daar (S)i helemaal niet op ligt.
Naast elkaar
Problemen kunnen naast elkaar leven en op een andere manier belangrijk zijn ook als dat niet zo lijkt op het eerste gezicht
178. Dus ja dan is vaginale droogheid misschien vervelend, maar ja het is dan toch echt belangrijker dat ze weten hoe ze met hun misselijkheid ons moeten gaan.
Sociale kaart trekken
Het is prettig om een sociale kaart te kunnen trekken wanneer jouw kennis ophoudt
100. Zij is in principe de eerste stap naar we naar toe doorverwijzen.
104. Maar ik vind het wel fijn als iemand het besprreekbaar maakt maar ja ik heb ben daar niet zo in geschoold als ***.
Sick and sex
Het is fijn als je alles kunt vinden en de informatie direct is

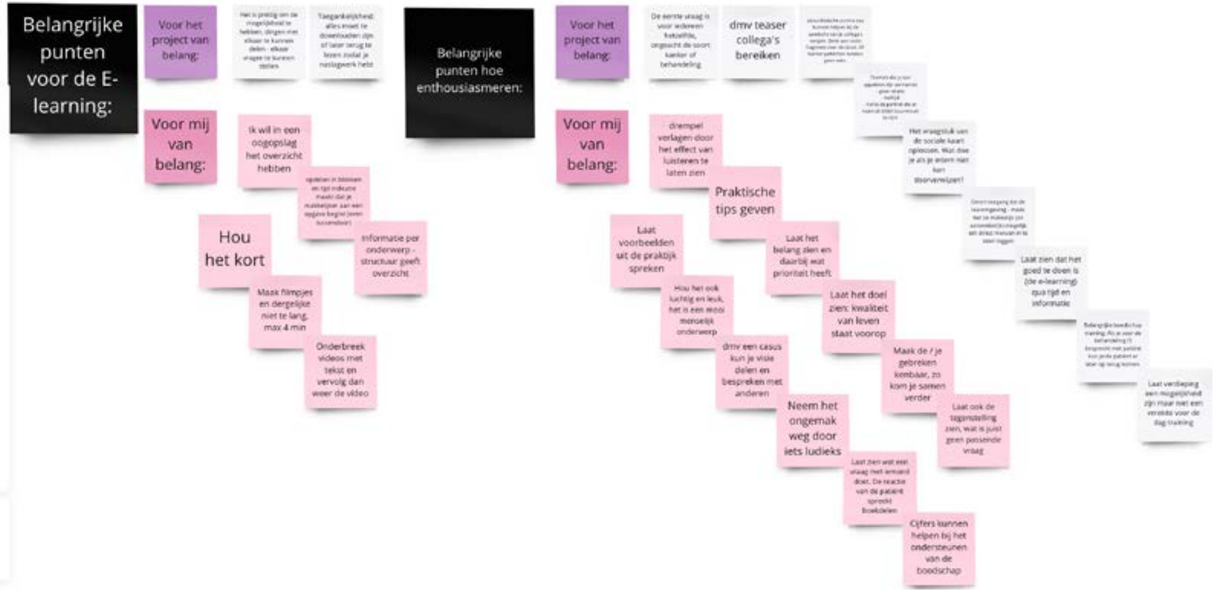


Gebrek aan kennis
Een goed begin is het halve werk
Tijd maak je
Seks is niet leeftijd gebonden
Zoek het extern
PLISSIT aanleren
Zoals de PLISSIT
Altijd benoemen
Drempel door kennis gebrek
Obvious of toch niet
Fris in gedachte
Leren en doen
Initiatief bij zorgverlener
Intentie en toestemming
Sta open voor verschillen
Respectvol communiceren
Timing
Opluchting zien

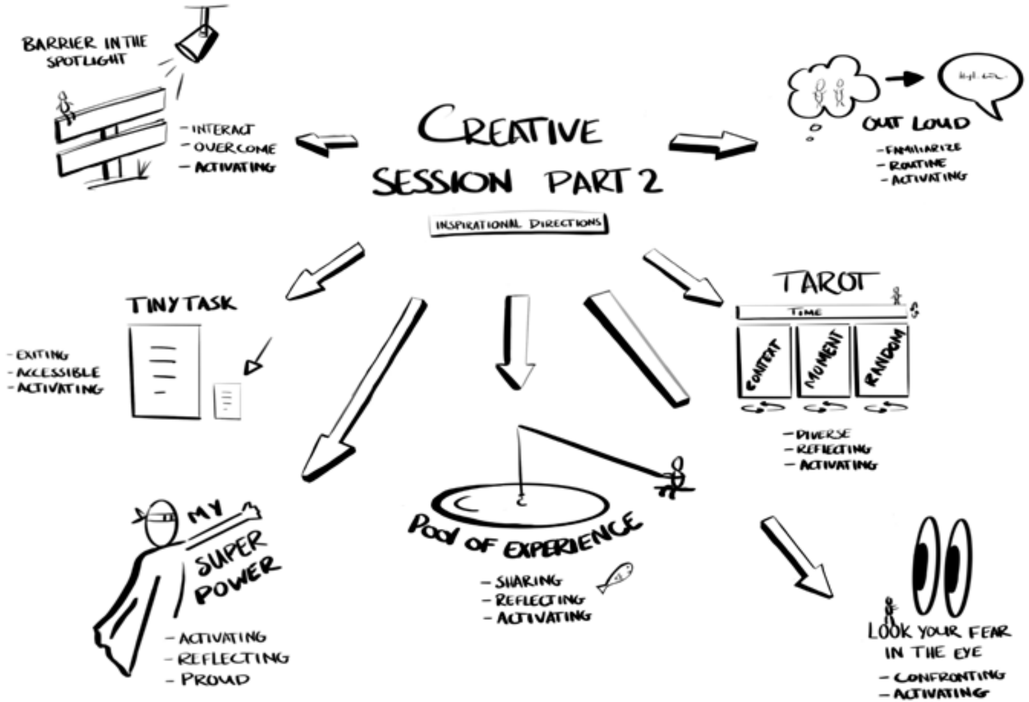


Grenzen stellen
Weet waar je grenzen liggen
Terugkoppeling acties
Tekortkoming E-Learning
Vertrouwenspersoon
Doet volgen
Ken je kracht
Niet alles hoeft opgelost
Ervaring voor expertise
Duidelijke taal
Weinig tijd
Al doende leert men
Openstaan voor diversiteit
Voorbeelden als handvat
Drempel verlagend
Moment vinden
Belang
Hou het kort

Appendix F : Notes Co-creation session one



Appendix G : Creative session ideas



Appendix H : Text concept

Introductie

Duik in de “zee aan ervaringen”.

Hier kun je “parels” aan ervaringen vinden door te luisteren wat de “oesters” jou te vertellen hebben. Zorgverleners vertellen in korte geluidsfragmenten over hun drijvende kracht maar ook over de barrières die zij tegenkomen tijdens of op weg naar een gesprek over psychosociale behoeften, intimiteit en seksualiteit.

Deze drijfveren en barrières kunnen voor jou anders zijn. Met de volgende opdracht willen wij je inzicht geven in jouw persoonlijke drijfveren en barrières. Weet jij wat jouw barrières zijn? Wat jou motiveert of steunt om het gesprek aan te gaan over psychosociale behoeften, intimiteit en seksualiteit?

Na ieder fragment krijg je een vraag om je te helpen op zoek te gaan naar jouw persoonlijke aanpak. Hoe kijk jij naar psychosociale behoeften, intimiteit en seksualiteit? Hoe wil en kan jij de patiënt ondersteunen bij deze onderwerpen? En wat heb je nog nodig om je te helpen dit te doen?

Ieder heeft dus zijn eigen manier. Laat je tijdens het zwemmen in deze zee vooral ook inspireren door de andere zwemmers, wellicht helpt het in de zoektocht naar die van jou.

Veel zwem plezier!

Context P1
Je gaat luisteren naar een fragment waarin een verpleegkundig specialist vertelt over zijn drijfveer om een aanvullende opleiding te doen en wat dit hem heeft opgeleverd.

Ervaringsverhaal P1
Nou ik ik ging het nooit uit de weg (zo’n gesprek), maar ik merkte wel op een gegeven moment dat ik dacht van: ja ik heb gewoon niet voldoende kennis en ook niet voldoende ervaring om die gesprekken te voeren dus toen heb ik bewust aangegeven. Nou ik zou graag die opleiding willen gaan doen. Dus Ik heb eerst de opleiding tot consulent seksuele gezondheid gedaan en ja goed, daar leer je wel hoe je erover kunt praten dus, je oefent je helemaal de blubber daar tijdens die opleiding dus ja en Dat is iets waardoor ik ook merk, ja weet je, niet alle collega’s vinden het even makkelijk om erover te praten maar ze weten gelukkig wel mij te vinden. Ze schromen ook niet om een patiënt naar mij door te verwijzen.

Vraag (reflecteren op eigen ervaring in combinatie met het hebben van een uitwijkmogelijkheid)
Hoe ervaar jij het bespreekbaar maken van intimiteit en seksualiteit?
Ben jij de collega die makkelijk praat over intimiteit en seksualiteit of heb je een collega naar wie je kan verwijzen?

Reflectie
1) Ik heb het wel eens besproken met een patiënt en dat ging eigenlijk best goed. Maar ik vond het wel fijn dat ik kon doorverwijzen naar een seksuoloog want ik wist ook niet zo goed alle vragen van de patiënt te beantwoorden. Achteraf was deze patiënt ook erg blij met de doorverwijzing.

2) Ik heb geen collega waarnaar ik kan doorverwijzen, dus ik probeer de patiënten zo veel mogelijk te helpen en te ondersteunen met de kennis die ik heb over hun ziektebeeld en de daarbij behorende ongemakken rondom seksualiteit. Vaak is dat voldoende.

Context P2
In dit fragment vertelt een verpleegkundig specialist over hoe hij gesprekken voert met patiënten en hun partner, welke inzichten dat met zich mee kan brengen en hoe het de patiënten verder kan helpen.

Ervaringsverhaal P2
Patiënten zijn heel soms heel verbaasd als ik uitleg wat intimiteit is, we hebben het over het knuffelen, elkaar aanraken, bij elkaar zijn, fijne dingen samendoen, het hoeft niet eens op seksgebied te zijn maar gewoon lekker samen wat muziek luisteren, samen dansen. Ja en dan realiseren ze zich, ja maar dat doen we nog wel, op dat gebied zijn we nog, hebben we het wel heel fijn samen.
Als je ze over die drempel heen helpt om erover te praten en je geeft ook aan dat het een probleem is wat heel veel voorkomt én wat ook mag zijn en wat ook eigenlijk heel erg past bij de ziekte en de behandeling, dat geeft al wel opluchting bij patiënten, sommige zeggen van oh ik voel al een stuk minder zwaar. Er zijn zelfs patiënten die zeggen van na dat gesprek ging het alleen al beter.

Vraag (nadenken over wat jij nodig hebt om de patiënt te helpen)
Sommige patiënten ervaren een drempel als het gaat om het bespreekbaar maken van intimiteit en seksualiteit. Wat heb jij nodig om er op dat moment te kunnen zijn voor de patiënt?

Reflectie:
1) Ik heb vooral kennis nodig zoals in het fragment te horen is over hoe je de patiënt eigenlijke gerust kan stellen of begeleiden.

2) In mijn instelling is er eigenlijk geen hulpmiddel dat kan worden ingezet, het zou fijn zijn als ik wel iets van een folder zou hebben om aan de patiënt te geven.

Context P3
In dit fragment is een verpleegkundige aan het woord. Zij vertelt waarom zij het belangrijk vindt om met patiënten over psychosociale behoeften te praten. Daarnaast geeft zij ook aan wat dit voor haar betekent.

Ervaringsverhaal P3
Ik vind het heel belangrijk dat ik niet alleen kijk naar de ziekte maar juist de hele persoon en daar hoort dit bij dus, dat vind ik wel belangrijk.
Wat ik merk is, dat het fijn is dat je zeg maar een luisterend oor bent voor iemand. Een vertrouwenspersoon eigenlijk. Dat is ook een beetje het doel van ons, dat wij een betrokken persoon zijn in het traject dat mensen doorgaan.

Vraag (reflecteren op invloed van betrokkenheid)
In het fragment vertelt de verpleegkundige dat het haar helpt om betrokken te zijn bij de patiënt om psychosociale behoeften bespreekbaar te maken. Hoe werkt dit voor jou?

Reflecties:
1) Ik voel mij eigenlijk bij alle patiënten wel betrokken, bij de een meer dan bij de ander maar dat hang ook af van hoe vaak ik iemand zie. Ik weet niet of het echt nodig is om betrokken te zijn maar het helpt mij wel als ik een band met iemand heb zulke dingen makkelijker te bespreken.

2) Met sommige patiënten heb ik meer een klik dan met anderen. Ik merk ook dat ik het dan veel makkelijker vind om dit soort intieme dingen te bespreken.

3) Ik probeer altijd wel betrokken te zijn en te informeren naar hoe het gaat met de patiënt. Maar betrokken of niet, over intimiteit en seksualiteit praten laat ik liever aan iemand ander over.

Context P4
Het volgende fragment laat je luisteren naar het verhaal van een verpleegkundige die terugblikt op een moment in het begin van haar carrière. Een ouder heteroseksueel stel waarvan de man onder behandeling is spreekt haar aan op het feit dat ze hen nog niet naar hun seksualiteit heeft gevraagd. Ze vertelt hoe zij dit heeft ervaren.

Ervaringsverhaal P4
Ik kan me nog een keer herinneren dat een patiënt zelf vroeg moet je niet eens vragen hoe het met de seks gaat. En daar was ik nog helemaal niet op ingesteld zeg maar. Het was een oudere heer 80 plus en die zat daar met z'n vrouw. En dat had ik helemaal niet verwacht want het was niet alsof hij een behandeling had gehad waarvan we weten dat die heel veel invloed heeft op die seksualiteit. Dus het zat helemaal niet zo in mijn systeem om dat te vragen en daarnaast waren het ook ouderen zeg maar. Ik werd een beetje verlegen daarvan en ze zeiden: oh meisje doe niet zo bleu. En toen vertelde ze wat over hun seksualiteit. Daar heb ik heel veel van geleerd om daarnaar te vragen bij andere mensen en dat het bij het leven hoort (en dergelijke). Dus dat was een beetje een eye opener. Dat kan ik me dus heel goed herinneren. Dat ik dacht moeten we het hier echt over hebben, met zo'n ouder stel echt een soort opa en oma. Dus ik kon hun ook niet echt iets vertellen, zij gingen mij wat vertellen en ik kreeg eigenlijk een soort advies van hun van: doe niet zo bleu het hoort erbij want dat is juist hartstikke belangrijk voor mensen.

Vraag (reflecteren op wel of geen ongemak ervaren en of dit een beperkende factor is)
"Doe niet zo bleu", een uitspraak uit het fragment. Ervaar jij wel eens ongemak tegenover patiënten als het aankomt op het bespreken van intimiteit en seksualiteit? Hoe voel jij je hierbij? Is dit iets wat je zou willen veranderen?

Reflectie:
1) Ik voel mij vaak verlegen en ongemakkelijk dus het lijkt me fijn als dit verandert.
2) De laatste jaren voel ik me helemaal niet verlegen bij patiënten. Ik heb nu een eigen riedeltje dat ik gebruik om intimiteit en seksualiteit te bespreken dus ik denk dat ik dat niet hoef te veranderen.
3) Ik twijfel soms wel of ik dit onderwerp zal bespreken met patiënten. Als die twijfel wordt weggenomen helpt dat denk ik wel om mij zekerder te voelen en minder terughoudend te zijn.

Context P5
In dit fragment ga je luisteren naar een verpleegkundige die uitlegt wat intimiteit en seksualiteit voor haar betekent. Daarnaast legt ze uit waarom het bespreken van intimiteit voor haar veel gemakkelijker is dan het bespreken van seksualiteit.

Ervaringsverhaal P5
Seksualiteit is vaak zeg maar tussen partners hè, niet altijd, maar vaak tussen partners. Terwijl intimiteit kan ook meer behelzen. Het is ook de warmte die je ontvangt van je kinderen of jouw familieleden of vrienden dat soort dingen hè Als je eenzaam voelen bijvoorbeeld in de ziekte. Ik zou me kunnen voorstellen dat dat ook bij intimiteit hoort.
Op het moment dat het op seksualiteit aankomt vind ik het op een of andere manier lastiger, echt een apart gespreksonderwerp. (Dan denk ik ja mijn hemel wat weet ik daar nou eigenlijk van, en dan begin je dus meteen te denken van ja maar hoe, waar moet ik dan de patiënt in begeleiden) terwijl bijvoorbeeld intimiteit dan ga je misschien al pratende misschien al veel makkelijk in over, heb je het niet eens zo In de gaten terwijl seksualiteit voor mij toch echt wel een heel ander soort drempeltje is.

Vraag (stilstaan bij eigen definitie en uitvoer)
Wat betekent intimiteit en seksualiteit voor jou? En wat zijn voor jou belemmerende of bevorderende factoren die meespelen bij het bespreken hiervan?

Reflectie:
1) Bij mij lijkt het een beetje op wat er in het fragment verteld is. Intimiteit is heel breed en bespreek ik makkelijk met patiënten. Seksualiteit is daarentegen iets waarbij ik niet goed weet hoe ik het gesprek aan moet snijden of waar ik de patiënt bij kan helpen.

2) Seksualiteit bespreken vind ik veel makkelijker omdat ik dan dingen kan uitleggen over de klachten van de behandeling of ziekte. Bij intimiteit komt zo veel kijken dat ik ook niet weet of ik overal wel antwoord op heb.

3) Intimiteit heeft wel meer raakvlakken voor mij dan seksualiteit. Maar of het nou intimiteit of seksualiteit is, ik vraag er gewoon altijd naar bij de patiënt en dan gaan we samen opzoek naar een oplossing.

Appendix I : Answers research questions interview

Tools are not available to everyone - *What conversation tools are being used?*

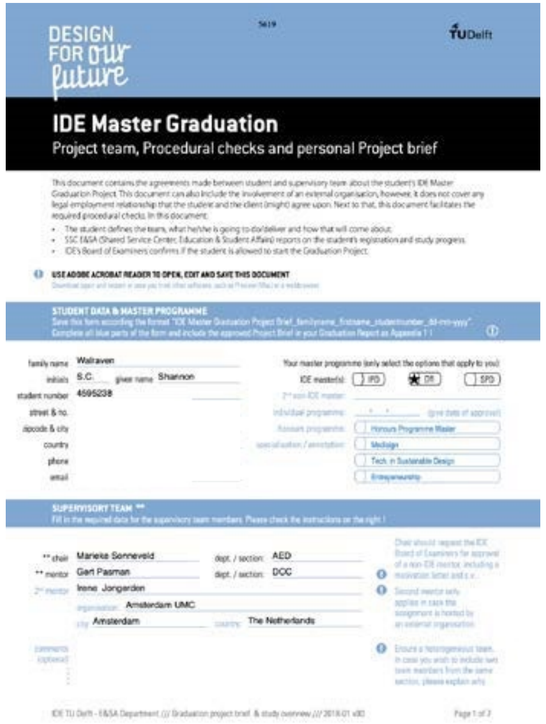
The interviews showed that not every participant has access to certain tools to start a conversation about intimacy and sexuality. The three participants who do have access to these tools also regularly use them. Often, within a department an agreement is made about when they should be used. Two of the participants who work in the same hospital addressed that they work in a different department and do not use the same tools. In fact, one of them is not in possession of such a tool in her department. This indicates that within one hospital, there can still be a lot of differences. The tools that are being used are mostly folders and flyers, which can be given to the patients and are used to bring up the subject.

Where the PLISSIT can be helpful, the Lastmeter is being avoided - *Are nurses and CNS informed about the Lastmeter and the PLISSIT and to what extent are they being used?*

Half of the participants were familiar with the PLISSIT model by following an additional training for sexual councelling. They mentioned that this model supports them and that they use it in every conversation about intimacy and sexuality. In contrast to that, the Lastmeter is known by every participant but is hardly used. The overall conclusion of the participants is that the Lastmeter creates the expectation to the patients that every question will be answered. Nevertheless, this almost never happens and therefore the Lastmeter is not inviting to be used.

"That makes the distresmeter very difficult for us, haha, really a distresmeter."

Appendix J : Design brief



DESIGN FOR our future

TU Delft

IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT

Download, open and explain in case you have other software, such as Preview (Mac), or a mobile viewer.

STUDENT DATA & MASTER PROGRAMME

Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy"
Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name: Wallraven
initials: S.C. given name: Shannon
student number: 4595238
street & no.:
zipcode & city:
country:
phone:
email:

Your master programme (only select the options that apply to you):
IDE master(s): IPD, DE, SPD
2nd non-IDE master:
individual programme: (give date of approval)
Honours Programme Master
MoMaps
Tech. in Sustainable Design
Entrepreneurship

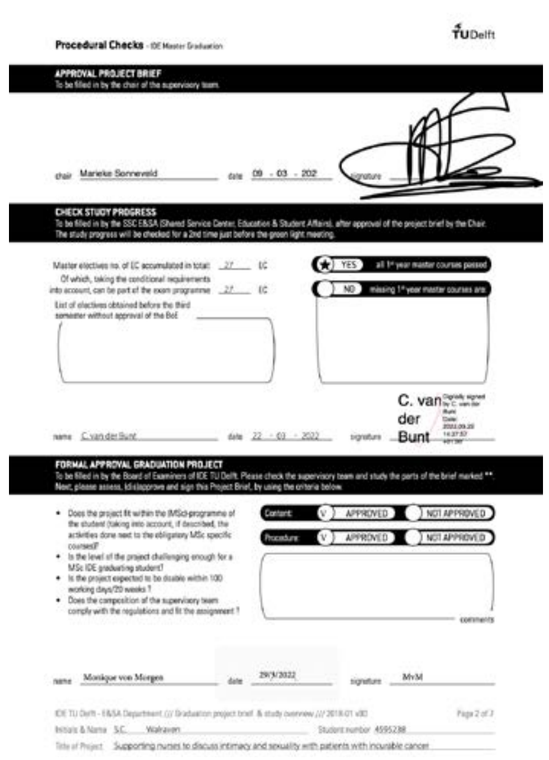
SUPERVISORY TEAM **

Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair: Marieke Sonneveld dept. / section: AED
** mentor: Gert Pasman dept. / section: DOC
2nd mentor: Irene Jongerden
organisation: Amsterdam UMC
city: Amsterdam country: The Netherlands
comments (optional):

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..
Second mentor only applies in case the assignment is hosted by an external organisation.
Ensure a heterogeneous team. In case you wish to exclude two team members from the same section, please explain why.

IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30 Page 1 of 3



TU Delft

Procedural Checks - IDE Master Graduation

APPROVAL PROJECT BRIEF

To be filled in by the chair of the supervisory team.

chair: Marieke Sonneveld date: 09 - 03 - 202 signature:

CHECK STUDY PROGRESS

To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair.
The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: 27 EC
Of which, taking the conditional requirements into account, can be part of the exam programme: 27 EC
List of electives obtained before the third semester without approval of the BoE:

YES all 1st year master courses passed
NO missing 1st year master courses are:

name: C. van der Bunt date: 22 - 03 - 2022 signature: C. van der Bunt Digitally signed by C. van der Bunt Date: 2022.03.22 14:37:57 +01'00'

FORMAL APPROVAL GRADUATION PROJECT

To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **.
Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: V APPROVED NOT APPROVED
Procedure: V APPROVED NOT APPROVED
comments

name: Monique von Morgen date: 29/3/2022 signature: MvM

IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30 Page 2 of 3

Initials & Name: S.C. Wallraven Student number: 4595238
Title of Project: Supporting nurses to discuss intimacy and sexuality with patients with incurable cancer

Supporting nurses to discuss intimacy and sexuality with patients with incurable cancer

project title

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

start date 15 - 02 - 2022 | 08 - 07 - 2022 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

Patients with incurable cancer are often facing psychological and physical changes which raise questions. These changes could be of influence on their intimacy and sexuality. Not being able to talk about these changes causes more suffering than needed. The communication between caregiver and patient is often focused on diagnosis and treatment, and not on its impact on intimacy and sexuality. Nurses and clinical nurse specialists (CNS) are not always aware of the importance of intimacy and sexuality for the patients. This could be caused by the assumption that intimacy is not a part of the patient's life anymore, due to age or the disease. Next to that, intimacy and sexuality can be a hard topic to talk about due to shame and discomfort, which makes it even more plausible to avoid this topic. In return, patients are also having difficulties to address this topic during consultation. Therefore, the role of the nurses and CNS is even more important. Education is of great importance in order to create more awareness and prepare nurses and CNS for addressing this topic.

Currently Amsterdam UMC is working on the Gesprekken over Psycho-Sociale behoeften (GPS) project where the focus lies on having conversations with patients about psycho-social needs, including questions about intimacy and sexuality. In this particular case the project applies to patients with incurable cancer and have reached the last phase of their life. By providing the right tools and training for nurses and CNS, the GPS project tries to open up the conversation about these sensitive topics. Therefore, the focus lies on creating a learning program for nurses and CNS in order to acquire conversation skills and gain insight in the role of intimacy and sexuality in this end-of-life phase. In this way the nurses and CNS can train how to interact with patients with incurable cancer when addressing the topics intimacy and sexuality. Not only Amsterdam UMC but also a large group of other care institutions are seeing this need for more awareness and skills concerning psychosocial needs, intimacy and sexuality. Therefore, they are now working together on the GPS project. Having this support base and connections offers many possibilities and opportunities for the project.

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introduction (continued): space for images

TO PLACE YOUR IMAGE IN THIS AREA:
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image / figure 1:

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image / figure 2:

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

The learning program that will help nurses and CNS to create awareness, signaling and discussing psychosocial needs, intimacy and sexuality with patients, consists of three parts: 1) a physical training day to practice conversation skills and 2) an online learning environment which provides the necessary information and preparation to follow this physical training day and 3) intervision.

The challenge of this project is to create the online learning environment. Currently there are various tip sheets, e-learnings and information on this topic. Nevertheless, they turn out to be not suitable for this particular training. Therefore, Amsterdam UMC wants an inspiring and motivating learning environment to increase the knowledge and skills of the nurses and CNS. Finding out how to reach the target group and how to effectuate this important interaction with the online learning environment is central within this research.

The overall GPS project focuses on psychosocial needs, intimacy and sexuality. In order to specify my project, the focus will be on intimacy and sexuality.

Furthermore, content is composed by the conducted research. Still, the exact content should be specified. Finding out the needs of the nurses as well as for the patients could be a way to select and formulate the right content. Nevertheless, the focus within this project lies on the nurses and their development of skills.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

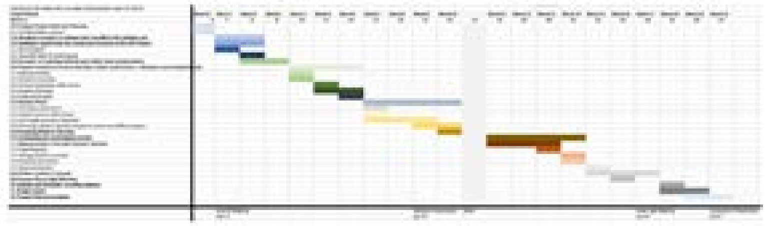
The goal of this project is to create an online learning environment for nurses which is engaging, inspiring and effective. It should be the base of their training about awareness and conversation skills and should contribute to a better understanding of the patients and their needs and questions in this important phase of the end-of-life.

Since the GPS project already has a clear view of what they want and what must be achieved, the focus of this project will be on creating the right content for the online environment in the right form. Looking at what makes an inspiring online training environment and taking culture sensitivity into account is important within this research. The aim is to deliver a 'product' that is co-created and tested by nurses and which could be immediately implemented if desired by the GPS project team due to their own agenda for this part of the training.

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and 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 activities.

start date 15 - 2 - 2022 | 8 - 7 - 2022 end date



I will work full time on the project, which means that the duration of the project will be 20 weeks. During the project I planned a one week break between week 10 and 11, which is right after the midterm meeting. Since much research is already done within the GPS project, the focus will be on the last stage, where a concept is developed in further detail. Within the GPS project they aim to upload content around June, therefore I tried to plan to have some parts of the concept ready by then and starting with the finalize stage soon after. I will make use of the tools Context Mapping and Facilitating a Creative session. Further evaluation methods will be chosen during the project to see which one suits most.

Personal Project Brief - IDE Master Graduation

TU Delft

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities etc.] and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge on a specific subject, broadening your competences or experimenting with a specific tool and/or methodology; ..... Stick to no more than five ambitions.

Something I find remarkable is that many of my interest gathered during my bachelors and masters seem to come together in this final project. First of all, during my bachelors I became interested in healthcare and followed the minor Geneeskunde voor Technische Studenten. The environment intrigued me and the interest stayed. During the elective Capita Selecta, I already did an assignment for Amsterdam UMC for the Verpleegkundig Innovatielab, from which the outcome is tested at the moment in the hospital. At that time I could not have imagined doing another project in collaboration with Amsterdan UMC.

The end of life, and how people look at it fascinates me. It is hard to define but when I heard Marieke Sonneveld talking about it in a few of her lectures, I knew I wanted something with this topic. This in combination with the healthcare aspect clicked. Next to that I followed the course Video for designers, making the video's and also exploring Premiere Pro and After Effects make me curious and wanting to learn more about the possibilities. A whish is to take more time to learn how to make animations. This might also be a good solution direction to reach nurses and create content.

Last semester I followed the course Context Mapping, I find this method a very interesting tool because it explicitly focuses on the human and its context. It is suitable for an emphatic way of understanding people and their situation, needs and desires. Therefore, I think it would fit the sensitive topic of this project and I would love to use it for my research.

Finally, I like to open conversations about topics people find hard to talk about. Intimacy and sexuality are included in those topics. Why being silent if talking about it could help you develop, prevent pain or dissolve an uncomfortable situation? Therefore, I would really like to contribute to this project which with right earns more and more attention in healthcare facilities.

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Initials & Name S.C. Walraven Student number 4595288

Title of Project Supporting nurses to discuss intimacy and sexuality with patients with incurable cancer