Master thesis

Palliative terminal care virtual training for inexperienced nurses on emotional/ spiritual capability

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ABSTRACT

Over recent decades, the quality of death and dying has received much attention in society. Many patients with terminal cancers or admitted to intensive care/acute units are in need of care for the end of their life (Susan, 2015). With this need rising up, palliative care service is gradually developed mainly as the setting of hospice or home care. However, some patients who are terminally ill are in a situation in need of hospital medical settings to manage their symptoms (Cotogni, 2018). Therefore, in-hospital palliative terminal care becomes important for those patients/ families in terms of guaranteeing quality of life in their last days or hours. Currently, most western hospitals, including Maasstad Hospital, implement palliative terminal care with the integrative model (Metaxa, 2019) which needs general medical professionals, especially nurses, to provide palliative care as a part of routine practice combined with a consultative palliative care team, which is a reported as a challenging work for nurses (Bratianu, 2015) (Johansson, 2011). The project aims to investigate how to support nurses in the Oncology Department of Maasstad Hospital to be able to provide palliative care to patients. Through a series of literature research and interviews from historical (trend), cultural, user and context, and technology aspects to understand and explore the context, the design opportunity, supporting junior nurses with palliative care on-site learning, is unearthed. Insights gained from supplementary research helps the project further define the design goal: to create virtual training of palliative care for inexperienced nurses on emotional and spiritual capabilities, where nurses gradually become mentally prepared to provide palliative terminal care for dying patients and families, to ensure nurses' mental well-being while being able to provide emotional and spiritual care to patients and families with quality. A VR demo is built for nurses to evaluate the concept. Due to the Covid-19 situation with limited access to nurses, the evaluation result is not quantitative which means further user tests and evaluation need to be considered. The final design is perceived by the nurse as to be promising to provide the inexperienced nurses or even other medical professionals with a safe environment to learn to cope with their own feelings, explore and make mistakes, and be eventually more comfortable and confident to look after dying patients and their family members. However, since the design mainly focuses on the training program structure and the experience journey, more opportunities and details of the interaction design still need to be developed and tested if the application is expected to be launched. The recommendations regarding these details and opportunities are provided as the end of this project.

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INTRODUCTION

This chapter introduces the project background that provides an overview of stakeholders and contexts. The main design question is defined and elaborated. An overview of the project approach is described that explains how to answer the design question.

INTRODUCTION

/PROJECT BACKGROUND

Patients admitted to the hospital are normally treated cure-oriented and aim to prolong their life. If they are diagnosed to be incurable, they will be moved to a hospice or a nursing home, or choose to go back home spending their last days, since aggressive medical intervention for them only leads to poor quality of life. However, some patients who are terminally ill are in a situation that it is impossible to move them out of the hospital at their limited last days or they are in need of hospital medical settings to manage their symptoms (Cotogni, 2018). Therefore, in-hospital palliative terminal care becomes important for those patients/families in terms of guaranteeing patients' good quality of life and their satisfaction at patients' end of life. In general, the role of palliative care for them is to relieve pain and other symptoms, as well as providing social, spiritual, and psychological support to patients and their relatives.

The awareness of providing in-hospital palliative terminal care has been raising among Dutch hospitals, and since the start of this century, palliative care teams (PCT) in the hospital become available throughout the country (Brinkman-Stoppelenburg, 2016). Maasstad Hospital is one of these hospitals who has its own palliative care team and is currently seeking interventions that address the specific needs of palliative care, supported by Maasstad Academie who is the client of this project. The main role of this team is to be consulted by patients/families, support professional caregivers in palliative care, and provide specialized palliative care (Brinkman-Stoppelenburg, 2016).

Maasstad Hospital currently doesn't have a separate section for palliative terminal care so that the PCT works as moving from sections to sections, which means the care for dying patients under palliative terminal care is part of the work of general medical teams, especially nurses. This can be really challenging and difficult for them, which also happens in many other hospitals. They are trained with limited knowledge on palliative care specialization while providing palliative care to terminally ill patients demands them to 1) cope with different needs compared with curable patients, which means palliative care focus on comfort, care, and peaceful death while curative care focus on cure therapy and avoidance of death, 2) be aware and adapt their attitudes and emotions between life and death in different wards. Many junior medical professionals feel unprepared for providing palliative terminal care to patients (Bharmal, 2019). An overview of the main differences between curative care and palliative care is illustrated in Figure 1. This overview is created by collecting and analyzing findings from Center for Medicare Advocacy (2016) and Brooker Wheeler (2018)'s insights into the comparison between curative care and palliative care, as well as Bratianu (2015), Johansson (2011), and Keidel (2002)'s research on nurses' experience on providing palliative care for terminal patients.

The opportunity in this project lies in visioning how nurses can be supported and empowered or collaborate with the palliative care team to improve their working experience by better preparing themselves, and provide patients with the care they need.

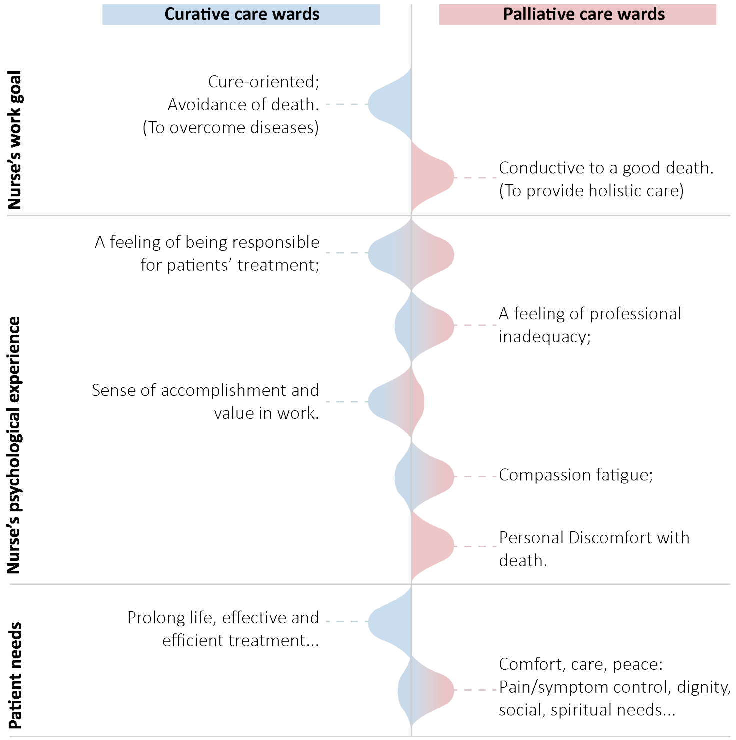


Figure 1. Differences between curative care and palliative care

INTRODUCTION

/MAIN DESIGN QUESTION

The main problem this project is going to tackle is how to support nurses to provide palliative terminal care to ensure good quality of life in the last days of terminally ill patients' life in Maasstad Hospital while taking care of both patients and nurses (formal caregivers). Therefore, the main design question of the project is formulated as:

What opportunity areas are there to support nurses providing palliative terminal care to dying patients in Maasstad Hospital?

This project aims to understand the current context and stakeholders of the nurses' work on hospital-based palliative terminal care via a literature&desktop research-led approach, finding out the design vision and opportunities, which leads to creating an intervention in the next phase.

The whole project will focus on bridging the current situation that the medical staff in the hospital are not well prepared for providing palliative terminal care and the long-term vision that there is a mature palliative care service system in hospitals equipped with well-trained caregivers to provide palliative terminal care.

/PROJECT APPROACH OVERVIEW

To get to the expected solution, comprehensive research is conducted to address the understanding of the current context and stakeholders, as well as looking for trends and inspirations. From there, a design question will be created to guide and inspire the following design phase. The research approach can be divided into two main phases visible in Figure 2: Exploration&Understanding, and Synthesis.

The general targeting context of the research is towards Maasstad Hospital in Dutch culture. However, since palliative terminal care service in hospitals is under relatively early developing stage, to gain a comprehensive overview and understanding of the status quo, the Europen and American contexts are also included as supplement and reference, especially in the historical research and comparison study part.

The following design phase will be based on the research insights, starting with ideation which will lead to potential design directions. Together with the client, one of the directions will be chosen to further developed, followed by several iterations. If there is still no access to the hospital, the iterations will be conducted by showing storyboards of the concepts to gain feedback. A final evaluation of the solution will be made, based on which the recommendations and implementation plan will be proposed.

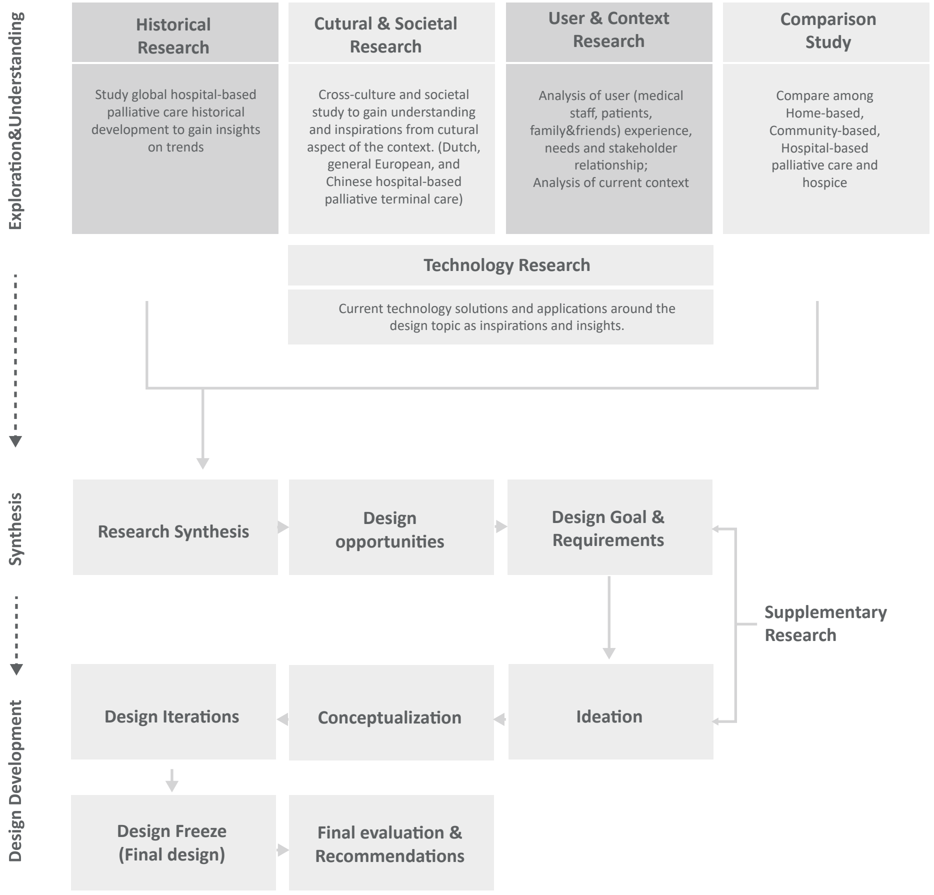


Figure 2. Project approach overview

1

HISTORICAL RESEARCH

To inspire the future from the past, this chapter creates an overview of global hospital-based palliative care historical development to understand the current and gain insights on trends of palliative care service and how nurses' role adapts to the changes over time.

CHAPTER 1. HISTORICAL RESEARCH

/1.1. INTRODUCTION

Aim of the research: To gain learnings from the trend of in-hospital palliative care and nurses' responsibility development.

Main research question:

"What are the changes and trends in palliative care and what do they mean to nurses?"

Sub research topics:
- Development history of hospital attitudes towards death;
- Development history of palliative care in the hospital context;
- Development history of nurses' role and responsibility.

/1.2. METHOD

The main methods used for historical research is a combination of literature research and desktop research. The information collected is organized into a timeline that thrives from the early stage of the twentieth century till the current situation and what is brought up for the future (Figure 3). Through this way, it is clear to observe the relationships among the sub-research topics and keep the insights future-oriented. The information resources are from published academic papers and organizational reports, with Western Europe and America background as their developing situation for this research topic is at a similar stage and mainly covering the Dutch situation.

/1.3. FINDINGS

Less death in hospitals but not less care

Death is not an easy and comfortable topic to talk about and encounter both in and out of the health and medical industry. Before the twentieth century when the medical domain had not been developed well, the ability to cure and the capacity of hospitals were relatively low so death mainly happened out of hospitals (Susan, 2015). However, with the rapid development of medical technology from the first decades of the twentieth century, the ability of cure of hospitals distinctly increased so that more lives were admitted to hospitals to accept medical treatment, but it at the same time led to more death cases in the hospital (Weatherford, 2010). With more and more people died in hospitals, the society, especially medical professionals, started to examine and reflect on how patients and their family experience their end of life phase until after death. From the mid-twentieth century, more attention has focused on improving the quality of death and dying (Robert, 2018). It can be noticed in the overview (Figure 3) that along with more forms like hospice were generated as a replacement of hospitals being the places for terminal patients to spend their last days of life, the number of death cases dropped in hospitals. Yet it doesn't mean the drop of attention and less acceptable to death in hospitals, but on the contrary, getting more awareness. This is mainly because of the facts that (1) death cases in hospitals are currently inevitable (2) the society and hospitals started to value the life quality of patients especially in the last stage of their life since the awareness of "good death" arising in the society (Susan, 2015) (3) there are needs from some patients and families who believe that hospital is a safer place to stay in the last days of their life (Ranjana, 2017). Although it is not embraced in every culture and society, it's indeed a common trend supported by many medical professionals and organizations especially in the western world, which will be elaborated in the chapter of cultural and societal research.

What are the cases of death&dying in hospitals nowadays

Nowadays and in near future, most of the cases about death&dying in hospitals are rescue-invalid death in ICU and acute units, as well as dying patients with terminal diseases who only have limited days or hours in departments like the oncology department (illustrated in Figure 4).

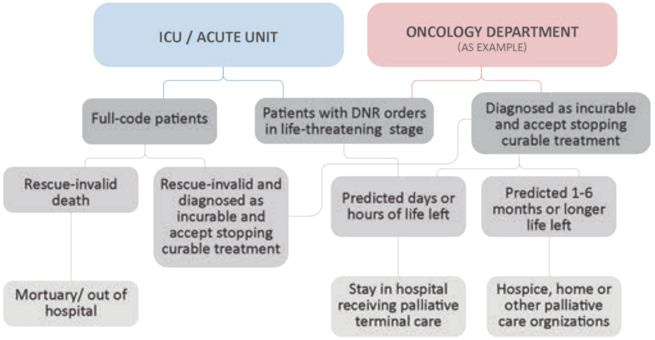
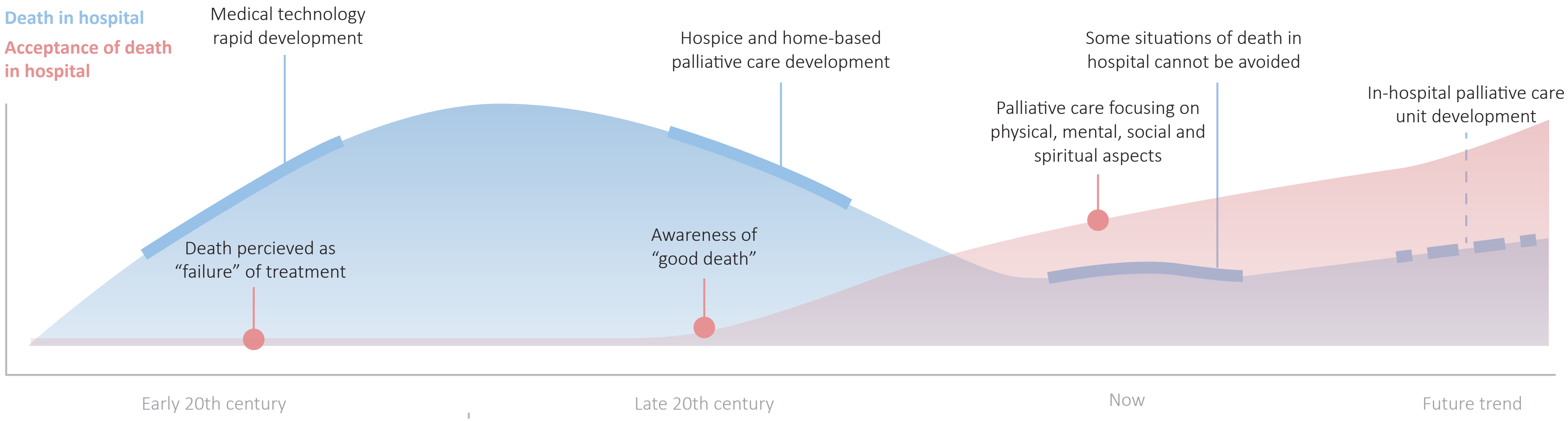


Figure 4. Death&dying cases in hospitals



Nurses’ perception	acting as the “obedient wife” to every patient	Doctors’ assistants	Medical professional	
Nurses’ responsibility	like “a household chore list”	Subservient caretakers; Taking more responsibility from the physicians	More interactions with patients; Involving more in shared decision making	Self-care
Nurses’ responsibility in palliative care		Comfort care for dying patients	Advocacy: information & support; Active listening and effective communication skills	
Nurses’ training&education	Informal apprentice	Schools and degrees to get qualifications; basic health care skills as well as hospital etiquette	Focuse more on the academic side	More medical professionals like nurses have general education on palliative care
Nurses’ training&education in palliative care		Learn from experience and peers	Specializing palliative care education programme for specialized professionals	

Figure 3. Historical overview

(continuing) Nowadays and in near future, most of the cases about death&dying in hospitals are rescue-invalid death in ICU and acute units (Robinson, 2014), as well as dying patients with terminal diseases who only have limited days or hours in departments like the oncology department (illustrated in figure X). They are dying in the wards of their original departments or acute/intense care unit but not specialized palliative care unit which has not been developed and equipped with sufficient recourses yet by most of the hospitals. The way that most of the hospitals provide palliative terminal care to the patients is the integrative palliative care model that forming a palliative care team to support medical professionals who provide routine care, and the team gives specialized palliative care consultations to patients and families (Metaxa, 2019), which is also how palliative care works in Maasstad Hospital currently. However, there is a lack of human resources in these specialized palliative care teams so that the main care work still lies on the normal caregivers like nurses. The dedicated space is also not adequate for terminal patients and their families (Robinson, 2014). Under this circumstance, it is evidenced that most patients and families are not satisfied with the end of life experience (Lai, 2018) meanwhile many medical professionals, especially juniors, report a feeling of unpreparedness to deal with death and dying patients. The reason behind is going to be discussed in the following finding section.

There is a gap between academic development and general medical professionals' attitude and skills , especially for nurses

As the "good death" concept is being aware and promoted gradually, palliative care and end of life care became a specialized discipline in both the academic and medical domains, evidenced by more and more academic research and applications appeared. However, as mentioned, it is still perceived as a specialized discipline so far, hence the corresponding education is also specialized, only towards hospice nurses and palliative care team in hospitals. In this case, to implement palliative terminal care to dying patients, nurses are involved to take responsibilities, while the education most of them received is only cure-oriented (Bharmal, 2019). Therefore, nurses' palliative terminal care skills and attitudes currently can only be learned from experienced medical professionals or peers. Besides, these palliative terminal care skills are becoming complex and more challenging with the changes of nurses' responsibilities along the time which are different from traditional education contents. This will be elaborated in the next finding section.

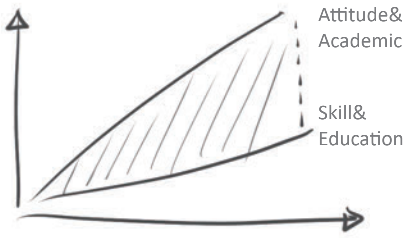


Figure 5. Not alligned situation

Switching the nurses' role requires nurses for more soft skills than before

Throughout the decades, nurses' role in hospitals has changed a lot. Compared with the past when they were perceived as an affiliate of a doctor who was only expected to assist work (All Answers Ltd, 2018), nurses nowadays are in a more independent and advocating position where they take more responsibility for active communication with patients&families and care coordination (ANA, 2012). However, it has two sides like coins for nurses. On the one hand, they are perceived as an individual health professional now, receiving formal and advanced nursing education at school, gaining respect and taking more responsibilities (Mishra, 2015). However one the other hand, it requires more capabilities for nurses to handle the routine care work, especially the soft skills which are not included in school education but become as important as professional skills. They are expected to more than only comfort patients, but also involve more interactions with patients and families like decision-making and guidance, especially for end of life care decisions and communications. (Haisfield-Wolfe, 1996) (Susan, 2015). There is also research mentioned nurses as the advocators of end of life care for patients and families (Hebert, 2011). The most common mentioned top soft skills in the healthcare domain that are discussed online are shown in Figure X. They are organized by if it's more inward (more personal) or more outward (more interactive).
Top soft skills in healthcare domain: (inward and outward)

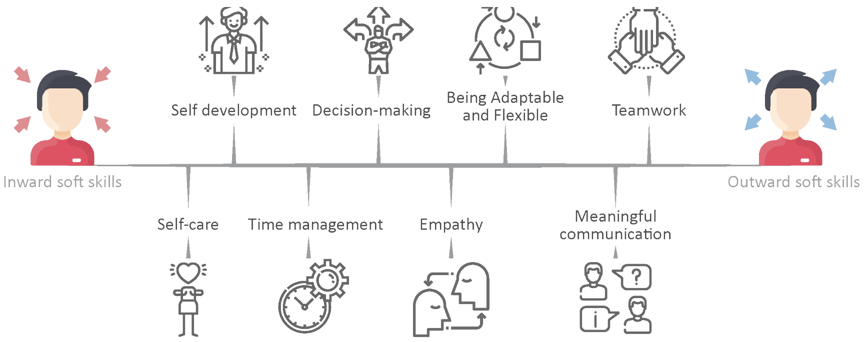


Figure 6. Top soft skills in healthcare domain

Within the sensitive and complex context of patients' death and dying, there are three soft skills that are assupted to possess higher significance than the others.

Compassion and Empathy

In this context, it is about the capability to understand what the patients and families are experiencing so that the nurse is able to help them with what they actually need at the moment and behave in the way that the patients and the families feel comfortable. Empathetic care is believed to be significant to dying well (Fernando, n.d.). However, There is discussion about struggling with being emotionally too close to the patients or building emotional wall, which will be elaborated in the User&Context research chapter supported by nurse interviews.

Meaningful communication

Meaningful communication (AAPC, 2019) (Meg, 2020). It's about actively listening and understanding to the patients and families, as well as adapting the way of communication based on patients&families' emotional status, culture&religions, making the conversations effective for both the nurses and patients&families. In the case of patients dying, the patients and families are likely to be emotional and hard to process information, so this skill is essential for providing palliative terminal care.

Self-care

According to Sherman (2004), self-care is "the self-initiated behavior that people choose to incorporate to promote good health and general well-being". It's about both the awareness of self-care and skills of self-care. The discussion center of nursing was all about the nursing skills that contributed to patients' value and health outcomes, while medical professionals' self-care is recently brought up for their own health and well-being (Mills, 2018). Especially in this research context, nurses experience stressors from personal discomfort with death, burnout, and compassion fatigue (Mills,2018), which makes them in need of promoting and learning self-care. There are barriers and enablers according to Mills and nurse interviews in real practice for the nurses working in the field, listed in Figure 7.

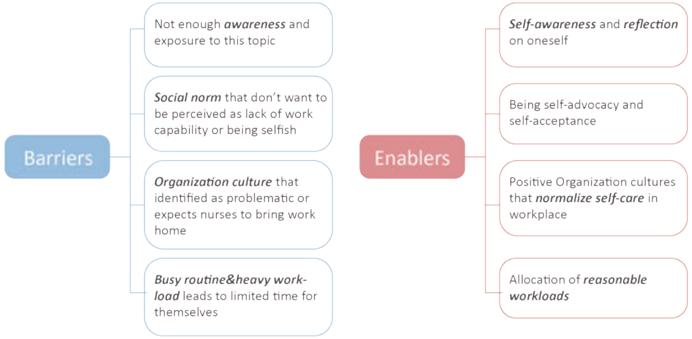


Figure 7. Self-care barriers and enablers

Education and training on caring for dying patients

- Learn how to cope with dying patients as well as how to cope with their own feeling.
Nurses receive education about life-prolonging treatment at school, which makes them form the mindset of looking at death as a failure so that they tend to shy away from dying patients who make them experience the feeling of failure in career (Lisa, 2001). Without relative education or training, nurses who care for dying patients face complex clinical situations suffer from concerning not able to provide proper help and witnessing a patient struggling to cope with terrible pain and other sufferings.
Besides, nursing students not only need to learn how to provide mental support to the patients and family, helping family members grieve, but also need to learn how to deal with their own feelings of sadness or loss (Cathryn, 2011).

- Both school education and on-spot education
Adding the comprehensive contents, especially the spiritual-psychological aspects of end of life care in nurses' school education is expected to be developed to help nurses better equipped with the knowledge coping with caring for dying patients. However, it is evidenced that even short courses in death education can contribute to reducing the death anxiety of nurses and improve nurses' performance coping with death and dying (Peters, 2013). Also, according to Cathryn (2011), how a nurse experiences her/his the first death patient and whether he or she is supported by colleagues or mentors can leave a significant influence on how that nurse reacts to future patients' death. This support for their first experience can be perceived as on-spot education.

Combining the knowledge from literature research and nurse interviews, although there are specialized training program in medical academies and organizations, many of the nurses still don't choose take the courses while already starting working in a hospital or nursing home. That's because it highly relies on their time management capability and self-motivation. Therefore, currently the main approach for general nurses to learn palliative terminal care is through on-site learning after starting their career.

Insights from this chapter

Palliative terminal care in the hospital setting still requires better implementation, where nurses play an important role since they are the direct care providers.

It requires nurses to develop more soft skills out of their working capabilities, including communication skills, empathy, and self-care strategies.

The education and training of palliative terminal care also needs to catch up the development and increasing awareness of palliative care, to be developed to support nurses adapting capability to provide a better quality of care.

2

CUTURAL AND SOCIETAL RESEARCH

To obtain a comprehensive understanding of the death and dying cintext, cross-culture and societal study is conducted to gain understanding and inspirations from cutural and societal different cognitions. (Dutch, general European, and Chinese hospital-based palliative terminal care)

CHAPTER 2. CULTURAL AND SOCIETAL RESEARCH

/2.1. INTRODUCTION

Aim of the research: Cross-culture and societal study to gain understanding and awareness of different attitudes towards context.

Main research question:

"How dying and death influence palliative care nursing under different cultures and social forms and what do they mean to nurses?"

Sub research topics:
- The cultural difference towards Death&Dying (end of life);
- The cultural difference in palliative care;
- What does it mean to nurses' work.

/2.2. METHOD

The main methods used for user and context research is a combination of literature research, desktop research, and online interviews.

Interviews consist of four Dutch nurses from Maasstad Hospital (representative for Western culture) and four Chinese nurses from Shanghai and Guangdong (representative for Asian culture) as a cultural comparison reference between Western and Asian cultures. The records of the interviews can be found in Appendix A&B.

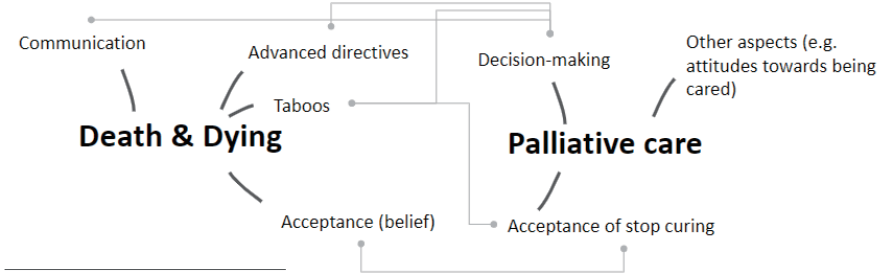


Figure 8. Research topic map

/2.3. FINDINGS

■ **Not all cultures are open to accept stopping life-prolonging treatment under certain circumstances and starting palliative terminal care**

While Western society mostly believe that the fact of severe, incurable disease and the message of death should convey to patients and family honestly (Searight, 2005), other cultures like Chinese prone to actively protect terminally ill patients from the knowledge of their condition (Li, 2013) (Lee et al, 2018). While the European and American society mostly value autonomy, they perceive conveying the fact to the patient as the respect and fair to the patients (Chater, 2008), the Chinese culture perceive this honesty as a way that would eliminate the patient's hope, as well as bring anxiety to the suffering patient, which is disrespectful at someone's last stage of life.

This cultural difference is also revealed in Chinese nurse interviews. Three out of four interviewed nurses mentioned their concern for the lack of advanced care planning in China. In a society where is more open to death conversations and acceptance, it's easier to plan for one's end of life in advance, avoiding the absence of one's own decision about the way to die under the circumstance that the patients are not able to communicate anymore. However, since most of the Chinese, especially the elderly, feel not comfortable to talk about death and dying and even perceive it as an ominous disrespected topic, people barely plan for their end of life and discuss with their relatives. This has led to lots of conflicts among the elderly's children outside the ward at the last stage of one's life, which is not expected from anyone.

■ **Decision-making drivers regarding end-of-life issue or general medical decisions can be different in cultures**

There are mainly four typical modes of decision-making among different cultures and societies recognized (Searight, 2005).

Individual centered	Typical case: American It's commonly existing in the society where values independency and autonomy.

Doctor/ physician centered	Typical case: Eastern European It can be found in the society where authority, respect, and deference to physicians are highly valued.
Family centered	Typical case: Asian It can be found in higher value on beneficence and nonmaleficence,death is family event.
Doctor/ physician centered	Typical case: Asian It can be found in higher value on beneficence and nonmaleficence,death is family event. Yet it gradually becomes a global trend.

Spirituality in palliative terminal care

According to Steinhauser (2017), spirituality is described as one of the fundamental elements of human experience. It includes one's cognitions and search of the meaning of illness and the meaning and purpose of existence and death, as well as one's inner connection and relationships with others and the surrounding world. Spirituality is also related to personal beliefs and religions.

As different cultures and societies shape different spiritualities and spiritual needs, it is an important care element in palliative terminal care which is highly related to the quality of care. It is able to influence the way to communicate about death and dying when it comes to different beliefs on death or fear and anxiety towards death. It also differs people's diverse ways to grieve, bereavement, and related ceremonies from different backgrounds. (Steinberg, 2011)

Other cultural and religious concerns

- In some cultures, when it comes to the communication about serious illness and death, the way of conveying the information may not be overt, it can be conveyed with subtlety, for instance, via facial expressions, voice tone, or other nonverbal cues (Searight, 2005).

- Religions also influence people to react differently in their end of life phase. For instance, some religions don't accept giving up life proactively so that they are not open to signing for DNR orders (Steinberg, 2011). In some other religions, perceiving pain and suffering a step to concentrate on God leading to their refusion to receive palliative care while dying (Cain et al, 2018).

- Many Chinese elderlies at their end of life phase consist of the thoughts that don't want to be others' burdens, which makes them report less of the facts they experience or concerns those they assume would become others' extra workload or worries (Ho et al, 2013) (Lee et al, 2018).

What does it mean to nurses

When it comes to multicultural communication, it includes both nurses' cultural backgrounds and patients&families' cultural backgrounds. Having the right to possess their own beliefs, nurses are encouraged to have a broad understanding on other different beliefs and preferences, which will support a better quality of care and the match of care and needs, avoiding communicating only from the perspective and preference from their own cultural background. Sensitivity to cultural diversity should be integrated within ethical principles for end-of-life care work. Accordingly, different behavior patterns or communication styles should be considered to apply for patients from different cultures or religions, as well as care preference.

Insights from this chapter

Preferences and needs of palliative terminal care can differ from each patient&family's cultural background related to cognitions, beliefs and values, which will influence the quality of care they receive.

To ensure the quality of care, to be able to realize and communicate on patients' and family's preference on end-of-life care is required to convey a good death, including cultural and personal traditions, decision making and communication styles, as well as spiritual needs.

Nurses also possess their own cultural backgrounds with their own cognitions on death and dying. It would be helpful for nurses to provide care to patients&families from different background if they can be first aware of and understand their own concerns.

3

USER AND CONTEXT RESEARCH

After the big picture of palliative terminal care is drawn, this chapter will focus on the understanding and analysis of user (nurses, patients, family&friends) experience, needs and stakeholder relationship, as well as the actual context of palliative care implementation in Maasstad Hosital, to investigate the problems and challenges there.

CHAPTER 3. USER AND CONTEXT RESEARCH

/3.1. INTRODUCTION

Aim of the research: Analysis of user (nurse) experience, needs, and stakeholder relationship in Maasstad Hospital; Understanding of current context in Maasstad Hospital.

Main research question:

“Who are these stakeholders and what’s the current experience of key stakeholders?”

Sub research topics:
- **Where** this care is given in Maasstad Hospital;
- **When** this care is given, under what circumstance and for how long;
- **Who** are the users and the stakeholders, how is their relationship, what’s their concerns and needs;
- **What** is happening: integrating experience;
- **Why** it happens: problem analyzing.

/3.2. METHOD

The main methods used for user and context research is a combination of literature research, desktop research, and online interviews. The context analyzing focuses on the oncology department of Maasstad Hospital, where experiences a relatively higher amount of dying patients, as a typical case to allow a more detailed and targeting context understanding. The interviews consist of four Dutch nurses from the oncology department of Maasstad Hospital, ranging from experienced nursing specialists to unexperienced trainee nurses. The interview outcomes are used to create personas and experience journey map. The records of the interviews can be found in Appendix A&B.

*Limitation:

Due to coronavirus situation, the field interviews and observations are not accessible, as well as the online interview amount is limited. To compensate for the deficiency of user data, story collection is used as a way to understand the target group more comprehensively, by creating an empathy map out of all the statements from the stories collected.

/3.2.1 ONLINE INTERVIEWS

A series of nurse interviews are conducted to understand the responsibilities and working experience in the cases of taking care of dying patients. Therefore, nurses with different career lengths are recrewing for the interviews to understand the individual differences and influential factors. They are experienced specialist oncology-palliative and hematology nurse, student nurse, nursing intern, and nurse in the training of oncology nurse.

/3.2.2 STORY COLLECTING - EMPATHY MAP

This method is conducted as a supplement to the limited amount of nurse interviews, to gain a more comprehensive understanding of the nurse group. By mining through up-to-date online nurse interview videos, news, and nurse documentaries about nurses sharing their feelings and memories about experiencing taking care of dying patients in their careers, their’ statements and concerns are collected into an empathy map. To recognize the common experience, concerns, and values, the statements are labeled into different categories shown in Figure 9.

/3.3. FINDINGS

/3.3.1 CURRENT SCENARIO (TO BE RENEWED AFTER INTERVIEWS)

The patients who enter their last stage of life stay in the wards in the oncology department of Maasstad Hospital (check through the interviews if the dying patient would be transferred to a separate room). The length of their stay is not fixed which can be days or hours, normally less than a week. It starts from the doctor’s diagnosis of incurable status: shared-decision making on if stopping life-prolonging treatment and starting palliative care. It ends with clinical death (heart stops beating) and biological death. It also includes the care after death which are care for the dead bodies and grieving.

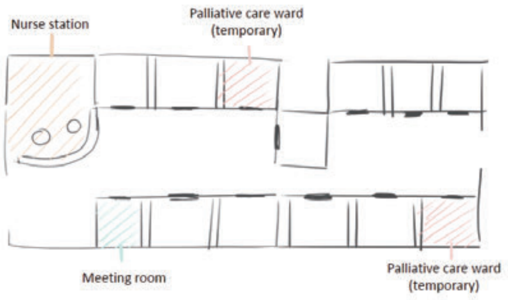
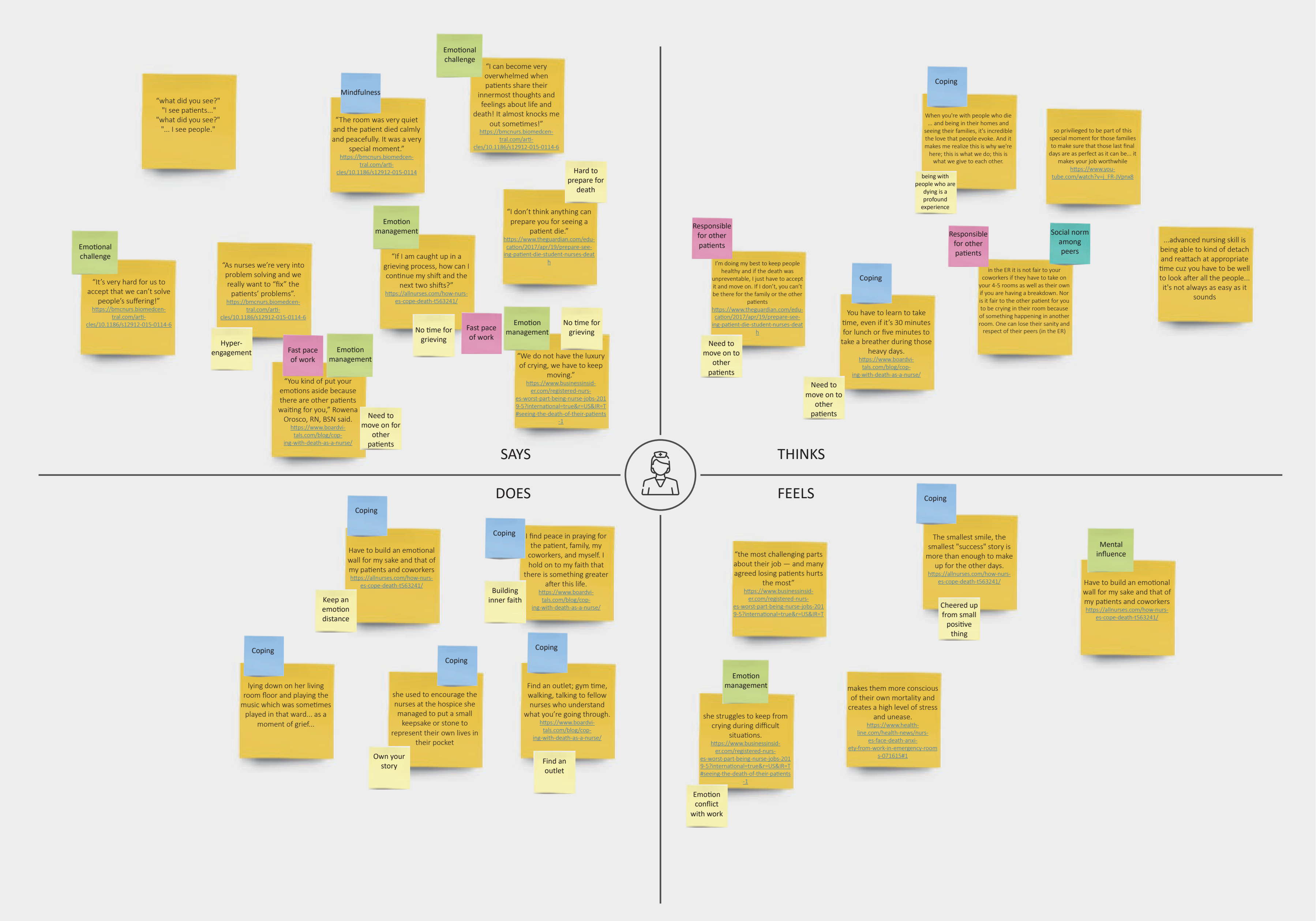


Figure 10. Layout of the field wards



SAYS

"what did you see?" "I see patients..." "what did you see?" "... I see people."

Mindfulness
"The room was very quiet and the patient died calmly and peacefully. It was a very special moment." https://bmcnurs.biomedcen-tral.com/arti-cles/10.1186/s12912-015-0114

Emotional challenge
"I can become very overwhelmed when patients share their innermost thoughts and feelings about life and death! It almost knocks me out sometimes!" https://bmcnurs.biomedcen-tral.com/arti-cles/10.1186/s12912-015-0114-6

Hard to prepare for death
"I don't think anything can prepare you for seeing a patient die." https://www.theguardian.com/edu-cation/2017/apr/19/prepare-see-ing-patient-die-student-nurses-death

Emotional challenge
"It's very hard for us to accept that we can't solve people's suffering!" https://bmcnurs.biomedcen-tral.com/arti-cles/10.1186/s12912-015-0114-6

"As nurses we're very into problem solving and we really want to "fix" the patients' problems". https://bmcnurs.biomedcen-tral.com/arti-cles/10.1186/s12912-015-0114-6
Hyper-engagement

Emotion management
"If I am caught up in a grieving process, how can I continue my shift and the next two shifts?" https://allnurses.com/how-nurs-es-cope-death-t563241/
No time for grieving

Fast pace of work
Emotion management
No time for grieving
"We do not have the luxury of crying, we have to keep moving." https://www.businessinsid-er.com/registered-nurs-es-worst-part-being-nurse-jobs-2019-5?international=true&r=US&IR=T#seeing-the-death-of-their-patients-1

Fast pace of work
Emotion management
"You kind of put your emotions aside because there are other patients waiting for you," Rowena Orosco, RN, BSN said. https://www.boardvi-tals.com/blog/cop-ing-with-death-as-a-nurse/
Need to move on for other patients

THINKS

Coping
When you're with people who die ... and being in their homes and seeing their families, it's incredible the love that people evoke. And it makes me realize this is why we're here; this is what we do; this is what we give to each other.
being with people who are dying is a profound experience

so privilieged to be part of this special moment for those families to make sure that those last final days are as perfect as it can be... it makes your job worthwhile https://www.you-tube.com/watch?v=j_FR-JVpnx8

Responsible for other patients
I'm doing my best to keep people healthy and if the death was unpreventable, I just have to accept it and move on. If I don't, you can't be there for the family or the other patients https://www.theguardian.com/edu-cation/2017/apr/19/prepare-see-ing-patient-die-student-nurses-death
Need to move on to other patients

Coping
You have to learn to take time, even if it's 30 minutes for lunch or five minutes to take a breather during those heavy days. https://www.boardvi-tals.com/blog/cop-ing-with-death-as-a-nurse/
Need to move on to other patients

Responsible for other patients
Social norm among peers
in the ER it is not fair to your coworkers if they have to take on your 4-5 rooms as well as their own if you are having a breakdown. Nor is it fair to the other patient for you to be crying in their room because of something happening in another room. One can lose their sanity and respect of their peers (in the ER)

...advanced nursing skill is being able to kind of detach and reattach at appropriate time cuz you have to be well to look after all the people... it's not always as easy as it sounds

DOES

Coping
Have to build an emotional wall for my sake and that of my patients and coworkers https://allnurses.com/how-nurs-es-cope-death-t563241/
Keep an emotion distance

Coping
I find peace in praying for the patient, family, my coworkers, and myself. I hold on to my faith that there is something greater after this life. https://www.boardvi-tals.com/blog/cop-ing-with-death-as-a-nurse/
Building inner faith

Coping
lying down on her living room floor and playing the music which was sometimes played in that ward... as a moment of grief...

Coping
she used to encourage the nurses at the hospice she managed to put a small keepsake or stone to represent their own lives in their pocket
Own your story

Coping
Find an outlet; gym time, walking, talking to fellow nurses who understand what you're going through. https://www.boardvi-tals.com/blog/cop-ing-with-death-as-a-nurse/
Find an outlet

FEELS

"the most challenging parts about their job — and many agreed losing patients hurts the most" https://www.businessinsid-er.com/registered-nurs-es-worst-part-being-nurse-jobs-2019-5?international=true&r=US&IR=T

Coping
The smallest smile, the smallest "success" story is more than enough to make up for the other days. https://allnurses.com/how-nurs-es-cope-death-t563241/
Cheered up from small positive thing

Mental influence
Have to build an emotional wall for my sake and that of my patients and coworkers https://allnurses.com/how-nurs-es-cope-death-t563241/

Emotion management
she struggles to keep from crying during difficult situations. https://www.businessinsid-er.com/registered-nurs-es-worst-part-being-nurse-jobs-2019-5?international=true&r=US&IR=T#seeing-the-death-of-their-patients-1
Emotion conflict with work

makes them more conscious of their own mortality and creates a high level of stress and unease. https://www.health-line.com/health-news/nurs-es-face-death-anxi-ety-from-work-in-emergency-rooms-071615#1

Figure 9. Empathy Map

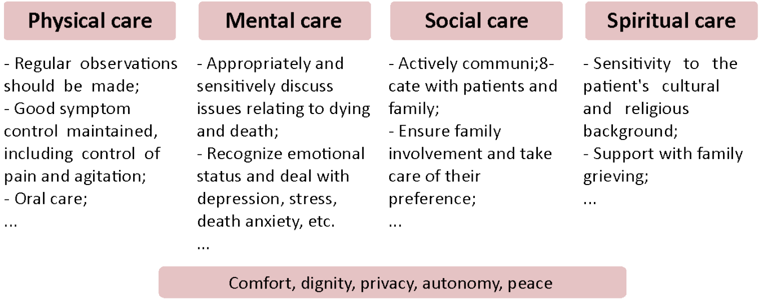
/3.3.2 STAKEHOLDERS AND RELATIONSHIP

Target user - Nurses in oncology department

Known from the interviews, the nurse who is assigned to care the patient is involved in most of the interaction with the patients through the daily care routine. They also take the responsibility of actively communicating with patients and their family/friends. When taking care of dying patients, their goal is to meet patients' care preferences and needs, provide them with the condition towards a good death, and to take care of both patients and families with comfort, privacy, respect, and dignity.

What they do as work routine in a day/night shift is to observe and check patients' status and symptoms to adjust medicine and other treatments. They need to switch from curative care wards and palliative care wards, and actively guide and communicate with patients and their families. There are challenges lying in their work including dealing with the fast-paced work routine, communicating with emotional patients and family, personal discomfort with death and relevant memory, stress, burnout and compassion fatigue, etc.

The specific care work that are expected in palliative terminal care to conduct to a good death for patientsis shown in Figure 11.

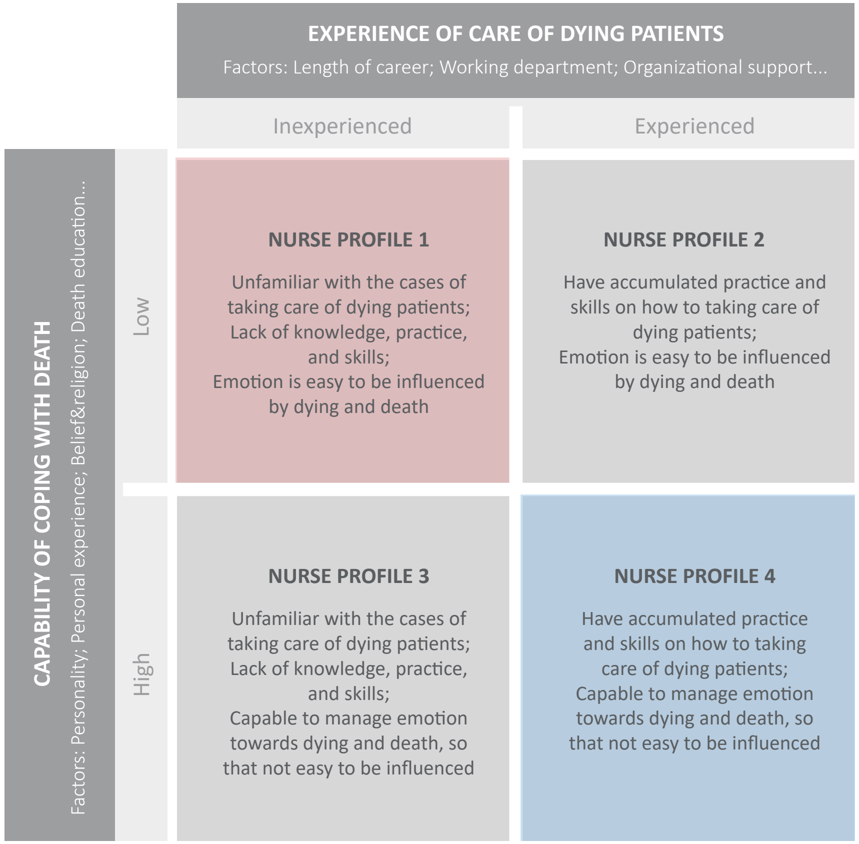


Physical care	Mental care	Social care	Spiritual care
- Regular observations should be made; - Good symptom control maintained, including control of pain and agitation; - Oral care; ...	- Appropriately and sensitively discuss issues relating to dying and death; - Recognize emotional status and deal with depression, stress, death anxiety, etc. ...	- Actively communi;8cate with patients and family; - Ensure family involvement and take care of their preference; ...	- Sensitivity to the patient's cultural and religious background; - Support with family grieving; ...

Comfort, dignity, privacy, autonomy, peace

Figure 11. Contents expected in palliative terminal care

The experience and challenges for nurses can be different from each other based on various influential factors like their length of career, working department, organizational support, personality, personal experience, belief&religion, education background... To gain a clear and targeted view of the character of nurses, a nurse profile is created to summarize and distinguish typical nurse characters in the context. The various influential factors are categories into their experience level of taking care of dying patients and their personal capability of coping with death&dying. From there, four types of nurse characters are created, as shown in Figure 12.



EXPERIENCE OF CARE OF DYING PATIENTS

Factors: Length of career; Working department; Organizational support...

CAPABILITY OF COPING WITH DEATH

Factors: Personality; Personal experience; Belief&religion; Death education...

	Inexperienced	Experienced
Low	**NURSE PROFILE 1** Unfamiliar with the cases of taking care of dying patients; Lack of knowledge, practice, and skills; Emotion is easy to be influenced by dying and death	**NURSE PROFILE 2** Have accumulated practice and skills on how to taking care of dying patients; Emotion is easy to be influenced by dying and death
High	**NURSE PROFILE 3** Unfamiliar with the cases of taking care of dying patients; Lack of knowledge, practice, and skills; Capable to manage emotion towards dying and death, so that not easy to be influenced	**NURSE PROFILE 4** Have accumulated practice and skills on how to taking care of dying patients; Capable to manage emotion towards dying and death, so that not easy to be influenced

Figure 12. Nurse profiles

Nurse Profile 1 and 4 are chosen as extreme characters to be more detailed analyzed in the form of creating their character personas (Figure 13. and Figure 14.), and will be further analyzed in the nurse journey maps separately.

Tess
van Bergen
Junior nurse, 20, unmarried

Nurse profile 1
Working in oncology unit

Rotterdam, the Netherlands

> I want to act professional for all of my patients, but I'm not used to care for dying patients. It's not easy to fully concentrate myself and to know what I should do for the patients... It leaves me hard time after getting involved in a patients' death...

Value and goals

- Be able to prepare myself for looking after dying patients
- Be able to cope with the unfamiliar feeling after witnessing dying and death
- Always be able to reach to guide and support from senior colleagues
- Be able to support the patients and families achieve a good death: make sure the dying patients are comfortable and peaceful
- Through communication with the patients and families, provide information helpful for them as the best as I can

Concerns

- If I can conquer my fear or uncomfortable feeling towards dying and death, and make sure it won't influence my other work
- If I'm motivated to get involved in palliative care work
- How can I prepare for it when I get involved in palliative terminal care work
- If I have access to the basic knowledge of palliative terminal care
- If I can manage the work as soon as possible
- If I'm doing everything right for the patients and families
- If I can hang in there and get used to it

Desired outcomes

I want to be capable with palliative terminal care work at ease through a period of on-site learning and experience accumulating, during which I can reach guidance and knowledge from others in the department. I want to become competent and comfortable caring for dying patients.

Design challenge/opportunity

- On-site education on palliative terminal care from experienced colleagues
- Be supported to be ready and prepare for going to the dying patients
- The potential relationship between me and the palliative care team
- Mental care
- Team support and peer interaction

Figure 13. Persona for Nurse Profile 1

Marie
van der Kamp
Experienced oncology nursing specialist, 38, married

Nurse profile 4
Working in oncology unit

Rotterdam, the Netherlands

> It's so privilieged to be part of this special moment for those families to make sure that those last final days are as perfect as it can be, It makes me feel my job worthwhile... This job gradually makes me feel my life is so meaningful. I really appreciate it...

Value and goals

- Be able to recognize the dying patients and advocate the discussion on the end of life care;
- Agood death: make sure the dying patients are comfortable and peaceful
- Through communication with the patients and families, provide information helpful for them as the best as I can to help them understand the situation
- Always be able to reach to extra support like palliative care team
- The team works together and be able to support each other

Concerns

- If I can maintain a balanced emotion connection with the dying patients
- If I'm doing good enough for the dying patients and families
- If I can solve the emotion before offwork, don't want to take it home
- If I'm able to manage to guide the juniors
- About the communication quality with colleagues holding a different point of view
- About my colleagues' feeling and mood

Desired outcomes

I'm equipped with sufficient knowledge and skills that allow me being able to manage the care work and communication with the patients and families, which will support them to achieve an expected good death, as well as share my experience and knowledge with others.

Design challenge/opportunity

- Effective interaction with patients and family to understand needs and receive feedback
- Coaching inexperienced nurses, knowledge and skill sharing
- Supportive teamwork infrastructure in day and night shifts
- Shared decision making among nurse, patient, family and doctor

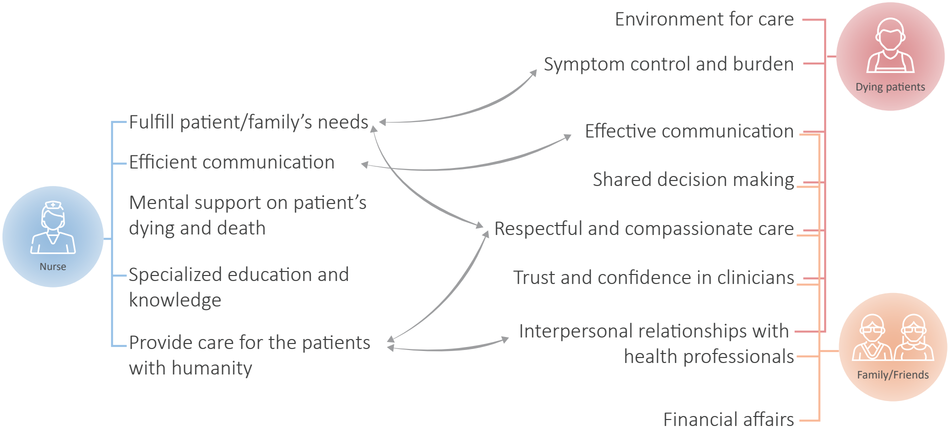
Figure 14. Persona for Nurse Profile 4

Key stakeholders

- **Patients:** The terminal patient is the center of the care, to be ensured with dying in comfort and dignity. The patients receiving palliative terminal care in the oncology department are who are diagnosed to be incurable and make the decision on stopping life-prolonging treatment. For them, keeping invasive cure-oriented treatment only leads to more suffering at the last stage of their life. Their main needs during palliative terminal care include following aspects:
  (1) careful management of pain and other symptoms;
  (2) patient dignity and independence;
  (3) family involvement and support;
  (4) Awareness of death and good communication with healthcare professionals

- **Patient's family/friends:** In palliative terminal care, the patient's family/friends are also supposed to be part of the care, receiving care in terms of mental support and shared-decision making.

The most important needs and demands that patients and their family/friends reported are summarized from Virdun's (2015) and Robinson's (2014) research, which are linked to the nurses' needs and goals in the figure below:



Seen from the figure, the common goals of nurses, patients, and family/friends are centralizing at the mutual effective communication and the care quality respect and compassion, which requires the nurses who are working on providing palliative terminal care to be able to recognize their needs and concerns, and communicate with the patient/family timely. This requirement is coherent with the soft skills mentioned in Chapter Historical Research.

Other stakeholders

- Nurse peers: There are peer interactions among nurses which is able to influence their behaviors. Besides, the interaction among nurses from different nurse profiles but working together can also be a strong influencer.

- Palliative care team: Nurses will be supported by the palliative care team on providing knowledge and specialized care work. A palliative care team normally consists of a number of doctors, nurses, social workers, and a coordinator, and if necessary, psychiatrist, psychologist, cardiologist, nurse specialists, etc. The team is the general palliative care advocator of the hospital, who possesses the most specialized knowledge and resources, and who drives the implementation and optimization of pallaitive care.

- Other patients&families: They share part of the same environment (common space like corridors) with the terminal patients, and also be possible to receive care from the same nurses and other medical professionals with the terminal patients, which creates the indirect influence between them and their family/friends.

- Other medical professionals: Other medical professionals like physicians can get involved in shared-decision making with other stakeholders, and engaging in and supporting nurses' care work.

- Maasstad Academie: Support and promote improvement and innovation for better care quality.

The relationships between all the stakeholders is illutrated in Figure 15.

/3.3.3 NURSE JOURNEY MAPS

The insights from desktop research and nurse interviews are integrated into two overview journeys. The first journey illustrates stakeholder's involvement during a complete process of a dying patient's palliative terminal care, with the problems and concerns from the nurses pointed out. The second journey demonstrates a day shift's journey of a nurse in the Oncology Department under the circumstance that she/he is assigned to terminal patients. Although the nurses state that they experienced more death during the night shift, it is less challenging and complex for them since it's less busy and more peaceful to deal with the situation, having more time for the patients and themselves. Therefore, the journey focuses on the day shift situation to cover more problems and concerns that nurses faced.

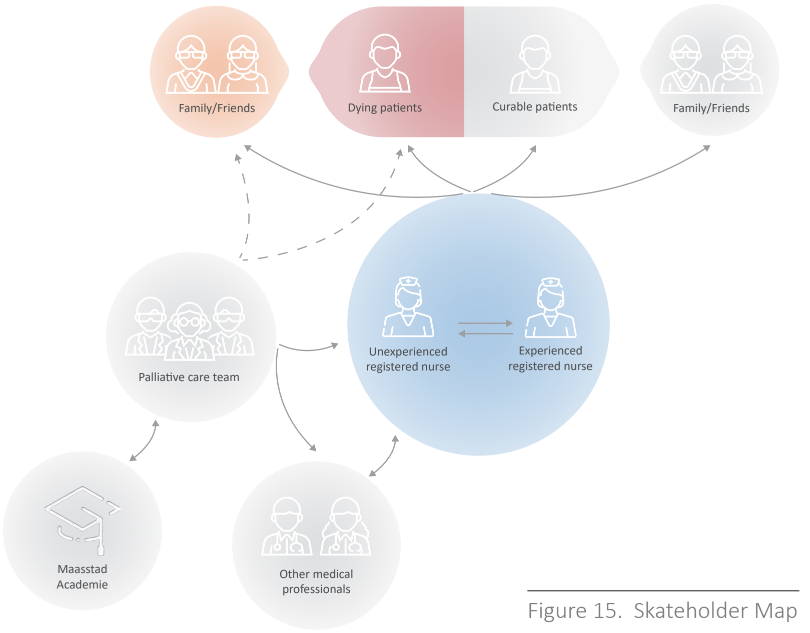


Figure 15. Skateholder Map

Insights from this chapter - Barriers and Enablers for nurses

Barriers

Lack of knowledge and practical skills at the beginning of providing palliative care;

Nurses need to face the inner conflict that they are trained at school to cure patients which becomes their motivation of career, but for palliative care it's not aiming for cure anymore;

Nurses' personal fear and anxiety about death and dying but no time to digest in fast pace of work;

Hard to balance the emotional connection with patients leading to compassion fatigue.

Enablers

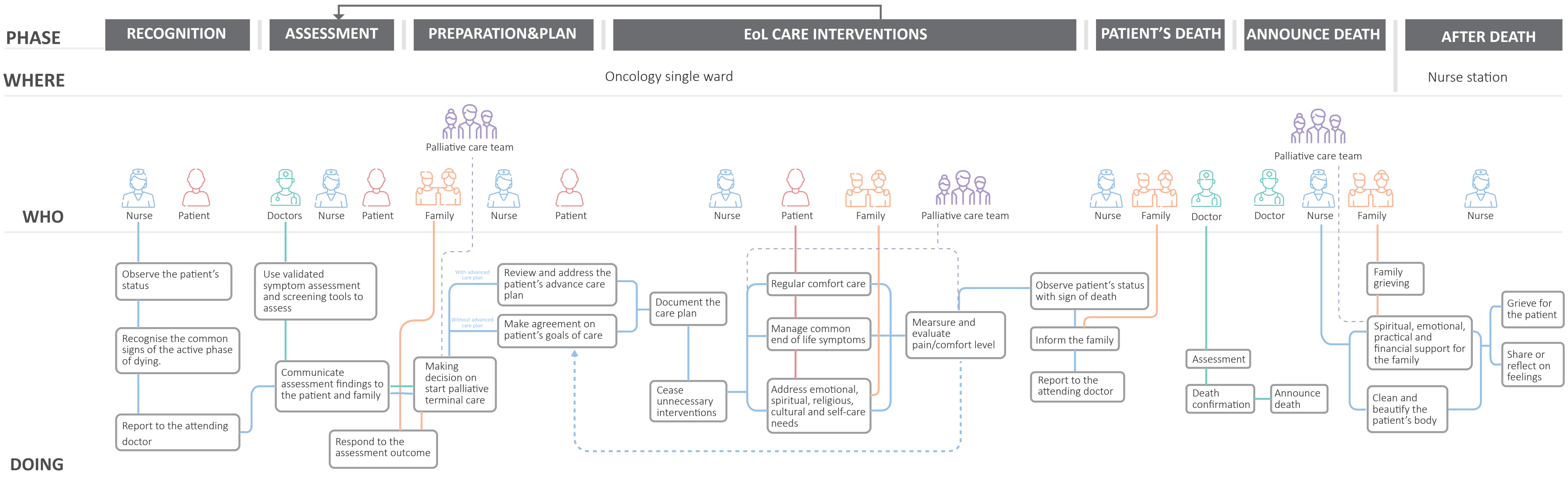
Observe experienced nurses and try out from actual practice;

It's always a team effort: peer support and gain support from specialized palliative care team;

Develop self-care strategies: learn to be aware of one's own negative feelings and explore the valid strategies that work for oneself, like practice meditation, self-care rituals, or keeping diaries;

Give oneself an opportunity for a closure after the negative feeling at the end of the day or a patient's death, letting it out and avoid bringing it into one's own life.

PALLIATIVE TERMINAL CARE FOR A DYING PATIENT



PHASE
RECOGNITION
ASSESSMENT
PREPARATION&PLAN
EoL CARE INTERVENTIONS
PATIENT'S DEATH
ANNOUNCE DEATH
AFTER DEATH

WHERE
Oncology single ward
Nurse station

WHO
Nurse
Patient
Doctors
Nurse
Patient
Family
Palliative care team
Nurse
Patient
Nurse
Patient
Family
Palliative care team
Nurse
Family
Doctor
Palliative care team
Doctor
Nurse
Family
Nurse

DOING
Observe the patient's status
Recognise the common signs of the active phase of dying.
Report to the attending doctor
Use validated symptom assessment and screening tools to assess
Communicate assessment findings to the patient and family
Respond to the assessment outcome
Making decision on start palliative terminal care
With advanced care plan
Without advanced care plan
Review and address the patient's advance care plan
Make agreement on patient's goals of care
Document the care plan
Cease unnecessary interventions
Regular comfort care
Manage common end of life symptoms
Address emotional, spiritual, religious, cultural and self-care needs
Mearsure and evaluate pain/comfort level
Observe patient's status with sign of death
Inform the family
Report to the attending doctor
Assessment
Death confirmation
Announce death
Family grieving
Spiritual, emotional, practical and financial support for the family
Clean and beautify the patient's body
Grieve for the patient
Share or reflect on feelings

TOUCH POINT

- HIX (patient record system)
- COW
- Communication toolkit
- Ward enviroment
- HIX (patient record system)
- COW
- Ward enviroment
- Cleaning tools
- Personal rituals

PROBLEMS/ CONCERNS

PROFILE 1

Lack of experience on the observation and gut feeling on judging patient's situation

Uncomfortable and anxious feeling about death

Not motivated to get involved

Not motivated to initial on-site learning

Upset by the fact

Not sure how to communicate the fact with the patient&family

Feeling weird or guilty and feeling of priviliged on someone's life

Not being pushed hard to it but need to be self-motivated

Not sure about the corresponding solution for all kinds of symptoms and situations

Hard to concentrate on the care work

Need to balance the relationship boundary with the patients

Bad feeling when witness patients in restless status-delirium

The fear of death

Recall the related memory in own experience

The fear and uncomfortable feeling touching dead body

Need to take care of one's own feeling

Try not to take the emotion back home

PROFILE 4

Conflict on the starting point of stop treatment with doctors or other medical professional in the team

Need of communication skill with the patient and family about the decision making

Hard for patient &famaliy to understand

Hard for patient &famaliy to Accept

Whether and when to involve the ppliative care team

Need of communication with the patient and family about their needs, wishes and preference

Need to balance the relationship boundary with the patients

Need to make sure if the care for the patient is effective and helpful

Take care of the patients for their comfort and dignity

Need to receive feedback from the patient and family to adjust care plan

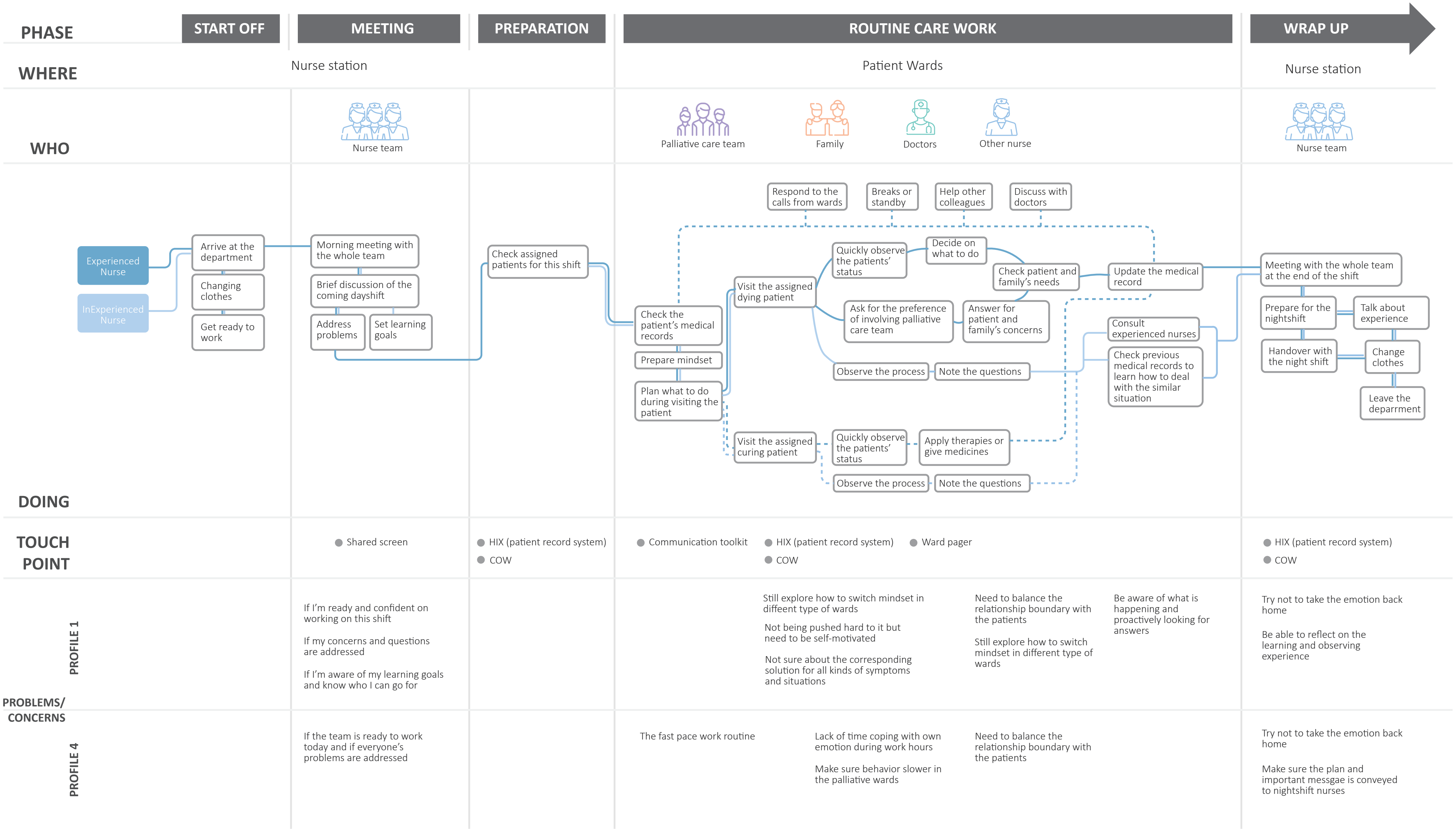
Bad feeling when witness patients in restless status-delirium

Conquer the sadness of loss/patient's death

Need to take care of one's own feeling

Try not to take the emotion back home

A DAYSHIFT JOURNEY OF A NURSE



PHASE	START OFF	MEETING	PREPARATION	ROUTINE CARE WORK	WRAP UP
WHERE		Nurse station		Patient Wards	Nurse station
WHO		Nurse team		Palliative care team Family Doctors Other nurse	Nurse team
DOING	Experienced Nurse InExperienced Nurse Arrive at the department Changing clothes Get ready to work	Morning meeting with the whole team Brief discussion of the coming dayshift Address problems Set learning goals	Check assigned patients for this shift	Check the patient's medical records Prepare mindset Plan what to do during visiting the patient Respond to the calls from wards Breaks or standby Help other colleagues Discuss with doctors Visit the assigned dying patient Quickly observe the patients' status Decide on what to do Check patient and family's needs Update the medical record Ask for the preference of involving palliative care team Answer for patient and family's concerns Observe the process Note the questions Consult experienced nurses Check previous medical records to learn how to deal with the similar situation Visit the assigned curing patient Quickly observe the patients' status Apply therapies or give medicines Observe the process Note the questions	Meeting with the whole team at the end of the shift Prepare for the nightshift Talk about experience Handover with the night shift Change clothes Leave the deparrment
TOUCH POINT		● Shared screen	● HIX (patient record system) ● COW	● Communication toolkit ● HIX (patient record system) ● COW ● Ward pager	● HIX (patient record system) ● COW
PROBLEMS/ CONCERNS — PROFILE 1		If I'm ready and confident on working on this shift If my concerns and questions are addressed If I'm aware of my learning goals and know who I can go for		Still explore how to switch mindset in diffeent type of wards Not being pushed hard to it but need to be self-motivated Not sure about the corresponding solution for all kinds of symptoms and situations Need to balance the relationship boundary with the patients Still explore how to switch mindset in different type of wards Be aware of what is happening and proactively looking for answers	Try not to take the emotion back home Be able to reflect on the learning and observing experience
PROBLEMS/ CONCERNS — PROFILE 4		If the team is ready to work today and if everyone's problems are addressed		The fast pace work routine Lack of time coping with own emotion during work hours Make sure behavior slower in the palliative wards Need to balance the relationship boundary with the patients	Try not to take the emotion back home Make sure the plan and important messgae is conveyed to nightshift nurses

4

COMPARISON STUDY

To broaden the scope of inspirations, palliative terminal care in the different settings are compared, including Home-based, Community-based, Hospital-based palliative care and Hospice, learning from other settings.

CHAPTER 4. COMPARISON STUDY

/4.1. INTRODUCTION

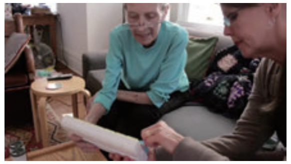
Aim of the research: Compare different models of palliative care with different settings and resources, to analyze the limitation of the current context and gain inspiration from other settings.

Main research question:

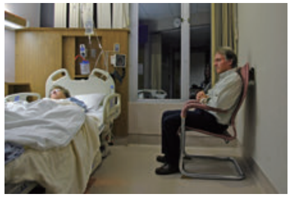
“How can palliative care in other settings inspire the hospital-based palliative terminal care? ”

Compared subjects:
- Home-based palliative care
- Community-based palliative care
- Hospice
- Nursing home
- Hospital-based palliative care


Home-based palliative care


Community-based palliative care


Hospice palliative care


Hospital-based palliative care

/4.2. METHOD

The main methods used for compassion research is a combination of literature research and desktop research.

Different aspects of various palliative care settings are compared, including their corresponding models, human resources involved, staff training, physical setting, essential requirements, as well as their pros and cons compared to each other. The information resources are thrived from Planning and implementing palliative care services: a guide for programme managers (WTO, 2016), as well as papers and reports describing the different settings of palliative care service in the Netherlands or other western countries (Murat, 2019) (Robinson, 2014) (Brandt, 2006) (Francke, 2000).

/4.3. INSPIRATIONS

Recourses balance

Compared to the service setting at home, community, and hospice where the resources of palliative care are center at one spot, hospital palliative terminal care meeting good care quality is facing the difficulty of lack of specialized human resources and environment. The only presence of a palliative care team is not sufficient for dying patients’ daycare. Traditionally, hospital is expected to be the place to cure patients where the resources and attention are centralized to curable patients. Therefore, to implement palliative terminal care with quality, how to balance the resources regarding human resources, time, space, and equipment for curable patients and terminal patients need to be reconsidered.

Desired environment

Many patients feel more comfortable in their home than in a health-care setting at the last stage of their life. Indeed a preferred environment is important for terminal patients to stay in peace and dignity, and enjoy their time with families. It is easier to implement in a specialized space where the main function remains the same, which is making the patients feel comfortable and like home. However, in palliative terminal care in the hospital setting, as the wards for dying patients are temporary, whose main function is monitoring the patients and optimizing treatment outcome, there is a lack of privacy (everything works for monitoring and efficiency). The opportunity lies in how to temporarily switch the ward setting for dying patients and their families.

Staff training

The medical professionals (doctors and nurses) working on palliative care service at home, community, and hospice gain certified training as a foundation of their job. To get certified training it could take years for a medical professional to learn and practice. However, the nurses and doctors working in hospitals mostly didn’t receive such education before they need to cope with dying patients, and it’s difficult for them everyone to take out a big amount of time out of their busy routine to learn palliative care systematically and comprehensively to be specialized. There are some alternative solutions inspired by the care in other settings. As the nurses reported the main skills they lack palliative care is the spiritual-psychological aspects, the shorter training programmes for community volunteers can be adapted for nurses training, which normally includes lectures, group discussions, and role play, lasting for only several days. Another solution is inspired by some nursing homes where similarly also not a specialized place for palliative care. Those nursing homes didn’t train all of their staff to be palliative care specialized or share a specialized team with other organizations, but always have one specialized physician on-site so that the support can always be reached.

	HOME-BASED	HOSPICE	NURSING HOME	COMMUNITY-BASED	HOSPITAL-BASED
CURRENT MODEL	Home-based palliative care provides care to people with chronic, life-limiting health problems such as cancer, advanced cardiac, renal and respiratory diseases, HIV/AIDS, and so on. Local resources and support networks can be utilized. Caregivers' training can be provided by community health workers in the local area.	Hospice is a building outside a hospital or other institutional context, where physical, as well as psychosocial and spiritual care, is provided to terminal patients. The caregivers try to make the patient feel at home. Relatives can stay day or night. It provides basic medical care with the hospice acting as a shelter for terminally ill patients with no homes or caregivers.	Some nursing homes have specialized units for palliative care. With respect to the size and home-like atmosphere, the palliative care units in question are largely comparable to such units in homes for the elderly .In nursing homes there is always a physician specializing in nursing home care who can provide medical care for the patient. Some staff said they would like training that addressed the potential emotional effects of end-of-life care work.	Some nursing homes have specialized units for palliative care. With respect to the size and home-like atmosphere, the palliative care units in question are largely comparable to such units in homes for the elderly .In nursing homes there is always a physician specializing in nursing home care who can provide medical care for the patient. Some staff said they would like training that addressed the potential emotional effects of end-of-life care work.	Community-based palliative care services are those offered at a community health center (CHC) or that are run with community participation. It could be the form of home visit care or outpatient care in CHC.
HUMAN RESOURCES	Doctors, nurses, community health workers and volunteers, psychologists/counsellors, social workers (suggested). Family as caregivers, others are support and additional service	Daily care is carried out by specialized nurses often in combination with volunteers. Medical social workers and counsellors. (Some of the hospices have their own doctors, others only the patient's personal general practitioner is in charge of medical treatment)	In nursing homes there is always a physician specializing in nursing home care who can provide medical care for the patient.	Health-care professionals (doctors and nurses who work at the CHC and support the community health workers or volunteers who visit patients and families at home) and community health workers/volunteers	The consulting teams often consist of medical and nursing personnel with specialist skills in palliative care. The team members function in an advisory role rather than in a practical supporting role. Often not only hospital personnel but also primary care professionals can call on the team
STAFF TRAINING	The doctors, nurses, community health workers need to take courses (foundation, Residential, or certificate) various from 10 days to a year. Family caregivers can receive basic knowledge and training from the community medical team.	The doctors and nurses need to take courses (foundation, Residential, or certificate) various from 10 days to a year. Volunteer are trained in training programme to learn how to provide non-medical care to patients and families.	Volunteer training: Basic palliative care course for volunteers (ap-prox. 16 hours theory plus 4 home visit days) covering communication skills, emotional support, patient assessment, nursing care, home care, basics of symptom management, reporting to higher level	Volunteer training: Basic palliative care course for volunteers (ap-prox. 16 hours theory plus 4 home visit days) covering communication skills, emotional support, patient assessment, nursing care, home care, basics of symptom management, reporting to higher level	Palliative care team members need a specialist qualification in palliative care. The other general medical professionals can choose to take part-time qualified specialized courses or trainings provided by some medical organizations.
PHYSICAL SETTING	Patient's home	In a hospice building with separate rooms for each patient	In a nursing home building with separate room for each patient	Community health workers or volunteers, supported by health-care professionals, will provide the basic home care or care at CHCs	It can be provided in any unit of the hospital if wards are available.
ESSENTIAL REQUIREMENTS	Basic infrasturation: central meeting point, storage facilities, transport for team and home-care kit (medication, equipment, documentation), method of communication;	Financial support and basic necessities – such as food, utilities, mobile telephone and travel subsidy, and the lending of equipment		At a minimum, the CHC should provide outpatient palliative care. It can also support home care by supervising community health workers or volunteers, by sending nursing and/or medical staff to visit patients at home as needed, or by keeping in touch with patients or families by mobile telephone.	Palliative care team with specialized nurses
PROS	Many patients feel more comfortable in their home than in a health-care setting; A home-based service means that family members are integrated into the process, which helps the patient and family maintain privacy and confidentiality.	The environment can be controlled and adjusted to provide hospitable, respectful and individualized care. Iti's able to provide physical care of the patient and psychosocial care of both patient and family. It is easier to do community outreach as there is a place where people can meet.	The environment can be controlled and adjusted to provide hospitable, respectful and individualized care.	Similar to home-based palliative care, but more flexible which could cover the situation that there is no possibility for the patients to stay at home with caregivers.	Easier to monitor quality and assess the symptoms with the sufficient medical recources there.
CONS	Limited accessibility to highly required medical equipment in cases of need	Highly-skilled medical and nursing care, if provided, is the most expensive form of palliative care, costing as much or possibly more than hospital care. Because of distance, cost or convenience, it may not be practical for families to visit often. If many deaths occur at a hospice, patients may become unsettled. The hospice may be labelled as a death house.	Some nursing home staff lack confidence and knowledge in end-of-life care	Highly rely on community recourses, network, and community health authority organizations.	Hospital settings especially in critical unit, lack of privacy (everything works for monitoring and efficiency). Not enough specialized human recourses for palliative care.

Figure 16. Comparison table

5

TECHNOLOGY RESEARCH

This chapter focuses on collecting current technology solutions and applications around the design topic as inspirations and insights for the further design phase, with several potential technologies highlighted with opportunity analyzing.

CHAPTER 5. TECHNOLOGY RESEARCH

/5.1. INTRODUCTION

Aim of the research: Discover and get inspired by potential technology that would contribute to the design subject, understand the relationship of technology and palliative terminal care, distinguish empowering or adding drawback to the care.

Main research question:

“How can technology empower or add drawbacks to support nurses to ptovide palliative care in the hospital context? ”

/5.2. METHOD

The main methods used for technology research is desktop research.

There are all kinds of technologies emerging in various industries and domains. To screen out the potentially relevant ones, six topics around nurses’ working context are defined as a starting point to explore the technologies, including technologies that applied in the hospital system, in nursing, in palliative care, in mental health (self-care), in education&training, and in communication (information transferring), which build a fundamental technology pool for opportunity mining.

The six topics are organized in the axis of the level of relevance to the design context and if it’s more about people or more about organization/system, to create a clear view of all the technologies.

The complete Tech Map is shown in Figure 16.

/5.3. FINDINGS

Hospital ICTs(information and communication system) VS Smart home system

Information and communication technologies (ICTs) embody all digital technologies that support the information capture, storage, processing, and exchange, empowering the healthcare domain widely (Rouleau, 2015). One of its important applications in hospitals is the electronic health records (EHR), which contributing to time efficiency of nurses’s work, especially on the work of documentation, data collection, nursing diagnosis. It can also link bedside terminals and central station desktops, shortening the virtual distance between patients and nurses.

The ICTs system used in hospitals can be analogized to a similar system- the smart home system. Both of them are based on IoT. These two systems share the following similarities:
- The ability to personalize information and instructions
- In closed and organized space
- Comfort as one of the users’ common goals

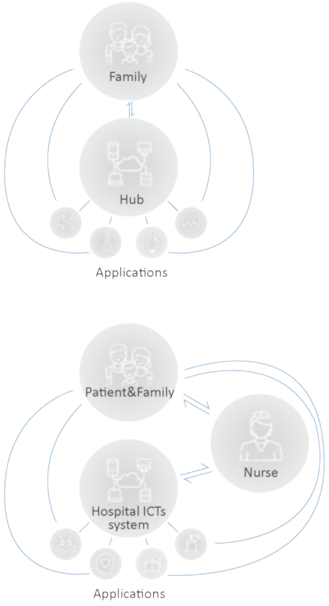
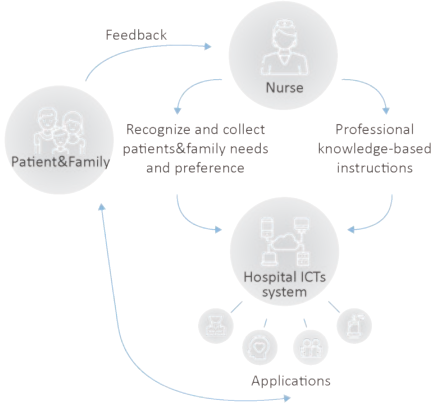


Figure 18. Analogy between ICTs and smart home system

There is one significant difference except for the different contexts, which is accessibility to the “hub” (Shown on figure 18.) The family members are able to directly give orders to the smart home system hub and receive feedback. However, because of the nature of the hospital, not like nurses and doctors, patients are not possible and not expected to have access to the information hub. Under this circumstance, the nurse is like a “housekeeper” added to the “smart home system” in this ICTs system in the hospital, collecting needs and preferences from the patients and send them to the hub to be processed.



Since the smart home is developed and applied more mature, ICTs system in the hospitals can be inspired from it to be more friendly to users.

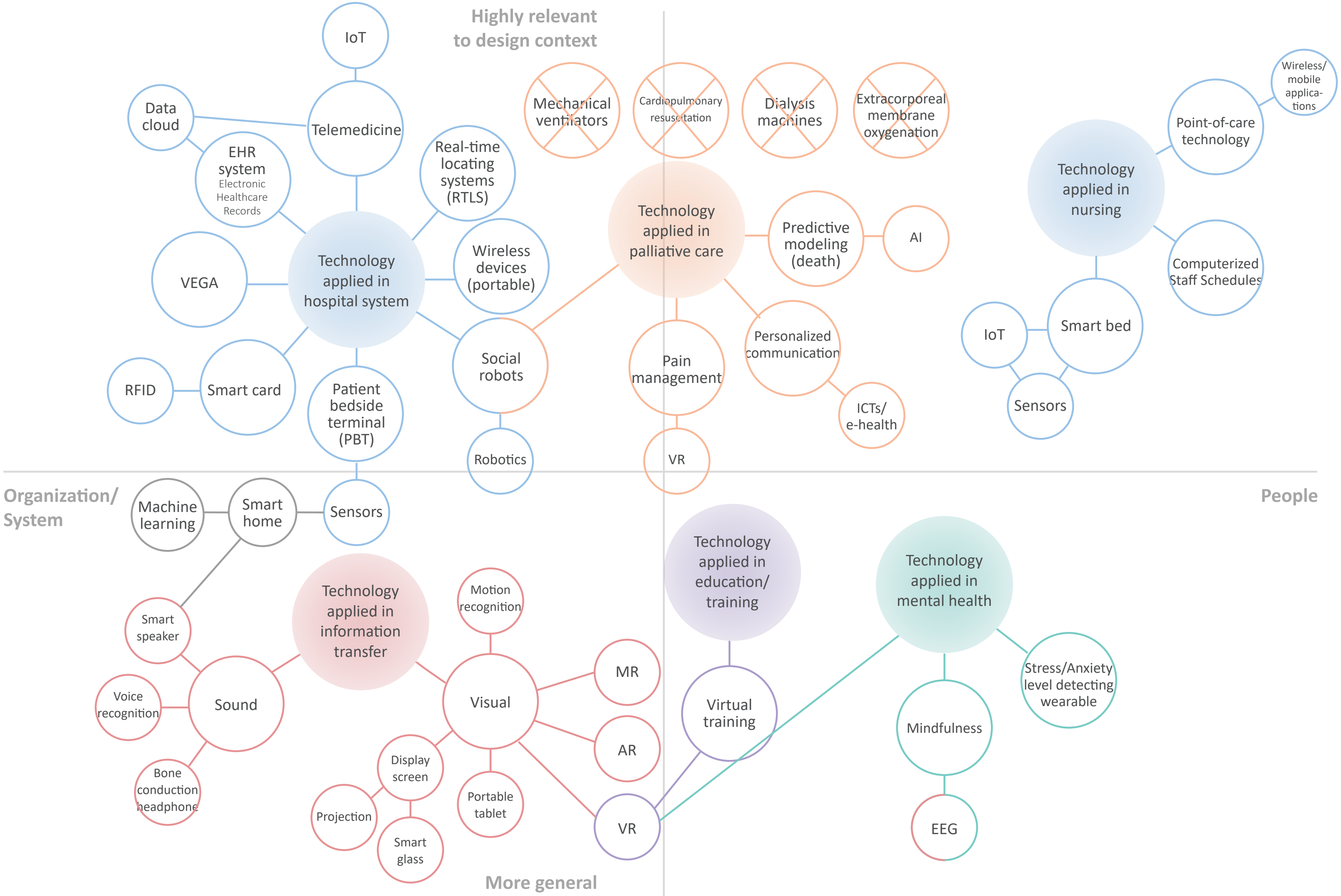


Figure 17. Technology Exploration Map

Technologies enabled by ICTs.

- EHR system (electronic healthcare records)

- PBT (patient bedside terminal)

- Remote montor and telecare for efficient palliative home care

Technology enables creating virtual environment for users.

1. VR training

VR (virtual reality) technology provides users with the immersive experience without the need of visiting the real places through wearing the VR headsets and headphones. It is seen as a promising technology that is currently developing for virtual nursing training for student nurses (Figure 19). The virtual practice helps nurse get familiar with the future working contents and context, at the same time reduce the risks of harming the patients in the unexperienced practice.

Figure 19. Example of VR in nursing training

Figure 20. Bone conduction headphone

2. AR and bone conduction technology: Create another environment for a indivisual

These two types of technology are able to convey information to an individual while keep the receiver(nurses) still able to sense surroundings and interact with others normally.

- Patients and family need peace and comfort while nurses need to keep track on other patients' condition (via bedside monitor screen/sound), which is not friendly for patients&family to notice. The technologies can transforming the way of medical notification for end-of-life care context

- They create opportunities of building a virtual personal space to manage emotion/calm down/reflect while keep being able to interact with surrondings.

Technology support nursing VS Humanity

Technologies are indeed empowering medical professionals' work and expanding its impacts in the healthcare domain rapidly. The improved effectiveness and efficiency of the treatment and care quality, as well as patient management, increase significantly.

However, it's also the time to reflect on this effectiveness and efficiency from the human interaction aspects, especially in palliative terminal care where the main goal is not only about physically comfortable but also mental care. Devices and applications that bring efficiency and speed can't and shouldn't replace nurses totally, but should earn nurses time for more traditional care and patient-centered activity in palliative terminal care.

"Patients and families will always need and want a human touch and a good patient experience." (Francis, 2019).

Figure 21. End of Life Care Machine: a robot questioning the quality of intimacy without humanity (Dan Chen's project https://2018.manifestations.nl/en/portfolio/dan-chen-end-of-life-care-machine/)

6

RESEARCH SYNTHESIS

In this chapter, all the research insights will be reviewed and synthesized in order to lead the project to a clear and focused design goal that guides the following design phase.

CHAPTER 6. SYNTHESIS

/6.1. CONTEXT REVIEW

Learned from history and context research, there is a rising trend of developing a comprehensive service system with high quality of palliative care for dying patients in hospitals. Since the main palliative care service was addressed at home or in hospices in the past, hospitals are facing the challenge to adapt the service and integrate it into a hospital system. As being in a transitional phase to the ideal scenario that hospitals are able to be equipped with specialized palliative care units and personnel, most of the Dutch hospitals are applying an integrative model (Metaxa, 2019) to provide palliative terminal care to dying patients and their loved ones. This integrative model consists of palliative care provided by general medical staff as a part of routine practice combined with palliative care teams providing consultations to dying patients and their loved ones.

At the current stage, an insight is brought up why the nurses are having difficulties in providing palliative care, one of the essential reasons is the lack of specialized and practical education and training are provided in nursing schools. Then when they start their work in hospitals, if they are assigned to dying patients, they are not exposed to extra training or support. Nurses can only learn in practice and ask for help from experienced nurses, which highly rely on nurses' self-motivation. At the same time, due to their quick working pace, there is little time left for themselves to digest and reflect everything they've experienced or learned, not to mention taking care of their own mental well-being. These factors drive the junior or inexperienced nurses away from a great opportunity at the beginning of their career to lay a good foundation on forming the skills of how to cope with death, dying patients and their loved ones, which also leads to the insecurity accumulated in their following career, causing personal mental stress or worse and reducing the care quality for the patients.

/6.2. PROBLEM STATEMENT

In general, the palliative-care-inexperienced nurses are lack of specialized education and training on palliative terminal care, as well as lack of time in their fast pace of work to cope with their own experience and emotions, while the patient&family are in need of physical&social&emotional&spiritual support and expecting their needs can be recognized and supported by nurses. The problems are elaborated in this chapter:

/6.2.1. THE PROBLEM OF THE CURRENT INTEGRATED MODEL

Analyzing the context, the problems existing in the current integrated model is discussed and summarized below:

For nurses:

- - Lack of specialized education or training;
- - Not used to death and dying;
- - Fast pace of daily routine- no time to deal with one's own feeling

For Palliative care team:

- - Limited reach to patients and families(<30%);
- - Limited human resources;
- - Many patients/families refuse their service since they are not aware of their needs to have consultations on preparation for death.

Other problems:

- - The higher requirements for nurses nowadays in terms of soft skills
- - Medical professionals also need to be perceived as a person, not a functional tool
- - The complex and different needs of the patients and families
- - Death&dying as a sensitive topic for everyone

These factors leave the consequence of:
- Nurses compassion fatigue and burnout in career
- Negatively compromise the quality of palliative terminal care to patients and their loved ones

Based on the nurse interviews, these consequences become more influential for junior and inexperienced nurses who just start providing palliative terminal care. It's essential for them to be able to reach supports in their early career.

/6.2.2. BARRIERS AND ENABLERS

To be able to clearly recognize what challenges and opportunities that nurses are facing in the research context, a list of barriers and enablers are summarized in Figure 22.

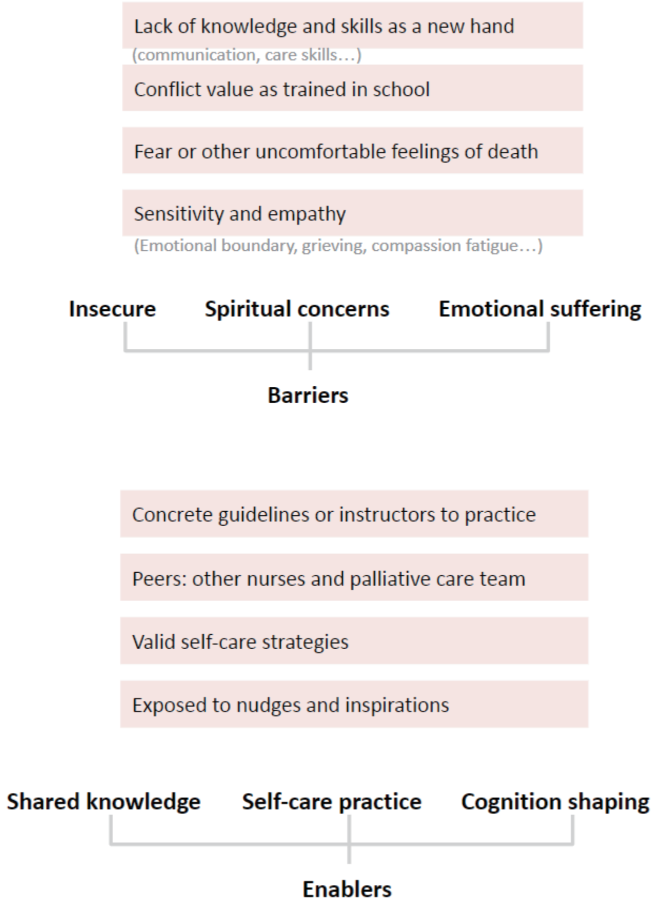


Figure 22. Main barriers and enablers for nurses to be capable and comfortable

/6.3. DESIGN GOAL

/6.3.1. INITIAL DESIGN QUESTION

After investigating from the literature/desktop research cluster (shown in figure 23) and nurses interviews (from Maasstad Hospital, the Netherlands, and Guangdong and Shanghai, China), the design scope is first narrowed down to focus on:

"How to enable on-site learning for junior and inexperienced nurses to cope with providing care to dying patients?"

Here the on-site learning emphases on a process to become prepared (capable and comfortable) for providing care to dying patients in their daily caring work. The junior and inexperienced nurse refers to Nurse profile 1, inexperienced nurses, new to the department, lack specialized palliative care education previously, which is not age-limited.

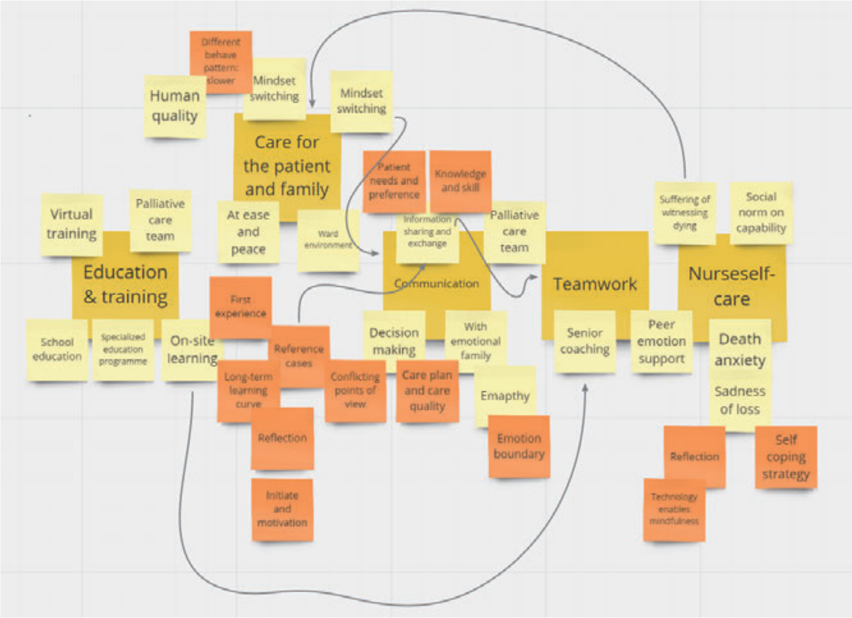


Figure 23. Research cluster

As the design will focus on nurses' on-site learning experience, it is important to understand and clarify what is expected to be learned on-site, and how to achieve this learning goal. Therefore, a summary of what to learn for the nurses on palliative terminal care generated from the research phase, as well as an envisioned learning circle to describe how to form this on-site learning experience generated from additional research, are defined below:

WHAT TO LEARN - LEARNING GOALS

Practical skills *Professional*	**How to provide palliative care to dying patients;** **How to communicate with dying patients and families;**
Emotion & spiritual *Personal*	**How to feel confident while working with dying patients;** **How to feel comfortable while working with dying patients;** **How to be able to aware of and accept one's own feeling;** **How to be able to cope with one's own feeling.**

HOW TO LEARN - THE LEARNING CIRCLE

The envisioned learning circle shown in Figure 24 is adapted from Kolb's Learning circle (McLeod, 2017) (Figure 25) and Ching-chi Huang's research (2016) (Figure 26) about nurses' emotionally suffering transformative process.

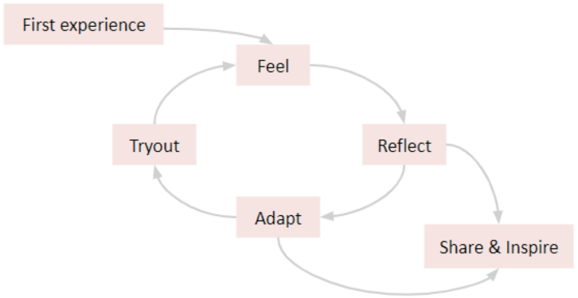


Figure 24. The envisioned learning circle

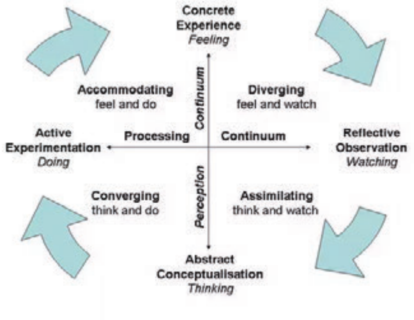
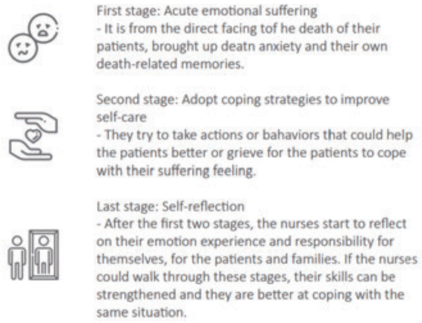


Figure 25. Kolb's Learning circle (McLeod, 2017)



First stage: Acute emotional suffering
- It is from the direct facing tof he death of their patients, brought up deatn anxiety and their own death-related memories.

Second stage: Adopt coping strategies to improve self-care
- They try to take actions or bahaviors that could help the patients better or grieve for the patients to cope with their suffering feeling.

Last stage: Self-reflection
- After the first two stages, the nurses start to reflect on their emotion experience and responsibility for themselves, for the patients and families. If the nurses could walk through these stages, their skills can be strengthened and they are better at coping with the same situation.

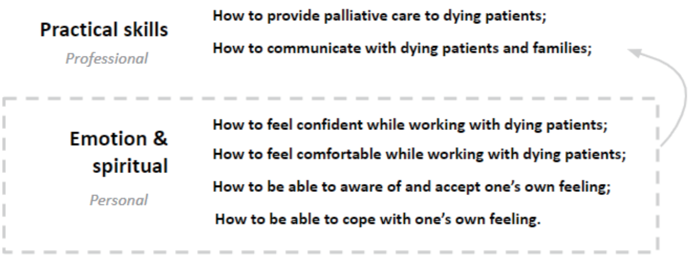
Figure 26. Ching-chi Huang's research (2016)

/6.3.2. FINAL DESIGN QUESTION

To scope down the final design and consider the implementation ability within this project, the final design direction is defined as:

"How to support junior and inexperienced nurses to be emotional and spiritual prepared to provide palliative terminal care for dying patients in Maasstad Hospital through on-site learning?"

The reason that choosing to focus on emotional and spiritual capability is because that
- Emotional and spiritual needs and capability of the formal caregivers in palliative care, like nurses, are rarely discussed and addressed compared with practical and professional skills and capability. However, the nurses in the medical system should also be perceived as a person like patients to be taken care of, not only to be perceived as a functional tool.
- The acquire of emotional and spiritual capability can, in turn, contribute to better professional skill gaining on palliative care, which gives the nurses the feeling of security and confidence to behave, practice skills, and interact with patients and their loved ones.



Practical skills
Professional
How to provide palliative care to dying patients;
How to communicate with dying patients and families;

Emotion & spiritual
Personal
How to feel confident while working with dying patients;
How to feel comfortable while working with dying patients;
How to be able to aware of and accept one's own feeling;
How to be able to cope with one's own feeling.

The emotional and spiritual aspects can be related to: personal cognitions of death from different beliefs and religions; death fear and anxiety; the meaning of illness and existence; emotional relationship with the patients; empathy and compassion for the dying patients, etc.

Remark:

The aim of learning on emotional and spiritual aspects is not to make nurses to be comfortable with death and dying. We all have the right to have our own visions and beliefs on death and dying. The aim is actually to support the nurses explore their own way of how to feel comfortable to encounter death and dying patient&family and figure our their own coping strategies, to achieve their own mental-wellbeing and a good quality of care.

7 DESIGN DEVELOPMENT

This chapter aims to create a feasible and viable conceptual intervention following the defined design goal. The way reaching to the final concept including exploring potential design directions, design ideations, conceptualizations and iterations which is expected to involve users' (nurses and experts) feedback and insights.

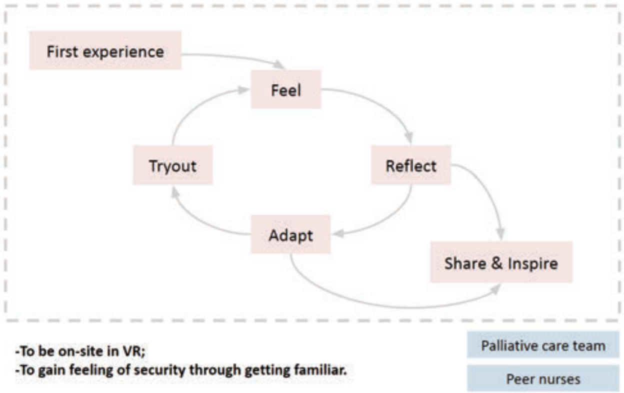
CHAPTER 7. DESIGN DEVELOPMENT

/7.1. DESIGN DIRECTIONS

Based on the envisioned learning circle (Figure X), three design directions that have covered different scopes of the learning circle are developed, inspired by research insights and brainstorming.

Exploring how to implement the envisioned learning circle into a design intervention is the first step bridging the research synthesis to the further concept developing.

1. VR virtual experience training



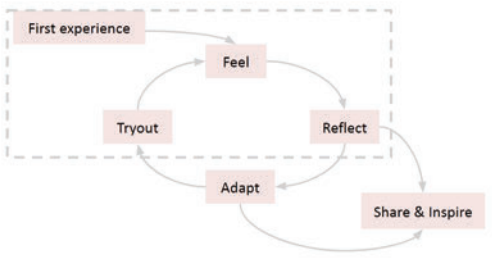
-To be on-site in VR;
-To gain feeling of security through getting familiar.

This design direction aims to reproduce the whole on-site learning circle in a virtual experience, to be on-site in VR. By creating a virtual training program, it provides nurses a flexible and safe way to get familiar with the palliative terminal care context and practice how to cope with their feelings without limitations.

Pros: - Experience and practice without risks of leaving an actual impact on real patients and families;
- Allow reflection at any time and anywhere in the virtual experience;

Cons: - There is a risk in emotional&spiritual VR training that it might cause psychological trauma while experiencing alone;
- A need for involving VR application development stakeholder (a third party).

2. Nudges in the environment and settings to influence cognition



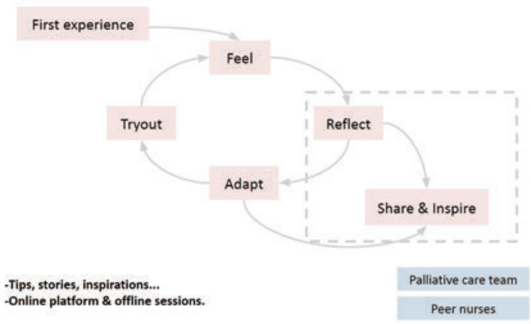
-Focus on personal (emotional&cognitive) perspective;
-Use visual, light, sound,...
-Cognitive reappraisal or acceptance strategy.

The second design direction focuses on the on-site practice part of the envisioned learning circle. By creating nudges in the working environment like the palliative care ward, nurse station, or inside mobile tablets, the nurses are imperceptibly learning and forming self-awareness behaviors to perform self-care on emotional and spiritual aspects, as well as imperceptibly adapting their cognition with anxiety and fear to peace and acceptance through everytime on-site practice.

Pros: - Nurses doesn’t need much extra time for learning and training;
- It’s an inspiring and not invasive way of learning, which is easier for nurses to accept and make use of.

Cons: - The nudges in the hospital environment settings need to strictly avoid influencing patients and families, as well as fitting in the hospital and medical system regulation, which might create difficulties in testing and implementation.

3. Palliative terminal care experience exchange platform

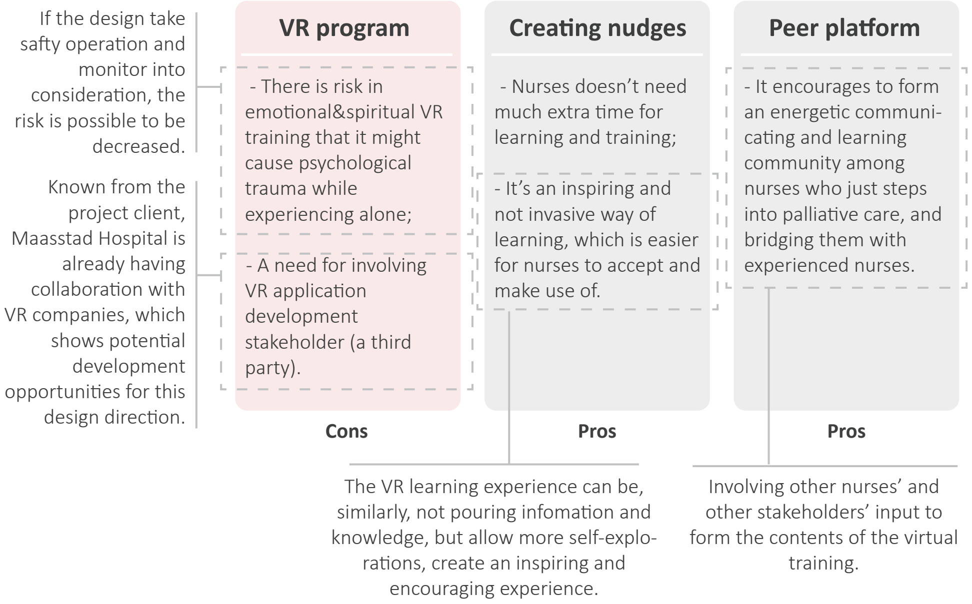


-Tips, stories, inspirations...
-Online platform & offline sessions.

learning circle. The intervention won't proactively give information, knowledge or inspirations to the nurses, but make use of the value of peer community. It's an online platform with offline sharing sessions that helps junior and inexperienced nurses reflect on their on-site experience, share their emotional&spiritual concerns or coping strategies, and inspired by other nurses with their different insights or coping strategies. Nurses learn from each others stories supported with self-reflection.

Pros: - It encourages to form an energetic communicating and learning community among nurses who just steps into palliative care, and bridging them with experienced nurses.
Cons: - It's difficult to gather nurses into groups to meet and share within their busy working pace and intense shifts.

Design direction decision:
The first design direction- VR virtual training program on emotional and spiritual aspects- is chosen to be developed further into a concept. As the advantages of this direction are already recognized, the other reasons and how it could be inspired by the other design directions are elaborated in Figure 27.



If the design take safty operation and monitor into consideration, the risk is possible to be decreased.

Known from the project client, Maasstad Hospital is already having collaboration with VR companies, which shows potential development opportunities for this design direction.

VR program

- There is risk in emotional&spiritual VR training that it might cause psychological trauma while experiencing alone;

- A need for involving VR application development stakeholder (a third party).

Cons

Creating nudges

- Nurses doesn't need much extra time for learning and training;

- It's an inspiring and not invasive way of learning, which is easier for nurses to accept and make use of.

Pros

Peer platform

- It encourages to form an energetic communicating and learning community among nurses who just steps into palliative care, and bridging them with experienced nurses.

Pros

The VR learning experience can be, similarly, not pouring infomation and knowledge, but allow more self-explorations, create an inspiring and encouraging experience.

Involving other nurses' and other stakeholders' input to form the contents of the virtual training.

Figure 27. Choice of direction and takeaways from the other two directions

/7.2. DESIGN BRIEF

After mapping out potential solution directions, discussing with Harry from Maasstad Hospital, and made the design decision, the project in the following design phase will focus on solving the question below:

"How to create experience journeys of interacting with patient&family in VR, where nurses are able to become emotional and spiritual prepared to provide palliative terminal care for dying patients in Maasstad Hospital, and be able to help patients&family recognize and cope with emotional&spiritual issues."

Define becoming prepared:
To be familiar with the experience and main interactions in palliative terminal care, and become confident and comfortable on providing palliative care to dying patients while being able to take care of one's own feelings.

Target user:
Inexperienced nurses refer to Nurse Profile 1, and it can be utilized by any nurses who are not feeling prepared emotionally&spiritually and feel a need of getting support on learning palliative care.

Stakeholders:

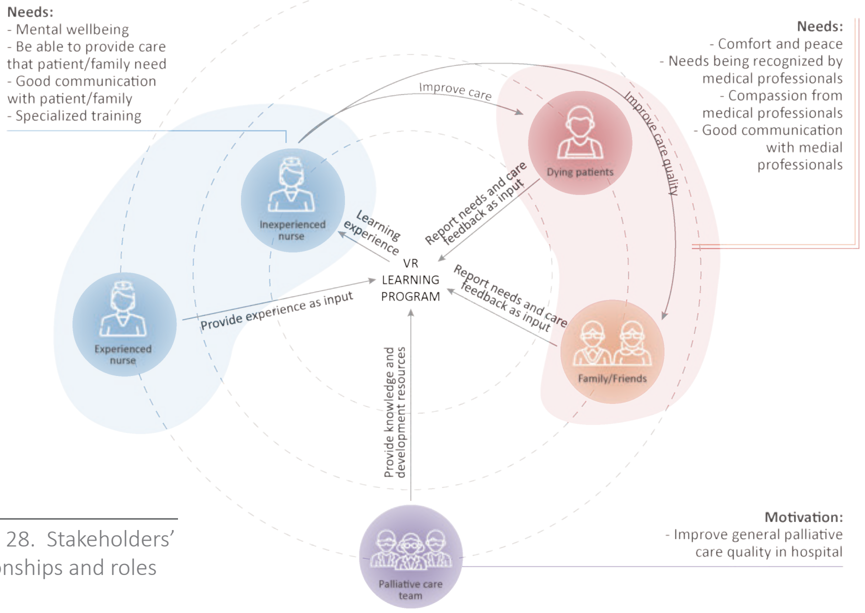


Figure 28. Stakeholders' relationships and roles

ENVISIONED OUTCOME

By creating the learning and experience journey in a VR application, the nurses are expected to gradually learn how to perceive and cope with their emotional and spiritual needs and burdens. From there, they are able to externalize their sensitivity and skills on influencing patients and their loved ones, including understand and recognize patient&-family's emotional&spiritual needs, as well as guide and provide support on those needs.

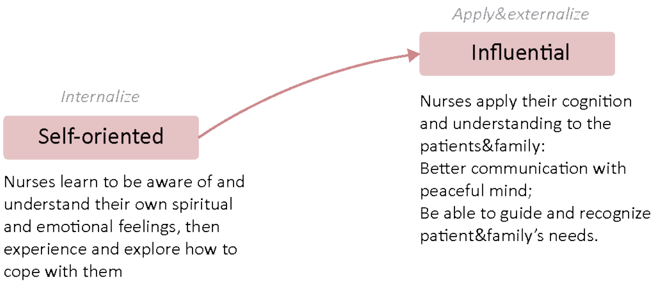


Figure 29. Envisioned outcome: from internalizing to externalizing

EXPECTED BENEFIT

For the nurses, as medical professionals should be perceived as a whole person but not a function, through the intervention, nurses' mental well-being is protected.

For the patients and family, after the nurses learning in the VR program, nurses are able to recognize spiritual distress in patients, caregivers and themselves, which is aligned with patient&family's demand: Patients and family hope to receive compassion from nurses and hope the nurses to be with them, guide them on emotional&spiritual aspects. Besides, since the nurses are able to work with a better mental status, the better quality of care for patients and families is guaranteed.

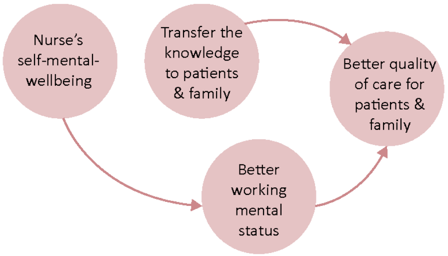


Figure 30. Expected benefit

ENVISIONED DELIVERABLE

The envisioned deliverable under this design goal for this project is a VR learning application design concept accompanied by a VR learning service system that aims to support the concept being implemented and benefiting key stakeholders.

VALUE OF VR

Figure 31. An example of VR nursing education (Healthy simulation, 2018)

- To be on-site in virtual experience;
- To gain feeling of security through getting familiar without having effects on real patients and families
- Flexible (anytime and anywhere)
- Create immersive experience to be easier to believe what's happening, and create relationship with the scenario
- Able to experience from different stakeholders' perspectives to enhance empathy.
- VR learning is four times faster than learning in classroom, with higher focused attention and easier emotional connection; (PwC VR soft skill training efficacy study, 2020)
- VR_learners have more confidence to apply what they've learn in real-context work since VR training provides them with an immersive and low-stress environment. (PwC VR soft skill training efficacy study, 2020)

INTERACTION VISION

The interaction vision is generated after the design goal and direction are well defined, which will further work as a design guideline to make sure the concept is able to reach the expectations elaborated in Design Brief, as well as a good quality of the user experience.

Adaptive:
The whole learning process is leveling-up based on users' own preference and learning speed:
- The whole learning process is adaptive which means the intensity and scenarios of the experience contents will be divided into different levels adapting to the nurse's current capability.
A single experience session is adaptively unfolding:
- In a single learning session, the beginning needs to be gentle and invited to help the nurse gradually adapt themselves to the coming death&dying context considering the risk of hurting mental health.

Encouraging:
Although it is virtual simulation of the context, the users can still feel insecure, confused, even panic when they are in the scene. This feeling will hinder their willingness to explore and try out themselves.
Therefore, the experience is supposed to be self-motivated exploring and trying-out, with the base of nurses feel safe and comfortable to go on. It's not going to be a structural guideline to educate nurses about what should happen and what should be done.

Reflective:
The experience is supposed to be able to trigger nurses' awareness and reflection on what they've experienced and their own feelings, but not educational knowledge and practical skills.

Inspiring:
The experience of learning is supposed to be able to inspire the nurses how to cope with the situations and how they can apply what they've gained in their real practice.
The "inspiring" here also emphasizes that it is to help the nurses to start think about or rethink about the topic and their feeling towards it. There are no right or wrong thoughts or fixed answers after getting inspired, since the aim of inspiring is to make a difference but not give a solution.

Remark:
The goal of the design doesn't emphasize on conquering the fear, anxiety, and stress of death and dying. Death is a difficult thing for anyone. The design hopes to support nurse to be able to be aware of what they feel as part of themselves and achieve to know how they can get along with their nevigate feelings. The design also aims to inspire the nurses that they are making a difference for the patients and families.

/7.3. DESIGN IDEATION

To develop the brief of design into a concrete solution, design ideation sessions are conducted at this phase. The ideation phase consists of individual brainstormings and a collaborated creative ideation session, both of which will be elaborated below.

INDIVIDUAL BRAINSTORMING

Ideate on small ideas and experience elements that could contribute to the design goal. Small idea examples are shown in Figure 32.

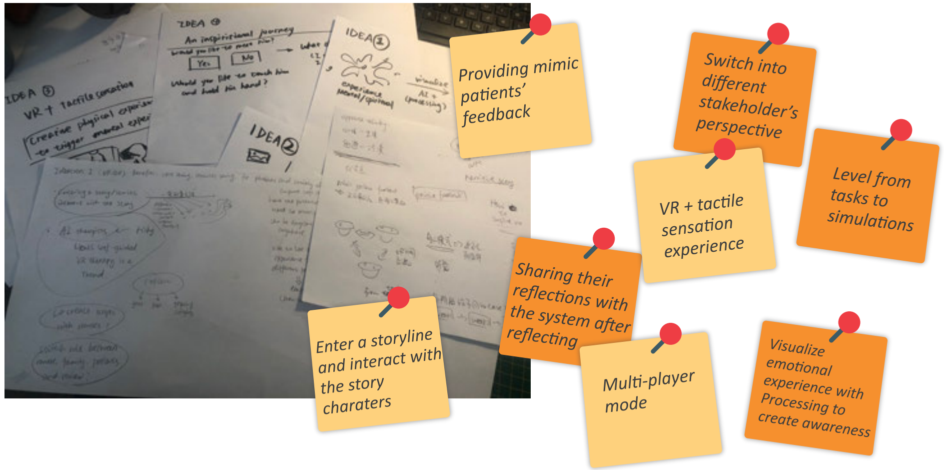


Figure 32. Brainstorming example ideas

CREATIVE IDEATION SESSION

Aim: To explore the possibilities in VR supporting junior nurses coping with dying patients and their loved ones. (what and how they experience)
Goal of design: By experiencing the interaction with patient&family in VR, get familiar, become confident and comfortable on palliative care, and be able to help patients&family recognize and cope with emotional&spiritual issues
Participants: Design master students from Integrated Product Design (1), Design for interaction (3), and Strategic Product Design (1).

Figure 33. Online creative session record

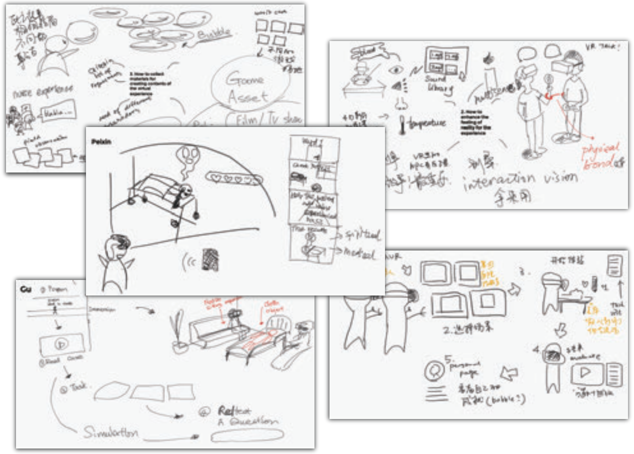


Figure 34. Part of the idea boards from the creative session

The creative ideation session is planned for absorbing fresh ideas and new perspectives to look at the design goal from different mindsets. This session was also expected to invite the nurses from Maasstad Hospital as a designer- stakeholders co-creation session. However, due to the special circumstance of pandemic with limited access to the hospital and nurses, the plan was adjusted to only have student designers from different design disciplines to inspire and challenge each other, and involve nurses at a later stage when iterating on the initial concept.

In this session, all the participants reviewed the design goal together and tried to interpret it from different scenarios, broadening the solution possibilities. The outcome of the creative session are several concept sketches of envisioned journeys of the training experience. These sketches inspire the generation of the initial concept with a complete user experience journey in VR. The setup of the session and outcomes of each step can be found in Appendix C.

Inspiring ideas from this chapter

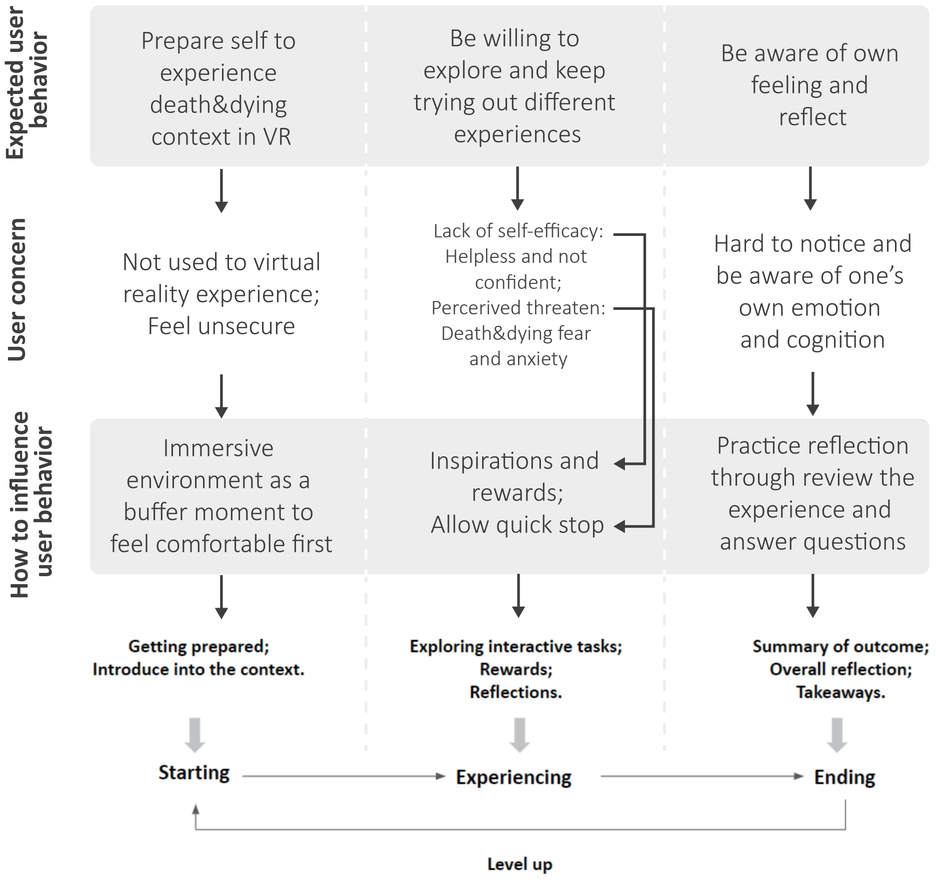
- Switching perspectives of patients and nurses to create empathtic refelction experience;
- Forming the experience journey in the way of storytelling to enhance the feeling of immersion;
- Multi-player mode, not experience alone but explore together;
- Experience in actual wards with virtual patients- augmented Reality;
- Gamification experience, tackle tasks in different levels;
- Visualize the achievement to trigger user’s motivation of learning;
- From small tasks to complete simulation to build up self-efficacy;
- Start from minutes of immersive adaption to the coming experience;
- Involve physical sensory esperience while using VR to enhanced realism;
- Involve non-player charaters to inspire the users;
- Collect stories from other nurses as fundementals of the experience journey;

/7.4. CONCEPTUALIZATION

/7.4.1. INITIAL CONCEPT INTRODUCTION

An initial concept is created by integrating ideation outcomes into the envisioned learning circle. Using VR virtual training application to create a virtual on-site learning experience for the nurses who are inexperienced with palliative terminal care, to gain a feeling of security through getting familiar without having effects on real patients and families. It focuses on nurses' emotional and spiritual aspects, including their feeling about death&dying and how they encounter dying patients and families, but not on practical skills. In this VR application, the nurses are able to observe the ward environment, interact with patients&family, reflect on their feelings, and get inspired.

/7.4.2. VR EXPERIENCE FLOW



Expected user behavior	Prepare self to experience death&dying context in VR	Be willing to explore and keep trying out different experiences	Be aware of own feeling and reflect
User concern	Not used to virtual reality experience; Feel unsecure	Lack of self-efficacy: Helpless and not confident; Percerived threaten: Death&dying fear and anxiety	Hard to notice and be aware of one's own emotion and cognition
How to influence user behavior	Immersive environment as a buffer moment to feel comfortable first	Inspirations and rewards; Allow quick stop	Practice reflection through review the experience and answer questions
	Getting prepared; Introduce into the context.	**Exploring interactive tasks; Rewards; Reflections.**	**Summary of outcome; Overall reflection; Takeaways.**
	Starting	**Experiencing**	**Ending**

Starting/warm-up

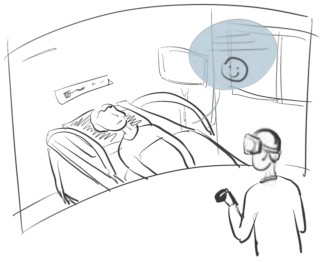
Aim:
To clear out the complex thoughts and burdens in mind in order to be more mindful in the following journey;
To get prepared and invited to the context of death and dying gently.

Experience:
Be exposed to a death poem or quote in a dark environment to evoke user's own thoughts or reflections on death&dying;
Start with standing in a ward to first only observe the environment to adjust themselves in a comfortable status to move on.

Experiencing

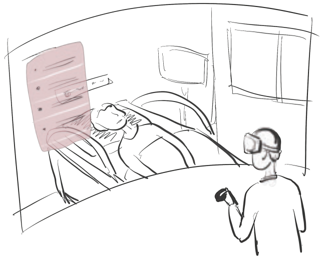
Aim:
To put the nurse in simulated scenarios to experience their own feelings and interactions with patients&family, as well as evoke reflections.

Experience:
Observe and interact with the scene:
- Cease life-prolonging equipment
- Be present with patients and family
- Explain to the family what's happening when patients have various dying symptoms;
- Recognize patient&family's emotional & spiritual needs and guide them on how



could they get support;
-Inform death to the family;
- Grieve for the patient with the family;
...

Receive mimic positive feedback from patients&family.
Get inspired by peers' insights and shared thoughts in certain situations.



Ending

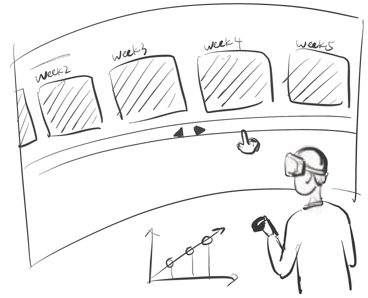
Aim:
To reflect on their experience and self-evaluate on their emotional&spiritual capability;
To let the system recognize the user's ability and learning speed to adjust and recommend learning contents.

Experience:
Review the whole experience from the patient/family's perspective;
Answering questions about self-evaluation;
The user is able to choose the environment they feel the most comfortable to stay in this phase;
Receive tips and takeaways in their email to support them when they are going to provide palliative care in the real context.

Level-up

Aim:
To achieve weeks/months of the adaptive learning process

Experience:
- Basic: Being familiar with the environment and setting in the ward
- Second-level: Being familiar with being present with the patient&family and the dying symptoms
 (Gradually exposed to scenarios that are difficult to cope with)
- Third level: Being familiar with interact with patients&family
 (Gradually exposed to scenarios that are difficult to cope with)



/7.4.3. DESIGN REQUIREMENT OF THE VR EXPERIENCE

General:
- Allow the user to takes control of the experience pace, avoid forcing on user's behavior;
- Avoid strict guideline or rules as information output;
- The user is able to understand the experience flow, and the aim of each step;
- Simple and clear interaction to avoid interrupting the feeling of immersion in the virtual scenes;
- The user is informed with what is happening and what is going to happen in the whole experience.

Starting:
- Give the user freedom to mentally prepare for entering the scenarios and decide when to enter;
- Provide recommendations while allowing the user's own preference;
- The user is exposed to a mindful environment in virtual reality.

Experiencing:
- The user can always reach to the operation of immediate stop and quit from the scenario;
- The user is able to recognize if the system detects their voice while speaking;
- Clear background information about the chosen scenarios should be provided to the user.

Ending:
- The user should be provided with positive feedback on their behaviors in the scenarios;
The user should be guided and supported to evoke reflections;
The user is able to collect information that is valuable for them and have access to it while not using the application.

/7.5. DESIGN ITERATIONS

/7.5.1 ITERATION 1

EXPERT FEEDBACK

The initial concept (refer to Design Introduction was elaborated and presented to Petra Bos, coordinator of Maasstad Hospital 's palliative care team, and Marieke Sonneveld, coordinator of End of Life Lab and project chair, as expert input. The aim of the design was first well recognized by the experts, especially the recap experience from the patient's perspective. Then there was a mutually inspiring discussion about the general structure of the design. Here are the items that were discussed and being taken into consideration of concept improvement:

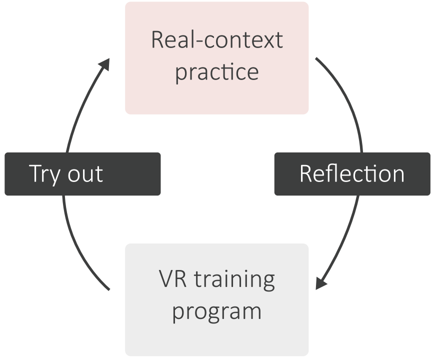
Tailored experience

There was a discussion about if the nurse should give self-identified information to the system at the beginning of using this VR program, for instance, how much she/he is experienced in palliative care communication, to make the training content tailored to the nurse's capability. Although tailored experience indeed adds value to the effectiveness of nurse's learning, the way that the nurse gives self-identified information might not be proper to reach the expected training outcome. It's considered that nurses might not be well enough aware of their emotional and spiritual cognition and needs, so there is a possibility that nurses provide assumed self-identification on capability which is not aligned with reality. Instead, the ideal scenario can be letting the system gradually know more and more about the nurse's learning preference, learning speed, and capability through the self-evaluation questionnaires after their VR learning everytime. In turn, the nurses are also able to take time to know themselves better and be able to recognize their own growth.

While the users are using the program from time to time, a huge amount of data are generated at the same time, including what sessions are taken and how many times are experienced, how is the users' reflection result in general, etc. From there a service opportunity is created that to make use of the data from nurses' reflection and evaluation to summarize common challenges that the nurses have a hard time tackling, which can be reported to the department or palliative care team to provide targeting training or support. This opportunity is further integrated into the concept, which can be found in Chapter FInal Design.

Bridge virtual learning and real practice

Since the program provides users a setting to reflect, it can also support them to make reflection after their practice in the real context. In this way, these users are able to receive more targeting experience sessions after they realize in real context what they actually need. Therefore, the system structure is reconsidered to add an advanced user more, which allows these users to first learn from virtual practice and apply their knowledge in real practice with real patients&family, then come back from the real practice to reflect in the application what contents they feel they need extra virtual training and receive targeting learning materials in the following sessions.



/7.5.2 ITERATION 2

NURSE INTERVIEW

After the expert feedback, the concept was adjusted and a series of storyboards (Figure 35) that showed the experience flow within the designed VR application was created to collect user feedback from nurses from Maasstad Hospital. The full version of the storyboards and the experience flow scripts can be found in Appendix D&E.

Figure 35. Concept storyboards

Figure 36. Interview nurses with storyboards

Two nurses were managed to join the feedback session, who found the concept promising and inspirational as a way of learning how to cope with palliative terminal care. The main insights that help improve the concept they shared are elaborated below:

Voice interaction as a preference

The interaction between the patient&family in VR wasn’t clearly defined in a certain way. From the interview, it’s known that the nurses would prefer voice interactions with patients and families but not only visual speech box, to gain a natural conversation experience and easier build connection with the scenario. The voice interaction is able to be implemented through VR headsets embedded with the speech recognition module, for instance, the Oculus VR headset supported by IBM Sandbox system, which will be elaborated in chapter Design Implementation.

Sessions content evaluation

The initial list of the basic scenarios for the sessions was shown to the nurses for them to review and evaluate what they thought that needed to be experienced and what was missed in the current list. The initial list is generated from the PALLIATIVE TERMINAL CARE FOR A DYING patient journey map, which are related to emotional and spiritual experience. The list and the added-on contents are shown in Figure 37.

All the listed scenarios are valued by the nurses and recognized to be in need of training in this VR program. Reviewing the list and inspired by the dying phases of a terminal patient (Susan, 2015), summarized in Figure 38, the experience sessions could be organized by a timeline of dying phases, which will be elaborated in chapter Final Design.

Initial list of scenarios

- Cease life-prolonging equipment
- Be present with patients and family
- Explain to the family what’s happening when patients have various dying symptoms;
- Recognize patient&family’s emotional & spiritual needs and guide them on how could they get support;
- Inform death to the family;
- Grieve for the patient with the family.

Initial list of scenarios

- Care after the death:
  Including care for the dead body, as well as support and tell the family how to go on.
  This is important to manage coping not only because it’s family’s mental need, but also a moment of closure for the nurses.

Figure 37. List of basic scenaiors to be experienced in VR

	Actively dying	Transitioning	Imminent	The Death
Patients status	Sedation and lethargy / Restlessness and confusion	Withdraw from the physical world around them, decreased interest in activities of life, less frequent and shorter interactions with others, hallucinations	Body is in the process of shutting down，multi-system organ failure. Becomes unresponsive to those around them and may appear to be sleeping， patient can still hear or sense the activity and loved ones around them	Clinical death and biological death. Without CPR, clinical death transits to biological death in minutes
Nurse’s role	Support the patient and family by educating them on what they might expect to happen during this time, addressing their questions and concerns honestly, being an active listener, and providing emotional support and guidance	Comfortable and peaceful keep lights soft, shades closed if possible, external noises limited to a minimum	Teach families to continue to talk to and gently touch their loved ones. The family must be informed that death is near. It’s also the time when some families may want clergy or pastoral care present	Assess for signs of life; Contact the medical examiner to notify them of the death; Preparing the patient for transport to the funeral home

Figure 38. Terminal patient’s dying phases

Multi-player mode

The design proposal of introducing the additional multi-player mode was commented by the nurses that it would be helpful if an experienced nurse joins an inexperienced nurse’s session to expend the various possible scenarios that they’ve experienced before and explain them to the inexperienced nurs, triggered by what they see in the existing VR scenarios. However, considering the difficulty of gathering nurses in pairs to have the whole session done, it could be developed into a supplementary function in the VR program.

Doctor‘s version

As the nurses recognized the value of the concept in terms of contributing to gain a better understanding and empathic capability on emotional and spiritual aspects of palliative terminal care, they suggested that this VR training program should be considered to develop a version for doctors’ training. Explained by the nurses, they found through their years of work in palliative care that doctors mostly prone to only see the symptoms but not patient&family’s emotional and spiritual needs. They receive this training would lead to a better communication between nurses and doctors towards patient&family’s comprehensive care. Due to the time limitation of developing this concept as a graduation project, the development of doctor’s version will be taken into a further recommendation for Maasstad Hospital.

EXPERT FEEDBACK

After the concept was further developed into a whole experience flow shown as the storyboards, the information structure behind the VR application experience was discussed and modified with Petra, in the following topics:

Level-up structure

The previously defined levels of the training in chapter Concept Introduction didn’t contain obvious boundaries of experience. After discussing with Petra on what could make the levels distinct with each other and contribute to an adaptive learning curve, the definition of the three levels of training is elaborated in Figure 39. It was highlighted that the user should be able to freely switch back to lower level when they feel uncomfortable in the current level.

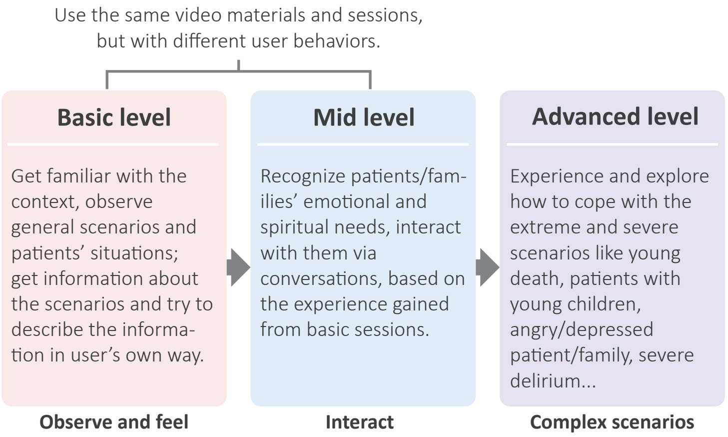


Figure 39. Three levels of the training sessions

Reflection questionnaire

The reflection questionnaire is a self-evaluation tool at the ending phase of the training, which is expected to work for evoking user’s reflections on what they’ve experienced and give input to the system on user’s learning progress. The initial questionnaire only emphasized on emotional experience, forming like “How comfortable/confident do you feel to be present with patient&family/ talk to patient&family/ recognize their emotional&spiritual needs...” using the Likert Scale from “1” to “7”. After discussing the expected effect of using this questionnaire with Petra, questions that focus on the learning outcome are considered to be added to the questionnaire, which can be formed as “To what extent do you think you are inspired by the learning content today?”. This would contribute to the update and optimization of this VR training program.

There are also other ways of self-reflection, like keeping self-reflection diaries used for nursing students in clinical practice (Mlinar, 2019). As the aim of the VR application is to be simple and self-motivated, keeping diaries as a way of reflection can be suggested as a supportive self-practice, but will not be considered in the VR application system design.

Due to the coronavirus situation and nurses’ busy work routine, only two rounds of design iteration was conducted. Taken the insights from the iterations into consideration, the final design will be comprehensively elaborated in the next chapter.

/7.6. FINAL DESIGN

/7.6.1. CONCEPT OVERVIEW

As caring for dying&death patients, for nurses who are inexperienced with palliative terminal care, is a job that evokes intensive emotions and generates stress and compassion fatigue, this project aims for supporting nurses to be better prepared for it. The final design is a product service system, using VR experience to create a virtual palliative terminal care training program for inexperienced nurses who are working with or will work with dying&death patients and families in their careers.

What makes the design different from other medical training is that the learning doesn’t rely on fixed knowledge and strict instructions, but motivate the users to explore themselves and find their own answers. The program will only witness the user’s growth and provide support when the user indeed needs, like guiding reflection or giving inspirations.

Through a certain period of training, the nurses are able to manage to cope with their own feelings and better prepare themselves emotionally and spiritually when they are assigned to care for dying patients, which not only ensure nurses’ mental wellbeing but also contribute to the increase of patient care quality. A journey of a single session of the training is illustrated below (Figure X):

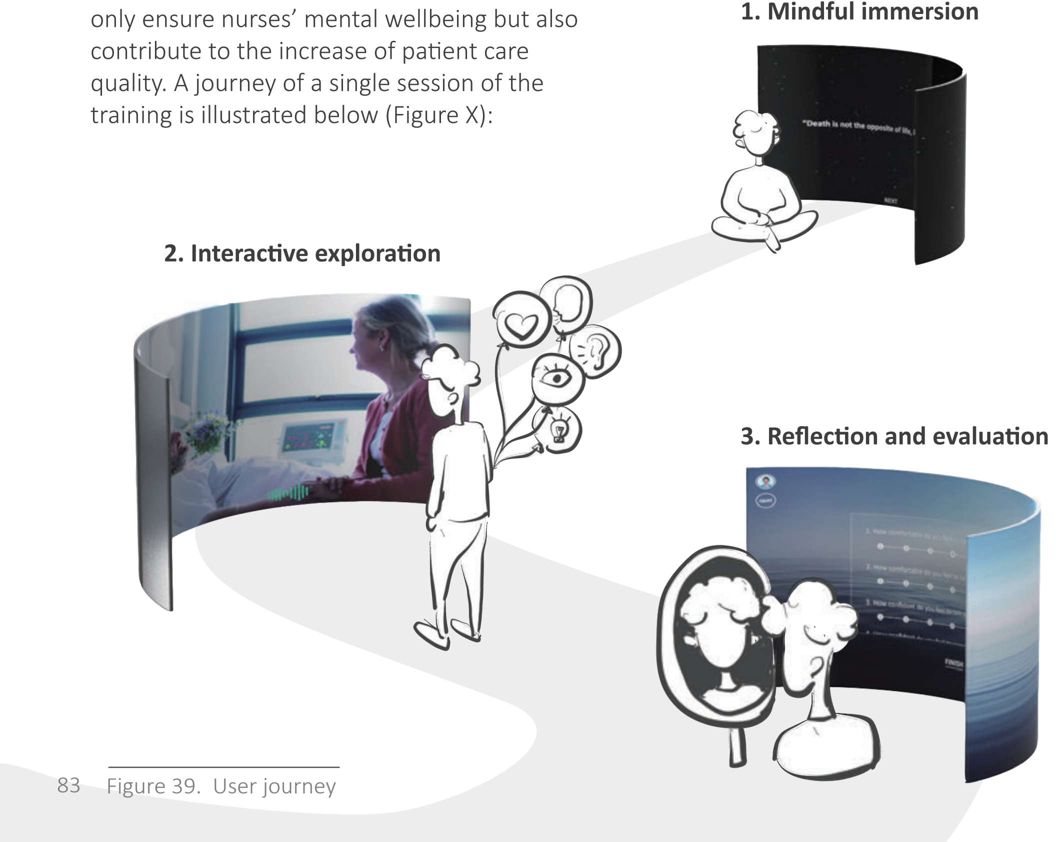
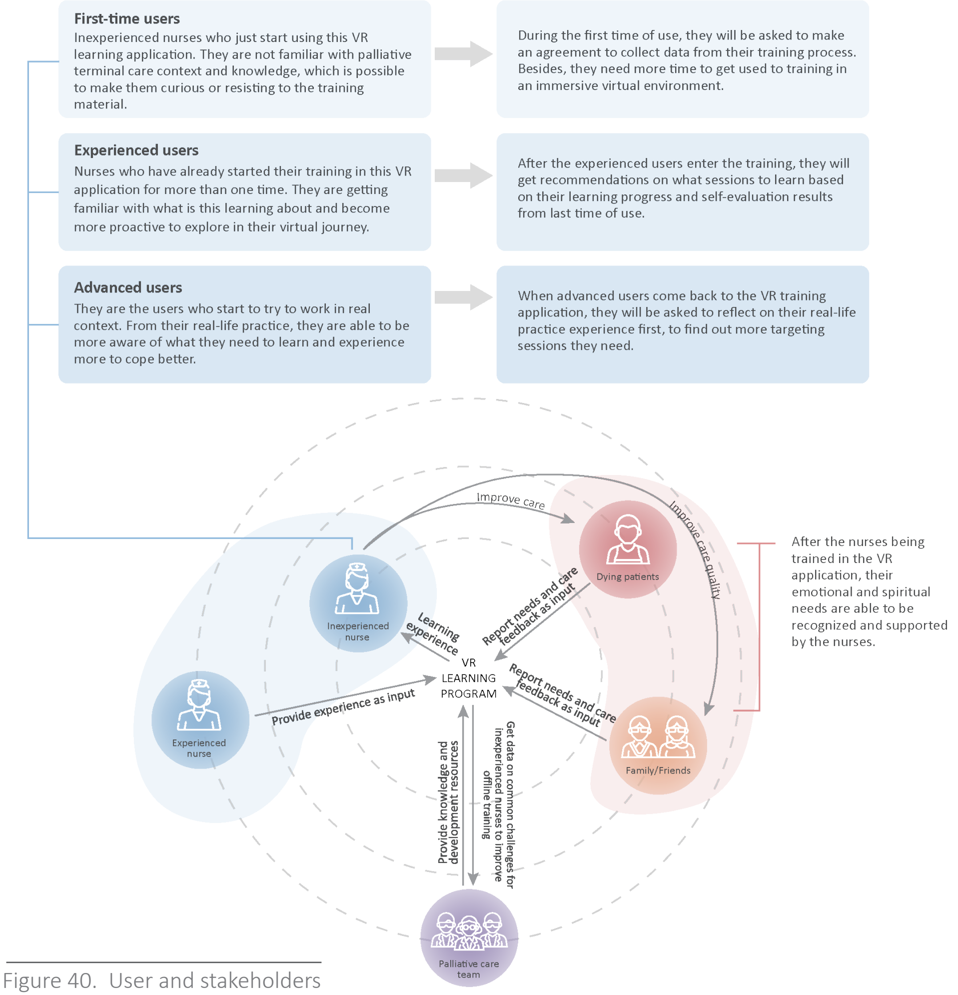


Figure 39. User journey

/7.6.2. USER AND STAKEHOLDERS



First-time users
Inexperienced nurses who just start using this VR learning application. They are not familiar with palliative terminal care context and knowledge, which is possible to make them curious or resisting to the training material.

During the first time of use, they will be asked to make an agreement to collect data from their training process. Besides, they need more time to get used to training in an immersive virtual environment.

Experienced users
Nurses who have already started their training in this VR application for more than one time. They are getting familiar with what is this learning about and become more proactive to explore in their virtual journey.

After the experienced users enter the training, they will get recommendations on what sessions to learn based on their learning progress and self-evaluation results from last time of use.

Advanced users
They are the users who start to try to work in real context. From their real-life practice, they are able to be more aware of what they need to learn and experience more to cope better.

When advanced users come back to the VR training application, they will be asked to reflect on their real-life practice experience first, to find out more targeting sessions they need.

After the nurses being trained in the VR application, their emotional and spiritual needs are able to be recognized and supported by the nurses.

Figure 40. User and stakeholders

/7.6.3. PRODUCT SERVICE SYSTEM MAP

The detailed concept system is elaborated in the map shown in Figure 41. It explains how the service supports the contents of the VR training application, as well as how the VR application supports forming the user experience journey.

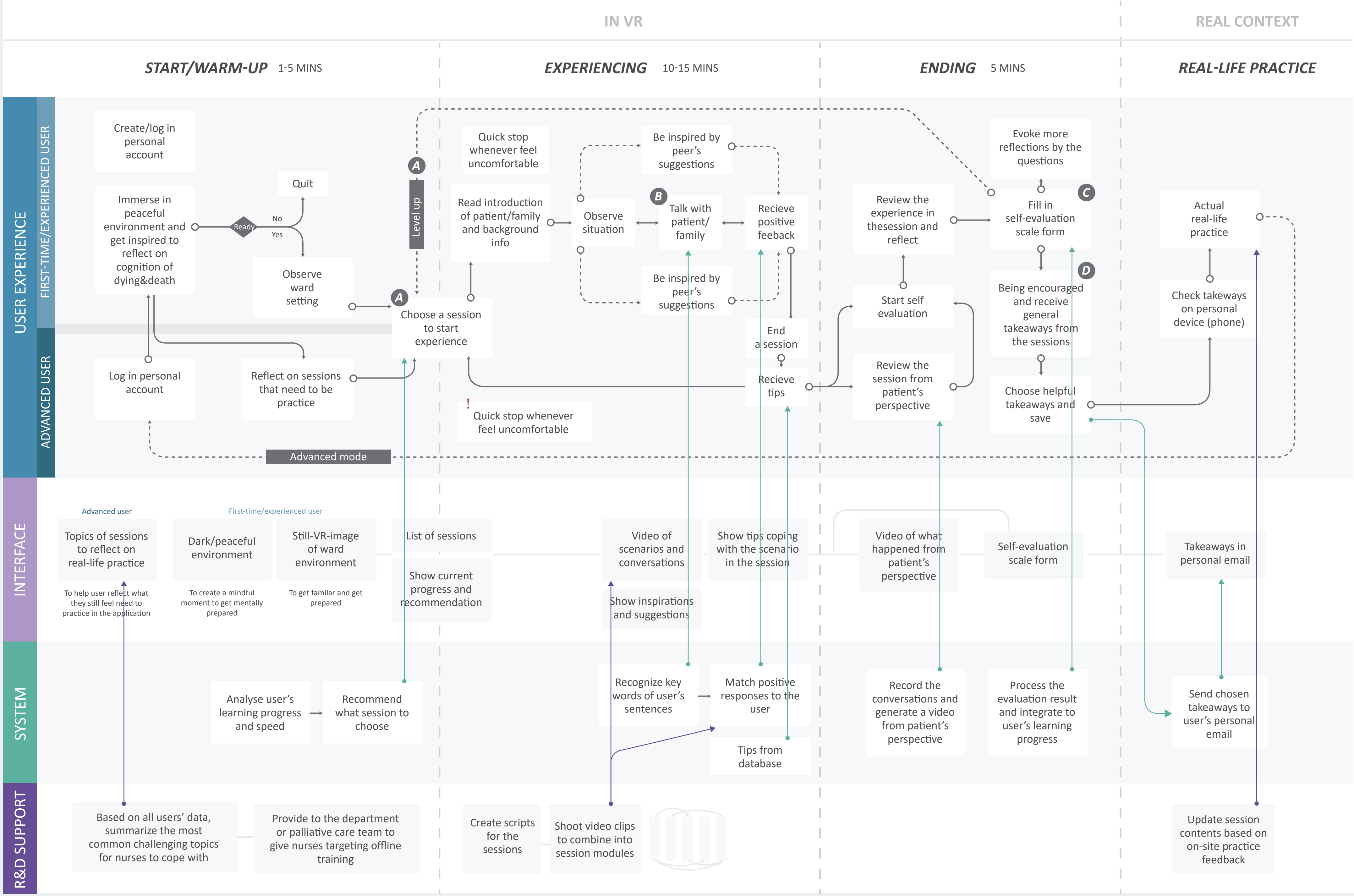


Figure 41. Concept system map

A Description of sessions and levels

Scenarios of palliative terminal care among the nurse, the patient, or/with the family are created into experience sessions. These sessions are divided into different training levels as basic, middle, and advanced. To choose which sessions at the current progress will be recommended by the system based on user's previous self-evaluation outcomes. The users are also free to go to the sessions with their own preferences, as well as to go back to a lower level whenever they feel not enough prepared.The differences and relationship among the three levels are elaborated below:

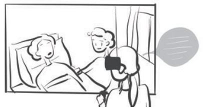
Basic

The learning goal:
Get familiar with the common scenarios in palliative terminal care in the hospital setting, become comfortable to observe the situations of patient and family; Gain basic information that explains the scenario, get start to be able to explore how to make use of the knowledge they receive.

Example storyboard:


Observe the scenario


Receive information to understand the scenario


Try to adapt own way to interpret

Mid-level

The learning goal:
The learning goal: Based on the same scenarios in the basic level, the users in mid level will explore how to interact with patients and families in the way that the user feel comfortable and confident. There is no standard answers of what is a good conversation. The aim is to support the users to try out and find their own way.

Example storyboard:


Recognize the scenario


Initiate conversations with patient/family


Get inspired and explore ways of interaction

Advanced

The learning goal:
In the basic and mid level, the users are supposed to gain capabilities to take care of themselves' and patient&family's emotional and spiritual needs. However, in the real context, the situation can be more complex and severe, harder to accept or cope with. In the advanced level, the users will be exposed to these complex scenarios.

An example of the scenarios in the three levels is illustrated below. The scenarios are organized along a timeline of a patient's dying process.

Basic/mid level

Start pallitive care	Actively dying	Transitioning	Imminent	The death	After death
Cease life-prolonging equipment	Visit patient: Dyspnea	Visit patient: Hallucinations	Visit patient: Restlessness	Life sign disappear	Care for the dead body
Prepare care plan	Visit patient: Anorexia	Visit patient: Agitation	Visit patient: Lethargy	Family support	Grieve for the patient
...	...	...	...	...	...

Advanced level

Severe symptoms	Emotional status	Other complex situations
Patient with delirium Patient with severe blooding ...	Patient with delirium Patient with severe blooding ...	Patient with young child Depressed/ angry family ...

B Example conversation

The example conversation is inspired by the End of Life course from Royal College of Nursing (2016). The user is able to start over with their any part of their conversations to explore different ways.

(After introducing the patient and his family member to the user...
In a while, the system detects the user doesn't react to the scene...)

If you already notice that Marie seems a bit worried, would you like to try to ask what makes her concern like this?

(Pop-up inspirational information for user)

Nurse Tess

Hi Luuk and Marie! I'm Tess, didn't see you in days, how were you all coping?

Patient's wife Marie

It's been really hard...he... he's just so poorly... he doesn't speak at all now... Sleeping most of the time. He wasn't like this when I last time came to see him...

Peer: What I always do is showing my compassion for them, they always need it

(Pop-up inspirational information for user)

Nurse Tess

Oh dear, that must be hard for you to see. But we are here to get him feel comfortable as much as possible.

Thank you, the staff here are really kind to us. But how things are going to happen with my husband?

Patient's wife Marie

Tone of voice is always important in this kind of interaction. Exlore your own way to be peaceful and supportive.

(Pop-up inspirational information for user)

Nurse Tess

He has been sleeping more of the time and is almost unconscious... that would continue... he still may be hear you, so talk to him. Be mindful of what you all talk about in the room in case he hear you... His breathing will change and may be quite noisy but actually that probably won't cause him any more distress...

...sometimes it's more upsetting for the family that the person... I understand this will be a hard time, you can always let us know your concerns and we are here to support you and your family.

It's helpful to explain the dying process for the family, prepare them for what to expect, as everyone needs time to prepare for death, as well as yourself.

(Pop-up inspirational information for user)

Thank you, that's really helpful... Thank you for your time Tess...

Patient's wife Marie

C Description of the self-evaluation form

At the ending stage, a reflection questionnaire is used as a self-evaluation tool, to evoke user's reflections on what they've experienced and give input to the system on the user's learning outcome progress. The questionnaire consists of two main parts: the first part is about evaluating user's own feeling and coping capability; the second part is about reviewing and evaluating how helpful and effective the sessions are for the users, as a way to help the user be aware of their learning experience and, at the same time, collect data that support system update and optimization on the quality of the sessions.

Answering with Likert Scale, the system processes the results and give the user recommendations on what sessions in what levels to take in their next-time training. An example of the questionnaire questions is shown below.

- How comfortable do you feel to be present with patient&family in this session?
- How comfortable do you feel to talk to patient&family in this session?
- How comfortable do you feel after interacting with patient&family in this session?
- How confident do you feel to talk to patient&family in this session?
- How confident do you feel to recognize their emotional&spiritual needs in this session?
- How confident do you feel to understand their emotional&spiritual needs in this session?

- To what extent do you think you are able to be aware of your own feeling by this session?
- To what extent do you think you are willing to explore more by this session?
- To what extent do you think you are inspired by this session?

The questions for reflecting on one's own feeling are inspired by the "Reflection Questions: Experiencing Your Feelings" (Dartmouth-Hitchcock, n.d.).

D Example encouraging tips at ending

The summarized tips for the experienced sessions at the end aim for sending the user a feeling of they've done a good job on what they've tried out and encouraging them to keep exploring in the later-on training. It's also a way to provide some takeaways for the users for them to prepare for real-context work. The tips are formed as "behavior + positive effect" like the examples shown below:

"Your soft and peaceful tone of voice made the patient and family feel peaceful and less anxious. Maybe you didn't notice, it also helped yourself calm down and had a better conversation with the patient and family."

"It's wise of you to proactively explain the dying process to the family member when you noticed they were anxious by witnessing the change of the patient's status."

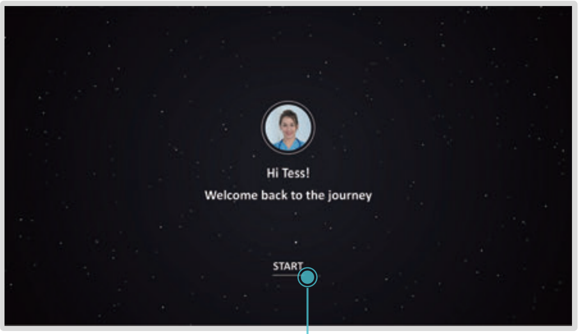
"If you feel uncomfortable or just have a feeling to share your thoughts after a session or after meeting a dying patient, it's always helpful to go to a friend, a colleague, or your family to let it out."

/7.6.4. INTERFACE AND USER FLOW

As the concept structure has been described above, the user experience within a training session is going to be further elaborated through the interfaces in the VR application following the designed user flow. Both the user flow and interface visual style are designed to keep concise and clear, so that they are less attracting and interfering users' vision, to achieve more immersive experience for users to feel what is happening in the scenes and interact like in real context.

START/WARM-UP

First-time/experienced user



Hi Tess!
Welcome back to the journey

LOG IN

Log in with nurse's personal account;

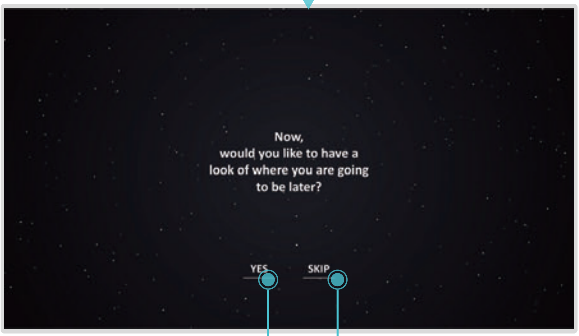
Use a dark and peaceful virtual environment to help the nurse start to get used to the immersive experience.

"Death is not the opposite of life, but a part of it."

GENTLE INVITE

Show a poem or quote about death;

As a gentle invitation that invite the user starting thinking about their own experience or cognition about death&dying.



Now,
would you like to have a
look of where you are going
to be later?

STEP INTO CONTEXT

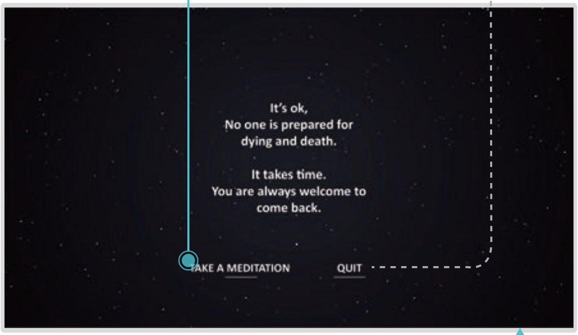
Ask if the user would like to have a look of where he/she is going to be later;

Get further prepared by getting comfortable staying in the palliative care ward.

MEDITATION

If the user still feel uncomfortable but try to continue, a meditation session is setup to help the user clear out thoughts and be more peaceful.

QUIT THE APPLICATION



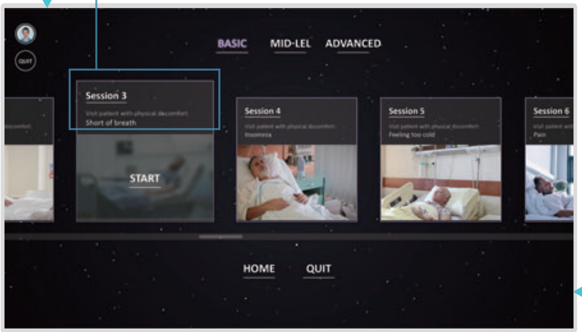
It's ok,
No one is prepared for
dying and death.

It takes time.
You are always welcome to
come back.

BUFFER MOMENT

Let user be aware that it's ok to say not yet.

System gives recommended session based on user'slearning progress

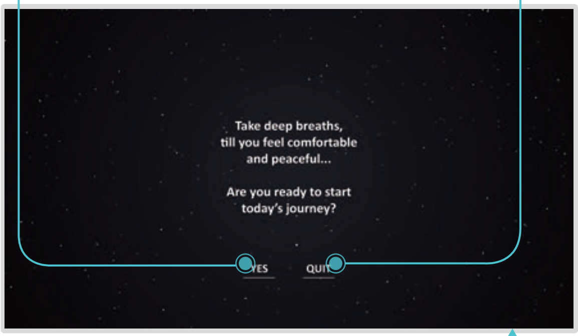


MAIN MENU

Main menu that shows the list of available sessions.

STEP INTO CONTEXT

Observe the environment of the ward.



Take deep breaths,
till you feel comfortable
and peaceful...

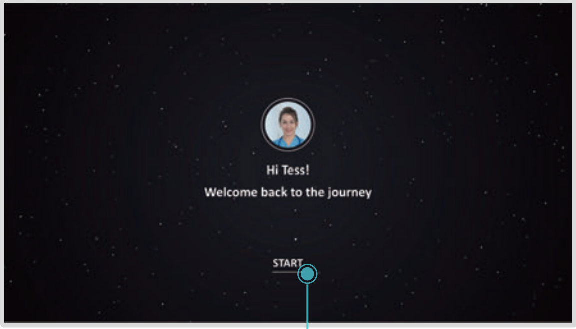
Are you ready to start
today's journey?

CONFIRM JOIN THE TRAINING

Confirm that the user is well prepared and feel comfortable to start the journey.

START/WARM-UP

Advanced user

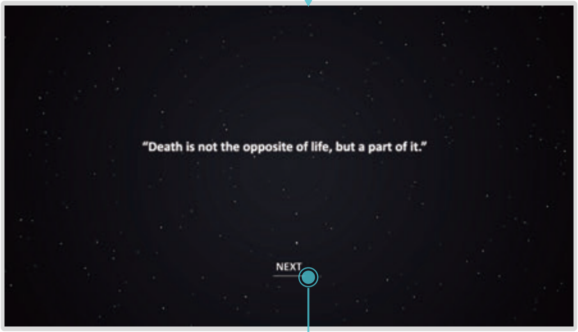


Hi Tess!
Welcome back to the journey

LOG IN

Log in with nurse's personal account;

Use a dark and peaceful virtual environment to help the nurse start to get used to the immersive experience.

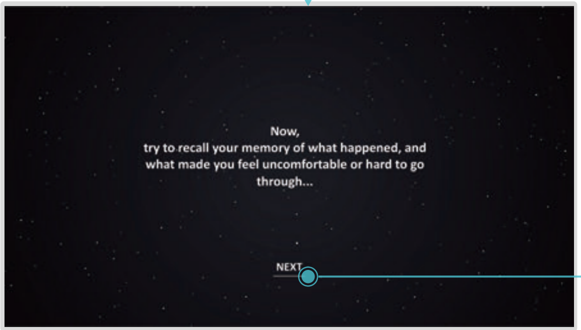


"Death is not the opposite of life, but a part of it."

GENTLE INVITE

Show a poem or quote about death;

As a gentle invitation that invite the user starting thinking about their own experience or cognition about death&dying.

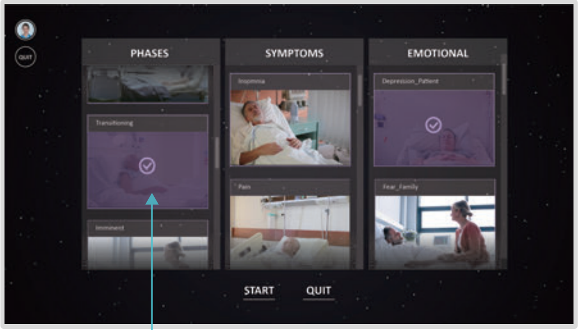


Now,
try to recall your memory of what happened, and what made you feel uncomfortable or hard to go through...

REFLCETION

Ask if the user to review how him/her feel in their real practice;

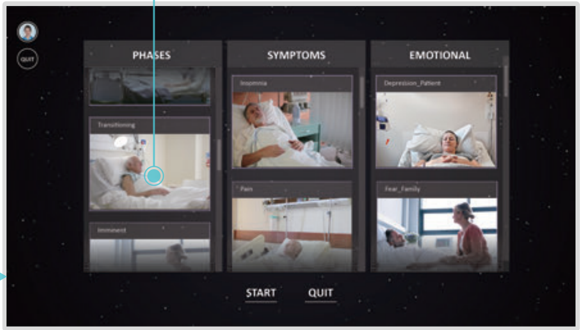
Based on real practice, be aware of what aspects the user needs more experience to be able to cope with.



CHOOSE SESSIONS

User chooses the sessions in the themes that they feel like they need more practice/-experience.

Allow mutiple choice, the user can take the session one by one or skip anyone.

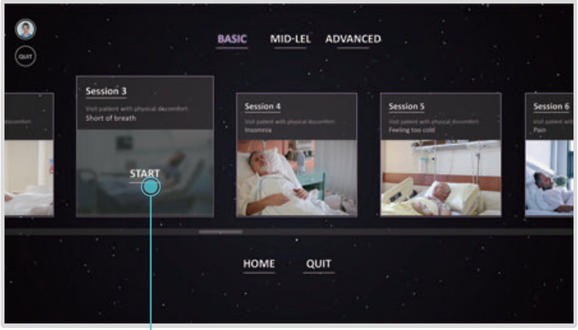


THEMES IN CATEGORIES

For the advanced users, the sessions are labeled directly in different themes which could help them easier related to their real-life experiences and feelings.

EXPERIENCING

Advanced user



CHOOSE SESSION

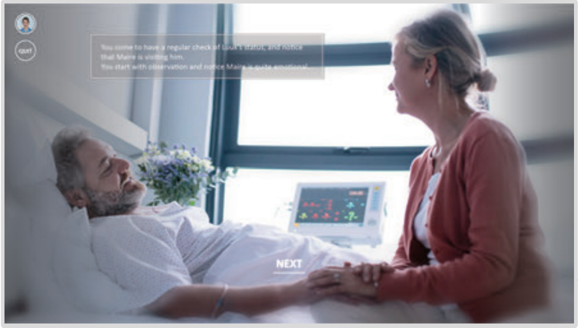
Taking system recommendation and personal preference, choose a session to start.


This is Luuk.
He was admitted to hospital two months later. From one week ago, Luuk and his family decided to transfer his treatment to palliative terminal care and hope to spend his last stage of life peacefully without pain...

This is Marie.
She is Luuk's wife. Marie was sad with the fact that her husband is leaving her. She always came to the ward to stay with Luuk during the day, except which she doesn't what else she could do for him ...

INTRODUCE CHARATERS IN THE SCENE

Introduce the patient (and family) to the user to create real feeling for later interaction.


You come to have a regular check of Luuk's status, and notice that Maire is visiting him.
You start with observation and notice Maire is quite emotional.

INTRODUCE BACKGROUND INFO OF THIS VISIT

Introduce the background infoma-tion of ths visit, according to the theme of the chosen session.


TIPS

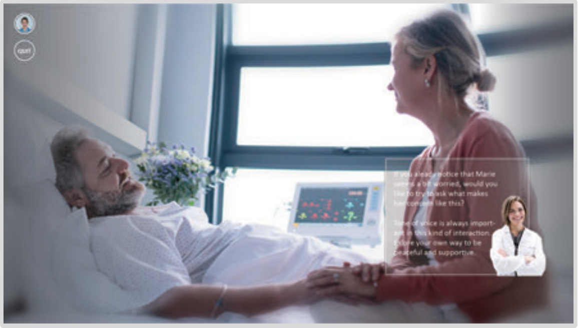
- It's important to talk to end-of-life patient's family members, this has a positive impact on patient's outcome.
- It's helpful to explain the dying process for the family, prepare them for what to expect, as everyone needs time to prepare for death, as well as you.
- You can always talk to a colleague or a friend when you feel your own emtion is influenced by your compassion for the patient and family.

GIVEN TIPS

At the end of each scenario, the user will be provided tips as a summary of inspirations on how to understand and cope with this situation.

CONVERSATIONS

The user is encouraged to explore their own way and pace to lead the conversations with the patient/ family, and will receive positive responses from the patient/family.


If you already notice that Marie seems a bit worried, would you like to try to ask what makes her concern like this?

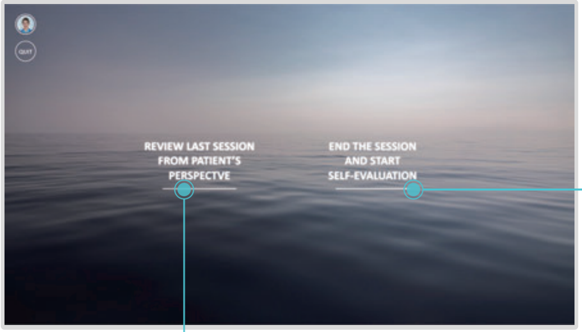
Tone of voice is always important in this kind of interaction. Explore your own way to be peaceful and supportive.

ENCOURAGE TO TALK TO PATIENT/ FAMILY

When it detects that the user doesn't react to the scene for a while, there will be a non-player charater, senior nurse, appear and provide inspirations on how to interact with patient/family in this situation.

ENDING

Advanced user

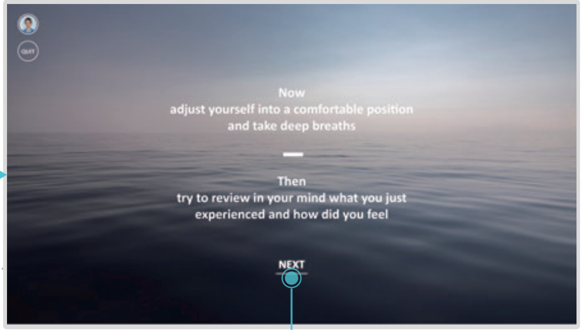


START REFLECTION

Choose to review the last session from patient's perspective first or directly start self-evaluation

PATIENT'S VIEW

A video of what just happened in the last session but in a patient's perspective.



Now
adjust yourself into a comfortable position
and take deep breaths

Then
try to review in your mind what you just
experienced and how did you feel

REFLECT MOMENT

Ask the user to reflect in mind what did they see, experience, and how they felt.

TIPS EMAILS

The tips that the user saved will be sent to user's personal email address, so thay the user can check them after leaving the application.

1. How comfortable do you feel to stay with the patient?

① ② ③ ④ ⑤ ⑥ ⑦

2. How comfortable do you feel to talk to the patient and family?

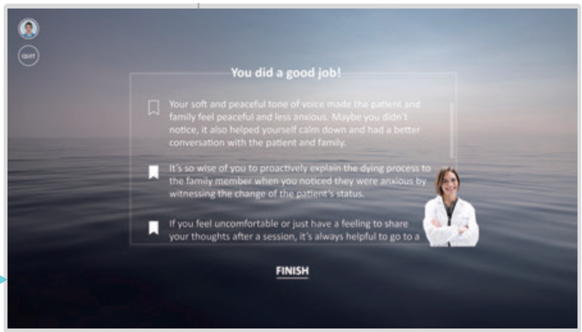
① ② ③ ④ ⑤ ⑥ ⑦

3. How confident do you feel to talk to the patient and family?

① ② ③ ④ ⑤ ⑥ ⑦

SELF-EVALUATION FORM

A questionnaire that ask the user to evaluate their capability of coping with palliative care scenaiors based on user's reflections of experience and feelings.



You did a good job!

- Your soft and peaceful tone of voice made the patient and family feel peaceful and less anxious. Maybe you didn't notice, it also helped yourself calm down and had a better conversation with the patient and family.
- It's so wise of you to proactively explain the dying process to the family member when you noticed they were anxious by witnessing the change of the patient's status.
- If you feel uncomfortable or just have a feeling to share your thoughts after a session, it's always helpful to go to a

SESSION SUMMARY

A list of key tips for the experienced sessions provided in an encouraging way. The user can save the tips that helpful for them.

/7.6.5. USER SCENARIOS

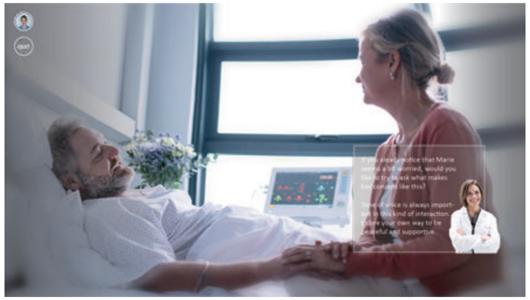
Several user scenarios are created to demonstrate how this application helps the users get on board and get inspired, as well as allow the users feel as comfortable as possible while using it.

Scenario 1

After entering a session and the user is in the environment together with paients and/or families, she/he has no clue how to start the interaction, what to do or say.

I'm not sure what should I do now...this feeling is really unfamiliar...

System recognizes the silent situation for a while.



If you already notice that Marie seems a bit worried, would you like to try to ask what makes her concern like this?

Tone of voice is always important in this kind of interaction. Explore your own way to be peaceful and supportive.

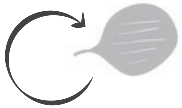
A floating window jumps out with tips that encourage the user to start the conversation.

Now the user is inspired and have an idea what to say.

Scenario 2

The user has got familiar with the scene, now she/he wants to try to explain the situation to the patient in another way to see how that work.

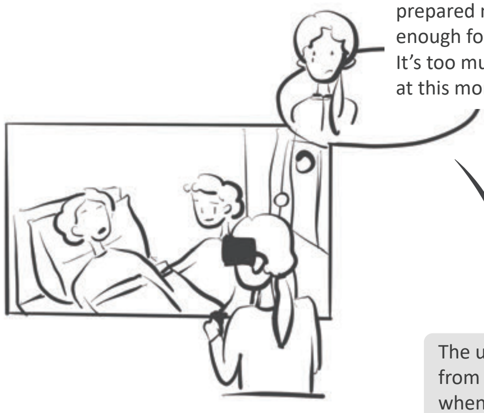
What if I explain it in that way...



The user can always start over a sentence or repeat same information. There is no requirement that it needs to be a complete flow of conversation in a session. The response from the patient will always only match to the last sentence of the user.

Scenario 3

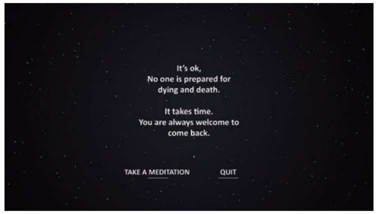
The user feels she/he is not feeling comfortable to handle her/his emotion that is evoked by the scene at the moment. She/he is now uneasy and insecure about being in this scene.



I think I haven't prepared myself well enough for this yet... It's too much for me at this moment...

The user can quit from the session whenever they hope.

The training program will let the user know that it's ok to feel unprepared. The user has the choice to take a guided meditation to relieve and then try again or leave the training.



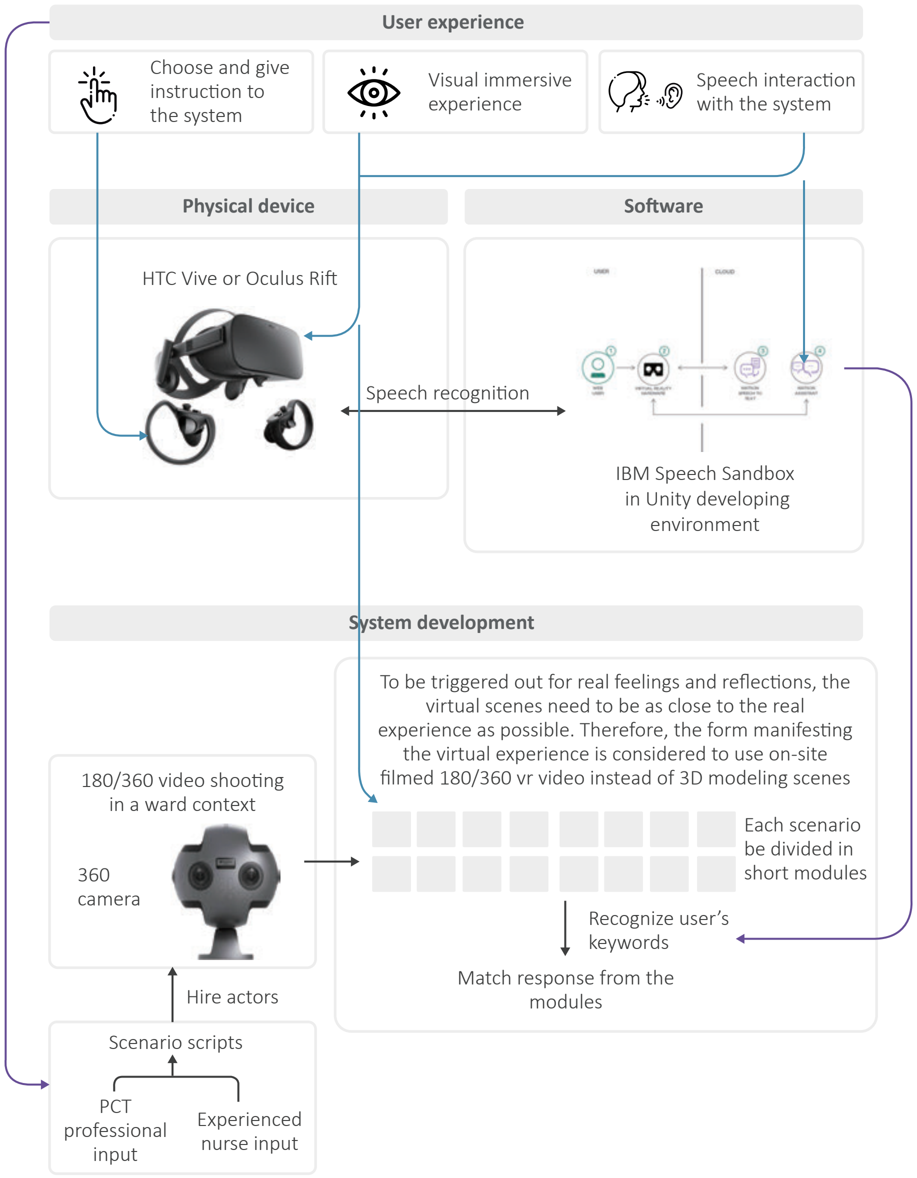
It's ok,
No one is prepared for
dying and death.

It takes time.
You are always welcome to
come back.

or

The user can choose to leave the training immediately.

/7.7. DESIGN IMPLEMENTATION



To be triggered out for real feelings and reflections, the virtual scenes need to be as close to the real experience as possible. Therefore, the form manifesting the virtual experience is considered to use on-site filmed 180/360 vr video instead of 3D modeling scenes

Figure 42. Ilustration of implementation plan

As the concept is only developed into a framework and a VR demo, the detailed implementation plan proposal is elaborated in this chapter. The implementation approach is described from levels of physical devices, software, and system development, shown in Figure 42.

Visual scenes in VR

To be triggered out for real feelings and reflections, the virtual scenes need to be as close to the real experience as possible. Therefore, the form manifesting the virtual experience is considered to use on-site filmed 180/360 vr video instead of 3D modeling scenes use in most of the current nurse training VR applications.

Know from the nurses from Maasstad Hospital, there is an organization **Lotus Nederland** which provides professional trained actors/actresses on medical training, who are able to reproduce the patients' realistic status and reactions for care providers to practice. To create a more realistic experience in this VR application for the nurses, it can be considered to hire the actors/actresses from Lotus Nederland for the scenario filming.

/7.8. FINAL EVALUATION

/7.8.1. APPROACH

DEMO MAKING

To gain valuable and relatively accurate feedback of the design from the users, an interactive demo which can be experienced with VR headsets is created, technically supported by VR Zone, TU Delft. The demo includes a basic user journey, that is close to the envisioned design outcome, from a beginning to the end of a single time of use, consisting of two scenarios which are interaction with a patient and interaction with a patient's family. Due to the time and technical limitations, the speech interaction isn't implemented in this demo but only simulated by the recorded users' voice.

Figure 43. Filming the conversation scenes in a hospital ward using 360 camera

Figure 44. Editing the 180 video and creating interactive journey with Adobe Premiere and 3Dvista

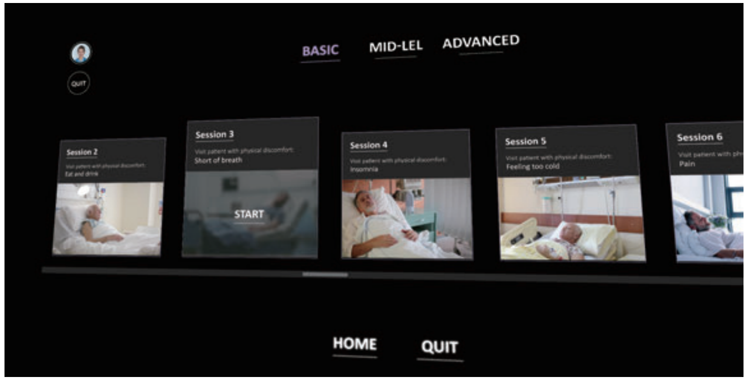
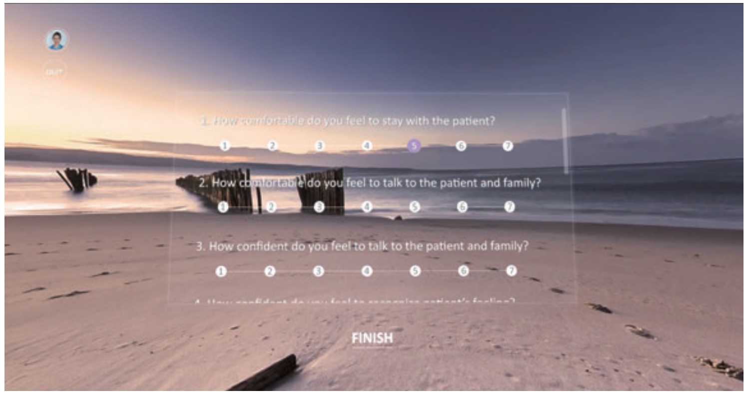


Figure 45. A screenshot of the VR demo (1)

Figure 46. A screenshot of the VR demo (2)



1. How comfortable do you feel to stay with the patient?

① ② ③ ④ ● ⑥ ⑦

2. How comfortable do you feel to talk to the patient and family?

① ② ③ ④ ⑤ ⑥ ⑦

3. How confident do you feel to talk to the patient and family?

① ② ③ ④ ⑤ ⑥ ⑦

Figure 47. A screenshot of the VR demo (3)

EVALUATION SETUP

Aim of the final evaluation

Based on the fact that the design focuses mainly on the users' experience flow and the structure of the application, but not the detailed interaction, there are two aspects that need to be tested: functional aspects and experience aspects.

- Functional: How users perceive the goal of the design that is shown to them, and where it matches or doesn't match with the original design goal
- Experiential: Evaluate the effectiveness of the current interactive experience. Also, using the current interactions as a reference, find out users' preference on the detailed interaction style and format that lead to design recommendations.

Evaluation materials

- VR demo

The demo works for creating an immersive interactive experience for the users to experience the design directly, but to explain to the users, the current demo is not the optimized experience, but a reference for them to comment and give feedback on the design.

- Design brief slides as an elaboration

Support the design demo, help users get a clear overview of the design.

Support the design demo, help users get a clear overview of the design.
It’s also for collecting feedback on the information structure of the design. (Sessions themes and level-up logic, sessions for different type of users, and self-evaluation questions)
- Supplementary examples as comparison elements since the design demo didn’t achieve the ideal interaction and multiple possibilities:
  Information feeding: visual interface, voice
  Interaction with NPC: positions and view, voice
  Reflection setup: environment, questions and answers

After the introduction of design biref and try-out the demo, an interview is conducted to collect user’s feedback on the current design. The full evaluation setup, protocol, and materials can be found in Appendix F.

Figure 48. A nurse from Maasstad Hospital is trying out the design demo

/7.8.1. EVALUATION RESULT

QUALITATIVE FEEDBACK

Because of the COVID-19 situation and the busy working routine of nurses, within the possible arrangement, only one nurse from the oncology department, Maasstad Hospital, was able to participate in the final evaluation interview. The interviewee, Priscila, is a specialized nurse for oncology and palliative care who has joined the interviews in the research phase and design iteration phase. After her interview, another two oncology nurses were able to quickly jumped in to experience the demo and give short comments. Since Priscilla is an experienced nurse in palliative care domain, she was able to evaluate the design from an integrative perspective on both an inexperienced nurse as she experienced in her past career and also an expert.

As general, from 1 to 10 scores, the nurse gave an 8 for the final design outcome as it’s a new perspective for them to get trained and adapted to palliative care practice, and she believed that the design would have a great contribution to young/inexperienced nurses’ palliative care education. In the figure below, the evaluation of how the design has matched with the interaction vision is elaborated.

How much do you think the current design is adaptive from the starting to the experiencing stage?

How much do you think the current design is encouraging in terms of supporting you explore yourself?

(It feels safe to feel and explore and make mistakes in the journey)

How much do you think the current design is inspiring?

How much do you think the current design is able to support you reflect on your experience and feelings?

(If it’s for beginning nurses, it’s higher for its guidance. And the patient’s perspective of view also helps a lot with reflection. However, for more experienced nurses like me, it’s lower since it’s too detailed for me and I’ve already been able to reflect on myself)

The nurse was able to recognize the goal of the design and the goal of the starting, experiencing, and the ending stages through her own experience with the VR demo. The evaluation outcome for the different stages is elaborated here:

Starting

" The starting with the empty dark environment and the quote helps me with realizing what we are doing and what is happening, and with the peaceful music which helps me breathe in and breathe out to get ready...It's a great start."

The created experience of the starting stage is able to give the user a moment to leave the other feelings or what happened in the day behind and get themselves into the situation. It also gets positive comment on the way user interacting with it, with which the user is able to control their own pace and free to skip or stay at any step. It conveys the feeling of security. Also compared with other environment visual options like natures, reported by the nurse, the empty dark environment is preferable since there is no interruption for the user to take their own moment.

Experiencing

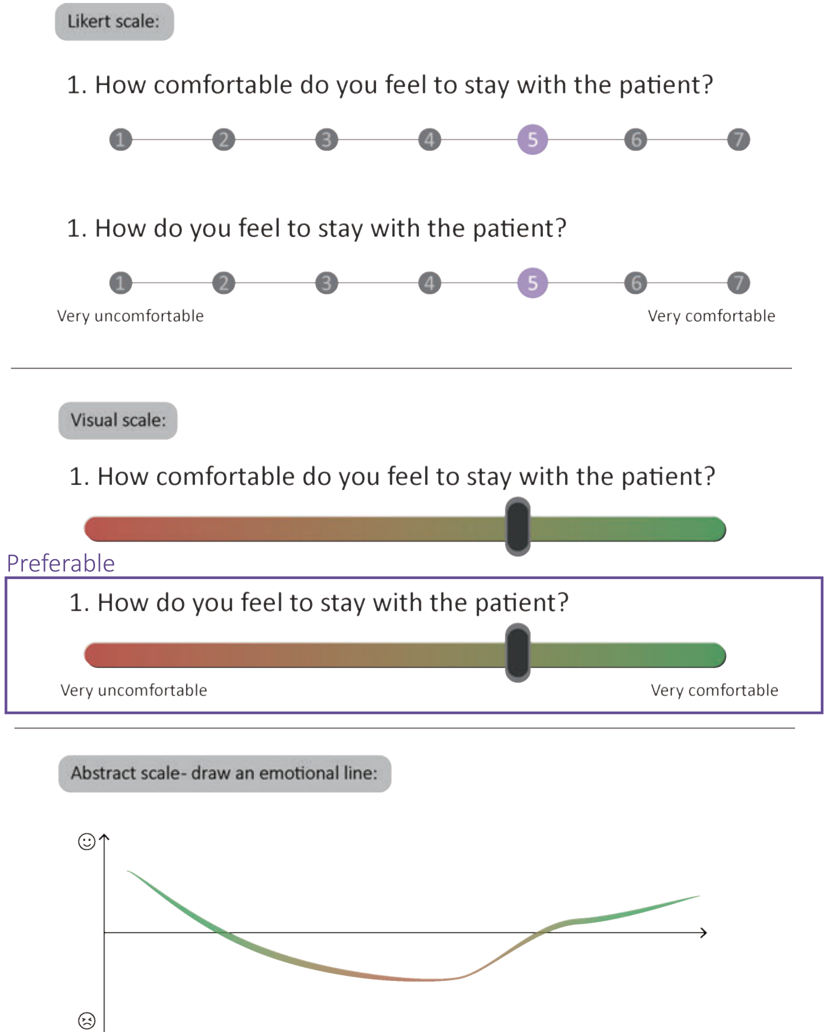
" I'd like to see the ward and the patient from different perspectives like what I actually see during my work..."

It is perceived as a good basic start of developing this program, but compared with the currently fixed angle of view, it would create a more realistic feeling if there are options on multiple ways to enter the ward and different views to observe the environment. This will become a design recommendation for further development. For the floating information windows, it needs to make sure they are clear and readable for all the users, and it would be better if there is option to pause the scene and have enough time to zoom in and check the windows carefully when needed. Since the current design only provides supporting information with visual texts, the question was asked to the nurse about preference on voice information feeding or visual information feeding. The nurse prefers visual information with the reason that the visual information is more convenient for users to take their own pace going through it with more security during the journey.

Ending

"In the end, I'm able to reflect on what I've experienced and to be gradually back to the real world...It created kind of closure moment, which is important for nurses to go back to the normal working status after training."

She commented that the nature environment that the user exposed to, which is different from the empty dark environment, create the opportunity after the self-reflection for the user to gradually slip out of the feelings generated from the scenarios they've experienced and won't take these feelings with them in their coming normal work. For the reflection questions, the nurse prefers more visual ways to answer instead of numbers, since visuals create less stress to choose and easier to help her describe her feelings. The options that were provided to the nurse is shown in the figure below. As mentioned, the nurse preferred the second option. Also, compared with two ways of answering the questions, the nurse preferred the question framed as "How do you feel about..." and answer the questions with each feeling individually which is easier for the nurse to reflect.



She also mentioned that this way of evaluation with these reflection questions is more likely to work for the new and inexperienced nurses, since it provides guidance on from what perspectives to reflect. However, for the more experienced nurses, it would be more helpful to only ask for general feelings.

Information structure

The sessions themes and level-up logic, sessions for different types of users (normal and advanced) were explained to the nurse, which received positive feedback on how they are organized and presented to the users. It's effective for the nurses to understand the reasons behind and make use of the materials. There is one comment about the further opportunities about the scenarios in the sessions, which is to integrate different symptoms or situations together in one scenario to create complex scenarios that are closed to realistic situations, especially for the advanced users. This opportunity will become a design recommendation for further development.

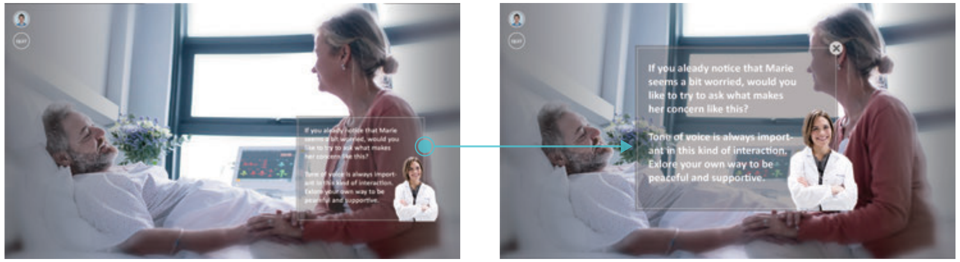
Since the other two nurses were only able to quickly try out the demo and needed to go back to work, there was no interviews with them. Even so, they still have expressed their expectations on this application which is innovative and potentially helpful being available for training as soon as possible.

> *"I talked with other colleagues in palliative care domain about this concept and found they are all enthusiastic about it for its freshness and looking at the problem from a different perspective, it's not only writing a model or playing something, but getting the nurses into real situations but in a safer environment where they can make mistakes. We'd love to see the project being developed as soon as possible and involve more beginning nurses to share their opinion on it, and spread the idea to other departments..."*
>
> ----- Priscilla

LAST MODIFICATIONS

After the evaluation interview with the nurses, some potential design recommendations are generated for the further development of this concept, which will be elaborated in the next chapter Conclusion--- Limitations and Recommendations. However, there are some small details about the design that can be adjusted quickly. They are elaborated here:

Interface of the experiencing stage



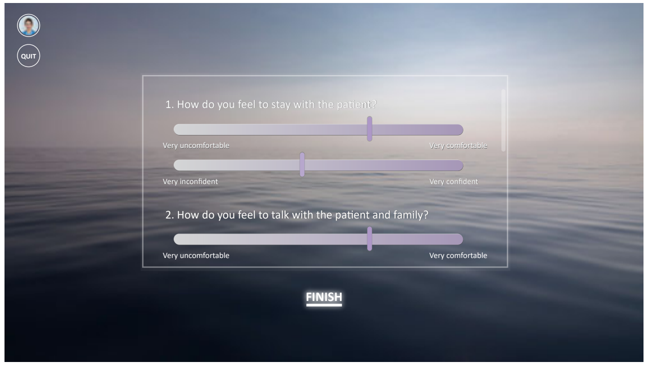
If you aleady notice that Marie seems a bit worried, would you like to try to ask what makes her concern like this?

Tone of voice is always important in this kind of interaction. Exlore your own way to be peaceful and supportive.

By clicking on the floating window, the scenario will pause as well as the window will be zoomed in for the user to go through, increasing the readability.

Closing the zoomed-in window, the scenario will continue to play and the user is able to continue the journey.

Interface of self-evaluation



1. How do you feel to stay with the patient?

2. How do you feel to talk with the patient and family?

Based on the nurse's feedback, the format of answering the self-evaluation question is changed from scores to a visual bar. By moving the position on the bar, the level of the user's feeling is indicated.

8

PROJECT CONCLUSION

This chapter will review the design question that is brought up at the beginning of the project and elaborate how this question is answered throughout the whole process until the final design outcome. Limitations of the project approach and the design outcome are discussed here, with the recommendations for the further development and implementation of the design outcome.

CHAPTER 8. CONCLUSION

/8.1. ANSWER TO THE DESIGN QUESTION

The project aims to answer the design question “What opportunity areas are there to support nurses providing palliative terminal care to dying patients in Maasstad Hospital?” To answer this question, the project starts with broad research on palliative terminal care. Due to the Covid-19 situation during the project period, the main part of the research is done by literature and desktop research. Based on the insights from the historical, cultural&societal, user&context, comparison, and technology research, the scope of the project is refined to support inexperienced nurses’ on-site learning on palliative terminal care to better prepare themselves in the case that they need to look after a dying patient.

With the inspirations taken from the comprehensive research, the concept of Palliative terminal care virtual training for inexperienced nurses on emotional/spiritual capability is proposed. The historical and cultural research points out the new working requirements and individual needs of nowadays’ nurses working on palliative care, which has supported defining the learning goal of nurses on palliative care in terms of its sensitive nature and diversity of cognitions on the death&dying topic, which leads to the soft skills and emotional/spiritual capability of palliative care nurses nowadays. The user&context, comparison research has provided the fundamental of the learning contents and the challenges the design tried to tackle. The technology research inspires the format of the on-site learning experience which is eventually decided on VR virtual training.

To reach the final concept, two rounds of design iteration with the nurses and experts from Maasstad Hospital are involved in the design phase. In the end, a final evaluation interview that is supported with an interactive VR demo is conducted to evaluate how well the final design matched with the design goal and bring up further development recommendations. The technical implementation plan of the application is also discussed in this thesis.

Based on the final evaluation result, the design is perceived as a good start of this proposed VR training application, which possesses potentials to provide the inexperienced nurses or even other medical professionals with a safe environment to think about the topic of palliative terminal care, learn to cope with their own feelings, explore and make mistakes, and be eventually more comfortable and confident to look after dying patients and their family members. However, since the design mainly focuses on the training program structure and the experience journey, more opportunities and details of the interaction design still need to be developed and tested if the application is expected to be launched.

Generally, the final outcome of this project introduces a potential solution for Maasstad’s nurses who don't receive specialized palliative care education or training to get themselves feel more prepared for providing palliative terminal care to patients and families, ensuring nurses’ own mental well-being as well as better care quality. If it is further developed and assessed as effective, it can be perceived as an intervention that bridges the current situation and the envisioned situation when palliative care education becomes available or compulsory for all care providers. However, when the envisioned situation comes, this solution is not necessary to be conflict or overlapped with the mature palliative care education & training system, but can be part of it, because of the different perspective to conquer the challenge of palliative care practice and an important supplementary to the knowledge gained from instructions and guidelines.

/8.2. LIMITATIONS AND RECOMMENDATIONS

/8.2.1. LIMITATIONS

Participant

Due to the Covid-19 situation and the busy working routine of the nurses during the project period, the participants for the user interviews, design iterations, and final evaluation are very limited, especially for the final evaluation. For now, the evaluation outcome is not representative enough for the user group as a quantitative result. More beginning nurses are needed to be involved in the tests and further iterations of the current design.

Demo

The current VR demo is created not fully functioned, especially on the conversation interaction experience, due to the time and technical limitation. The envisioned interaction is simulated by recording the user’s voice that forms the conversations in the demo. Therefore, the technical implementation suggestions are given in the chapter Design Implementation, to support the further development to implement this interactive conversation experience.

Long-term effect

The design outcome of this project is expected to contain a long term effect on users that they are able to gradually grow emotional and spiritual capability on palliative terminal care, which is hard to assess within the limited project time. The result can be different from using the application for one time and for a month. The assessment and testing plan on how the design could support users in long term needs to be developed to ensure the value and effectiveness of this training application.

/8.2.2. RECOMMENDATIONS

Current design optimization

- Integrated scenarios:
The current training scenarios are all independent themes separated by different symptoms, activities, or family status. Based on the evaluation interview, since the realistic context can be much more complex, there should be scenarios that combines different symptoms and situations to reproduce the realistic experience for the users.

- Multiple views:
The VR demo that is created for final evaluation only contains one fixed view which is nurse standing at the patients' bedside. Based on the evaluation interview, the user prefers more flexible and free views to simulate a more realistic experience.

- Personalization:
Although the current designed experience is confirmed to be effective by the interviewed nurse, there are indeed different preferences existing on the way one feels comfortable to reflect and immerse. Therefore, if the environment and inspirations at the starting and reflecting stages can provide different options for the users, allowing them to stay in their preferable environment, it will help them reflect with a higher quality.

- Scenario material filming _ Lotus Netherlands:
To produce effective scenarios that help the users experience the real context and evoke their real feelings, the scenario filming is suggested to be done with the support of Lotus Netherlands with professional actors and actresses, which has been elaborated in the chapter Design Implementation.

Further developing possibilities

Due to the time limitation of the project, some potential developing possibilities that could be considered to add on to the current design from ideation phase and nurse interviews are listed here.

- More personal experience considering different personality, belief, and religion:
As the users will have different life experience, personalities, religions, or beliefs which will have impact on how they respond to the scenarios and their learning effectiveness, it can be considered to create more tailored materials for them to experience.

- Enhance the realistic feeling of the experience like introducing other senses like physical touch:
The current design only includes the senses of vision and sound. However, in the real context, other sensory experiences like physical touch are also an important part of palliative care interactions, which can also highly influence nurse's feeling and confidence on providing palliative care to the patients and families. By reproducing multi-sensory experience, the nurses might be able to prepare themselves better and lead to a better quality of care.

- Introduce multi-player mode:
Since the embedded scenarios are limited compared with the various and uncertain real-world possibilities, suggested by the nurse during the design iterations, the multi-played mode can be an option to expand the scenarios that the beginning nurses are going to encounter. If an experienced nurse join the session with an inexperienced nurse, she/he could be trigger by the existing scenarios and explain the other possible scenes from her/his own experience as supplementary content for the training.

- Develop doctors' version
Known from the nurse from the evaluation interview, the idea of the design is shared with doctors from the department and they are very open to using it and have their own version. Based on the design iteration interview, the value of this doctor's version lies on similar aspects of nurses, and also on contributing to better communication between nurses and doctors regarding palliative care decisions. The main difference from the nurse's version is most possible on the interactive activities with the patients and families because of the different roles in their work. There is also the possibility for nurses and doctors to experience from each other's perspective to have a better understanding of each other's work to achieve a better collaboration.

/8.3. PROJECT VALUE

Reviewing the project outcome and the feedback from Maasstad's nurses, the project proposes a new perspective on medical professionals' training experience, different from receiving instructions and fixed guidelines. It also looks at the nurses' skills and their own needs at the same time, perceiving them as a whole person instead of a function.

If the design can be implemented in the department, it has the potential to become a trigger for health workers working together in the hospital to discuss the palliative care topic in their free time.

REFLECTION

Throughout the five-month graduation project under the Covid-19 situation, I believe that I have learned a lot and overcome many difficulties, and achieved most of my goals set from the beginning.

There is indeed a big pity that compromises were made because of the coronavirus pandemic. Since the access to the hospital and to talk to the nurses was very limited, I was not able to create enough communicating opportunities with the nurses for user research and design iterations. To conquer these challenges, I went through changing project direction and adjusting project approach to improve the feasibility of project execution. At the beginning, my confidence to the project dropped and I felt insecure to make big changes on the set plans. Encouraged by my supervisory team and driven by my own motivation on design for palliative care, I was able to quickly adjusted my mindset and started to embrace the beauty of being able to be a flexible designer, making the best use of the accessible resources, adapting plans and design methods accordingly and taking control on the pace of the project. Looking back to the project process, I can say that flexibility indeed helped me a lot to manage my learning goals and project progress, which will be a precise capability for my future career.

Standing from a distance to reviewing the design phase of this project, it is interesting for me to find out that I have worked on this death & dying related topic from a non-religion-person's perspective. I can imagine that this might help me to be easily open to other different perspectives from different beliefs and religions, and easier to understand the overall diversity of the cognitions of death and dying. However, am I actually able to stand in the shoes of those who have different beliefs and values from mine? Did I understand them like I thought without the actual experience? Is it a good thing for a designer to stand in a complete no-bias position to design or to be in that shoes first and then step out to see the full picture especially for this type of topic? I don't have the answer for it yet, and I believe there is also no right or wrong answer. It is something I would like to explore and reflect based on more research and design practice.

Working on this project, I feel that I have not only gained professional and academic growth, but also personal growth. Especially at the first two months of the project, sometimes I had stress to work on this topic since I was easy to be led to a deep and heavy thought on death and dying of my own and my loved ones at the middle of research, as well as I felt it was such a privilege for me to work on palliative terminal care. This stress gradually faded away during I reviewed documentations and interviews which care providers shared stories of their own or what they've witnessed. These stories helped me realize my connection with my loved ones, the importance of being aware of and taking care of my own spiritual concerns and needs, and the importance of talking about death and dying with my loved ones. I'm glad that I am able to do it now.

Looking back to the whole project process, there are definitely things that can be improved or to be done differently, especially the iterations of the design. I constrained myself on the fact that there were rare opportunities to test the design with the nurses in the hospital, so that I was mostly focusing on building the design as comprehensive as possible to show to the nurses, but ignored the various other possibilities that I can explore together with nurses. Although the final evaluation indicated the potential and the acceptance of the current design, I would like to start from multiple different basic demos of different interactions or stories, to demonstrate the possibilities first, if I will work on this project again. It may lead to a totally different outcome.

I sincerely appreciate the opportunity to initiate this project, with my supervisory team and Harry from Maasstad Academie, to support nurses who will work or are working on palliative terminal care. I believe this project is an unforgettable experience for me and a good starting point for my future career, and hope the research and design outcome of this project will be further developed and be really able to support nurses.

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At the beginning of the pandemic, it was hard to get contact and arrange interviews with the nurses in Dutch hospitals. I needed to send flyers on Chinese online communities to invite nurses for the interviews. Hui, Danyu, Limei, and Anran, thank you for trusting me and sharing your stories with me.

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Without Arno Freeke and Jan Douma’s technical support from VR Zone, this project wouldn’t have ended up with an interactive VR demo for the nurses to actually experience the design and give feedback. Thank you, Arno and Jan, for your professional and patient support on my project. Also, thank you for providing such an amazing space and opportunities for students to explore and create all kinds of VR possibilities!

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APPENDIX

APPENDIX A. CHINESE NURSE INTERVIEW SCRIPTS

Nurse Profile 4

- **Part 1: Personal background information**
    - How long have you been working as a nurse?
      7 years, used to work in the emergency room and geriatric wards.
      (Northern City Hospital in Shanghai)
    - What's your current department/unit?
      Surgical department
    - What's your main task or responsibility at work as a nurse?
      Provide care to 12 patients per day: Medicine administration, vital sign and symptom check, daily care. Other nurses are also involved in providing help occasionally like changing brine, but the 12 patients are mainly my own responsibility to care that day. Doctors normally don't involve in palliative terminal care except when there is a need to deal with extreme pain.

      There was constantly several dying patients in the unit, but share wards with other patients in double-bed wards or four-bed wards. Their average inpatient length is about 3-5 days, no more than a week. The other patients could understand the situation so they rarely complain.

      In China, normally only rich people and in the private hospital could use a single ward for palliative terminal care in the hospital.

- **Part 2: Personal story sharing and reflecting**
- Have you experienced providing palliative terminal care to dying patients? If experienced, can you share one of the experiences that impressed you with me?
    - Supportive questions: What type of patients was he/she, what was the situation, where and about how long was his/her hospital stay?
    - How did you feel when this happened? What was the reason that made you feel that way?
    - What did you miss in that situation? What supported you in that situation?

During my work in the surgical department, there was a young patient with bone metastases from advanced pancreatic cancer. He couldn't move enough a little bit since it caused huge pain. So I pasted Fentanyl to the area where he felt pain or if that wasn't working, giving Morphine injection instead. I tried to constantly walked to his bedside and talked to him when I wasn't that busy to provide mental care to him. He was as fragile as most of the other dying patients, not able to bear anything a little bit heavy. However, his family assumed he was cold, so they put layers of thick quilts on his body which he was not able to bear at that moment.

His parents were in great sorrow which was impossible to avoid, but they were able to accept our suggestions of care like reduced the quilts for the patient. People are higher educated nowadays so that it's relatively easy to communicate with.

It's also quite different from young cases and elderly cases. For elderly cases, their family normally already have mental preparation like preparing the graveclothes. For young cases, their family takes time to accept the fact and sometimes really irritable, which I really understand so I have my patience for them.

- In this experience, did you understand what was happening? What you valued most? What were your needs?
  Yes, till now, I think so. The patient was in great pain and there was no more meaning and hope to rescue or try to cure him intensely. We unplugged all intubations for him. Normally the patients will be still connected to ECG monitor, but in the cases that the family refused connection since they perceived it as suffering, we respect it and disconnect, but observing the breath instead.

  I really wanted to help him going through his last phase peacefully without pain which also helped his family more at ease with it. We have a pain level evaluation sheet with levels and corresponding coping strategies as a reference for our care work, quite clear guidance for what I can do. In the case of patients who couldn't speak, we observed their expressions to define their pain level.

- How did you cope with dying patients after it happened?
    - Supportive question: do you talk about it with colleagues, is there a special programme, do you have rituals?
    - How do you feel about these coping strategies?

Now I'm already quite experienced with it, I just told myself every time that I'm doing the best for them so I have nothing to feel guilty or dissatisfaction. This was how my mentor told me when I first experienced caring for dying patients. Gradually I release my burden for the fear of death and caring for dying patients.

- **Part 3: Sharing about the training of palliative care**

Thank you for sharing your experience with me, now I'd like to know about how you prepared for palliative care work?

- How palliative care is addressed when you were educated? How did you experience the education?
- How are you supported for palliative care work now?
- If you experienced no previous education or support, how did you cope with it yourself?

It is mainly op-spot learning, and gradually become a fundamental skill for us frontline nurses. We learned from our nurse mentors at the beginning, by a lot of observations and then bring up questions, since the mentors are really busy occupied by work so that they cannot guide us step by step. Their experience and knowledge are really important to fresh nurses, I believe, since this is almost the only and direct way that we learn how to deal with it. And it's also about time and accumulation.

- **Part 4: Reflecting on the experience**
- How this experience and other similar experiences influenced your future work? What would you like to have as supports in the further? What do you need in the future?

The most support, I think, is the guidance when nurses start working with dying patients when it's an important time to sculpture our attitude and mindset.

Nurse Profile 2

- **Part 1: Personal background information**
    - How long have you been working as a nurse?
      14 years, used to work in the medical wards, surgical wards, and emergency center.
      (General Hospital in Guangdong province)
    - What's your current department/unit?
      Dental clinic. Quit from frontline nursing due to the huge stress which was not able to be coped with successfully.
    - What's your main task or responsibility at work as a nurse?
      For each assigned patient, I just ordinarily inject medicine on time, change the wound dressing, turn over, and clean as scheduled. For terminal patients, I would try to take some of my extra/resting time for them to have a talk or act slower for them.

- **Part 2: Personal story sharing and reflecting**
- Have you experienced providing palliative terminal care to dying patients? If experienced, can you share one of the experiences that impressed you with me?
    - Supportive questions: What type of patients was he/she, what was the situation, where and about how long was his/her hospital stay?
    - How did you feel when this happened? What was the reason that made you feel that way?
    - What did you miss in that situation? What supported you in that situation?

Normally our hospital doesn't accept terminal patients, instead, tries to persuade them to go back home since there is no need to keep on treatment. The hospital hopes to centralize all medical resources to curable patients.

However, I indeed experienced several times in the cases that the patients are the relatives of the head of hospital or they are sort of VIP. During I worked in the internal medicine department, there was a patient with terminal respiratory disease at his last stage of life. He kept being in a panic and hard to breathe himself. I spent time to sit beside him as company and asked for his needs, but he was too weak to respond.

After the relatives assigned the death agreement, I entered the room, turned off all the life support equipment, waited till the vital signal became a straight line... After I finished all of these, I really needed to find an empty room and breathe deeply for a while, to suppress the heavy feeling and continue the following work for other patients.

It's not easy to see a patient pass away, and it's not the end of bad feelings. Another wave will come when the other day I see that bed already empty or change to a new patient... My heart will start to hurt again...

The hospital is not supportive at all, since here we are expected to express and vent no emotion to avoid the emotion influence our professional work and decision, but they forget that we are also vivid human with blood and flesh...

- In this experience, did you understand what was happening? What you valued most? What were your needs?
  Yes I understand it not only because I experienced in my career, but also I'm really empathic. I wish to try my best to let the patients feel accompanied and comfortable, so I always checked with the relatives if they want to remove the intubation from the patients and I expected the answer to be a "yes". I also think palliative terminal care is also about their relatives. I wanted to help them out from their panic and sorrow but I wasn't able to since no one told me how…

  I needed three things mainly. The first thing was more time I can spend with the patients. However, I couldn't obviously since we already kept in a lack of nurses. And we will be blamed if we took more time on one patient than expected or asked help from another colleague because that was perceived as lack of capability of work… so ridiculous...That's not fair to me and the terminal patient. And if the working resources is not enough, obviously end of life care is not possible to happen. 99% of the medical organization in China is lacking of

  Another thing I needed was regulation and legalization support as a medical professional. For example, if the terminal patient wants to drink cola, for me personally I would give him whatever he wants at this moment, but I'm hindered by the worries that if the patient gets worse or something happened after drinking cola, the relatives would blame me and let me take the legal responsibility… In reality if I experience like this, I almost ask every single family member there to sign an agreement together so that I feel safe… but the thing is it's highly possible that the patient would pass away during we are working on the "agreement". It would be a big pity that no one wants.

  The last thing I hoped to see in our medical system is advanced decision-making. I cherish the wishes of the patient and relatives, but it always happens that the children are arguing with end of life decisions since they haven't asked for it from their parents before their parents turn unconscious. I understand why this happened, since in our society, everyone especially the elderly are not willing to talk about it and perceive this topic as ominous and couldn't realize it's important. Nowadays advanced decision-making is more and more realized and accepted, but sadly only among medical professionals since we've seen too many tragedies.

- How did you cope with dying patients after it happened?
    - Supportive question: do you talk about it with colleagues, is there a special programme, do you have rituals?
    - How do you feel about these coping strategies?

I always had a hard time after that…Those experiences influenced my personal and professional life a lot. Those negative feeling were accumulating gradually and I didn't have time to let go and digest them because my work routine was already really busy. That's the same for all my other colleagues so we barely talked about it with each other. So I tried to keep diary years by years as a way of outlet. But I don't think that's enough for me. One day when I realized there had been zero motivation for me to step into the wards I was going to work and every cell of mine was struggling fighting this feeling but without success, I knew it was the time for me to stop this job. Yes I agree this is an irreversible burnout. That sounds not good but my coping strategy, to be honest, is quitting...

- **Part 3: Sharing about the training of palliative care**

Thank you for sharing your experience with me, now I'd like to know about how you prepared for palliative care work?

- How palliative care is addressed when you were educated? How did you experience the education?
- How are you supported for palliative care work now?
- If you experienced no previous education or support, how did you cope with it yourself?

I never received death education and end of life care in my education and career. I only learned from my own life. Actually there was a part of education about the end of life when I was in nursing school but it was mainly about how to deal with the dead bodies. It wasn't about mental care at all.

I started to learn end of life care last year since I noticed there were more and more elderly in society and I'm also turning old, but dying with dignity is an extravagant desire for most of us. No one cares how the patients feel inside. I want to do something with it. I joined a course which is organized by a non-government organization, which is sad for me since I believe the government or hospitals should be the host of this education but they are not. The course is basic life and death education and about communication skills in the end of life care. The communication part is quite helpful for me, but what makes me feel horrible is that the participants of the course are all volunteers or social workers with no medical background and they are working in nursing homes without other professionals' collaboration. As a medical professional, first I believe the ones who need this course the most are the medical professionals but my colleagues are more willing to spend time on curable treatment, and I believe the volunteers and social workers are only using this knowledge well with the collaboration and communication with doctors. That's because I realized by my experience that they are only driven by their passions but lack medical knowledge so that sometimes they convey improper information to the patients causing bigger problems for us, such as wrong expectations or unstable moods of patients. Accompany of terminal patients is not easy and obvious at all...

- **Part 4: Reflecting on the experience**
- How this experience and other similar experiences influenced your future work? What would you like to have as supports in the further? What do you need in the future?

I really want to have a platform for all the medical professionals to talk about death and end of life care, also where I can share my knowledge and thoughts. That's so difficult for now...

Nurse Profile 3

- **Part 1: Personal background information**
    - How long have you been working as a nurse?
      10 years, from nurse to nurse lead (General Hospital in Guangdong province)
    - What's your current department/unit?
      ICU nurse, now medical department nurse lead
    - What's your main task or responsibility at work as a nurse?
      Ordinary care work. Now mainly in charge of care work management
- **Part 2: Personal story sharing and reflecting**
- Have you experienced providing palliative terminal care to dying patients? If experienced, can you share one of the experiences that impressed you with me?
    - Supportive questions: What type of patients was he/she, what was the situation, where and about how long was his/her hospital stay?
    - How did you feel when this happened? What was the reason that made you feel that way?
    - What did you miss in that situation? What supported you in that situation?

When I was working in ICU wards, there was a man around 60 years old with chronic respiratory failure as my patient. He was hanging in there with the ventilator. The family gradually couldn't afford the expensive cost of the life-prolonging intervention. After some discussion with us, the family decided to stop using a ventilator and end his life. However, they didn't want the patient to know about this decision although the patient had been conscious all the time. While I was stopping the ventilator, the daughters were standing outside the ward crying with big sorrow.

This was indeed a frustrating situation and unexpected compromise… I'm that kind of person who is not afraid of death and disease and I can understand the situation, but it's always hard for me to talk to the families. I feel sorry for them but I never know what I should say and not.

- In this experience, did you understand what was happening? What you valued most? What were your needs?
  My goal is to try to put myself, my own emotion out, and have discussions with the families and share my professional knowledge as much as possible to help them out when a decision needs to be made, so that I feel comfortable and won't question myself too much afterward as long as I feel I was supportive enough…

  What I observed the young nurses working with me is that they are more taking this work as a "job". Being a nurse is already tiring so they only follow the medical instructions given by the doctors and that's all. I always try to tell them to be friends with the patients, but almost no one could achieve it. They have their emotional fence there during work so that they won't suffer from their patients' death.

- How did you cope with dying patients after it happened?
    - Supportive question: do you talk about it with colleagues, is there a special programme, do you have rituals?
    - How do you feel about these coping strategies?

In the beginning, I did feel sad and helpless, so I tried to talk to my colleagues about my feelings and thoughts. It didn't help me much since people around me trying to avoid this topic and don't want to say much. I just took time to get used to it, and it took years. Sometimes I said I can face it now but I felt maybe I was pretending to avoid thinking about it too much. So what I did is focusing more on my own life other than others' stories.

- **Part 3: Sharing about the training of palliative care**

Thank you for sharing your experience with me, now I'd like to know about how you prepared for palliative care work?

- How palliative care is addressed when you were educated? How did you experience the education?
- How are you supported for palliative care work now?
- If you experienced no previous education or support, how did you cope with it yourself?

No there is no education here, at least in our province. We are used to cure people in the hospitals, so everyone just flows with this inertia and no one starts to talk about the end of life care and death.

- **Part 4: Reflecting on the experience**
- How this experience and other similar experiences influenced your future work? What would you like to have as supports in the further? What do you need in the future?

Nurse Profile 1

- **Part 1: Personal background information**
    - How long have you been working as a nurse?
      3 years (Guangdong province)
    - What's your current department/unit?
      ICU nurse
    - What's your main task or responsibility at work as a nurse?
      Ordinary nursing care work.
- **Part 2: Personal story sharing and reflecting**
- Have you experienced providing palliative terminal care to dying patients? If experienced, can you share one of the experiences that impressed you with me?
    - Supportive questions: What type of patients was he/she, what was the situation, where and about how long was his/her hospital stay?
    - How did you feel when this happened? What was the reason that made you feel that way?
    - What did you miss in that situation? What supported you in that situation?

We are a second-class hospital. In the urban area, our intensive care unit has more elderly patients than others, and often faces death. What impressed me most was an old patient who was often hospitalized in the Second Department of Internal Medicine. The COPD patient came in to use the ventilator. The patient was conscious and could communicate well with each family visit. Taking off the ventilator failed after repeated attempts. There was a period of time, it seemed almost a month, the family decided to give up, in fact, this is really a very difficult decision because he is so sober. When the family arrived, we helped him go offline and watched as he saw a sign of a little loss of life from a sober person: the beginning was breathing difficulties, and the beans were all sweaty and face covered; It's slow; finally it won't work slowly. This is really a cruel thing. It requires the patient to experience the fear of death directly, but in addition to constantly wiping his sweat and saying some pale and comforting words, there is nothing we can do.

If it is a patient who is unconscious, it is not so touching. After this patient died, I was sad and frightened for a long time. It has been a year now, and I can still think of his dying appearance with my eyes closed.

- In this experience, did you understand what was happening? What you valued most? What were your needs?
  The goal of nursing can only be to minimize his fear and increase his comfort. All the treatment can not be done, you can only do a little basic care and psychological care.
  The difficulty is the feeling of powerlessness, and I am not sure whether I have done anything useful or not, which makes me feel stressed for days repeatedly thinking about if I'm doing right or enough.

- How did you cope with dying patients after it happened?
    - Supportive question: do you talk about it with colleagues, is there a special programme, do you have rituals?
    - How do you feel about these coping strategies?

The patient was treated with the head nurse at the time together with me, but I did not tell her about my psychological activities. It was because of busyness, and there was no suitable time to mention it later. Later, I talked to a very good colleague, but it didn't help much, maybe because that the impact at that time was too great at that moment and I didn't cope with it timely, instead, accumulating all my bad feeling together.

- **Part 4: Reflecting on the experience**
- How this experience and other similar experiences influenced your future work? What would you like to have as supports in the further? What do you need in the future?

There has been nearly a year till now, I keep trying to escape from the dying or elderly patients during my work, which made me struggle between responsibility and fear. I was trapped in this negative mental situation and my memory. I'm currently looking for chances to talk to some seniors about my upcoming career, how I can deal with it.

APPENDIX B. DUTCH NURSE INTERVIEW INSIGHTS AND QUOTES

Nurse 1 - Priscilla van Wieringen (Experienced oncology, palliative and hematology specialist nurse)
Care coordinator in the department. Thermotherapy. Administration of the patients on the beds and wards.
First experience coaching is really important for new beginners.
It's helpful for juniors to know how to prepare for it before going into it
Communicate with the family and discuss end of life care decision is sometimes really hard. Some families have hard time accepting it. There is a toolkit design to support nurses communicate with families (she will send me the relevant documents). It it developed by one of her colleagues.
Senior guide junior
It;s really depending on new nurses' initiative to learn how to deal with that situation. They normally learn by observations and proactively asking questions from the observations.
Young nurses may feel afraid to take care of dying patients
Always have a morning meeting with the whole team, including addressing the problem they meet, what they want to learn today. But it's only a 5-min morning meeting with the whole team about feelings and learning goals...
There are 22 wards in the department in total, 4 patients each nurse per day. But the other department can be 6-8 patients.
Dayshift is busier (a lot of activities), night shift less busy (patients are sleeping) Different night shift: 2 nurses only. 3 rounds of checking. The preparation for the nightshift will be done in the dayshift
Dying patients will be free from vital sign devices, only observe their breath and report to doctors to assess.
They keep most of the discussion with the patient and family together in the ward.
There is a nurse room for team meetings and preparation work.
If you have a mental problem there is a psychological team for you to consult
I will talk and comfort the family as a closure to one patient's death for myself
End the day with the whole team as well.

All single wards. They try not to move patients. If the patients turn into the dying phase, they will keep them in the same room. That's also applying to daycare for normal patients under treatment.
There is limited education about this topic in nursing school. I'm currently taking a course in Eramus more specialized in palliative care which is helpful.

Nurse 2 - a two-years nurse in oncology department
21 years old
Two years as student nurses and two years as nurses in oncology departmet
Take care of the patients, give medicines, provide information and guide patients and families on dealing with the illness.washing...
Make sure they have no pain and short of breath
A person came to the department with the possibility of cancer.
The conflict: some doctors don't accept dying and couldn't recognize the dying stage, they keep treatment. The patients die in suffering. The nurses stay 24/7 with the patients so they know what's happening and they have the feeling when patients' dying. But doctors only stay with the patients 5 mins each time, they only focus on technical aspects and the symptoms.
When she died, vomiting fooding things came out of everywhere. That's not a good way to die. She had no chance to say goodbye to families... All the preparation was able to be done.
I hope the doctors could hear and listen to us, nurses.
I talk it out to my husbands or colleagues, then it's ok
DUring education, Little subject about palliative care. Learn most by experience, see what others do.
Go to school now for cancer nurse specialization, there they talk more about palliative care
Good to talk about it and how to give good palliative care, useful in this department
Good to know how to prepare for dying patients
First time, really scared and don't know what to do... A nice colleague told her how to pay attention and what to do, makes her feel more ease.
Important to be able to approach to a good colleague to guide you through
At the first times, some nurses would cry
Palliative care team visit us very often. We call them when needed.
Easy to call for PCT, but not in other departments, they don't know what to do in this situation (cuz less death happening). These supports need to be integrated into the whole hospital, but not only in our department. It's really sad to see for patients and families, no one comfort and guide them.
We see a lot of people die. We get used to it and more experienced.
PCT has more time to stay with the patients and discuss about the decisions than us. If families can't understand the nurse, the team will coach them instead of the nurses.
PCT only provide help to 30% of dying patients who want to use the team. 70% of them, not necessary to have the team, cared by regular nurses.
For students, more guidance is needed (lessons and attention). More important for others departments need extra support.
More people die at night. Work with other nurses only. Get involved with more patients at night. More quiet and peaceful at night, easier to take care of patients (more death at night). More time for people when they die (no doctors and therapies). The people die in a good way
In day shift you see them more.
You got to think about life. Enjoy life more after witnessing death. Learn the meaning of life. You look different to life and appreciate this experience. Your health is bought by money.
Clean up the body and make it beautiful to the family. Giving him a kiss or hold his hands.
At first time, it's really weird and you gradually get used to it. You need to go on. It's a really young age like 16-17 years old. You grow up quickly through working experience.
The coaching is very important. That's why she saw the beauty of this work. If she didn' get coached well she would have chosen something else.

Nurse 3 - Trainee in the oncology department
27 years old
10 years of experience in healthcare, including elderly care. Studying to be a full capacities of nurse. Currently, trainee in the oncology department for 3 months. Used to be in lung diseases (including lung oncology) for half a year as a trainee.
Responsible to provide care supported by a nurse who trained him. Assigned to a trained nurse. Know who I can rely to.
It's always a team effort. Communication is important.
Have experienced 40 deaths in career. It's a mindset. I'm always asking myself how do I want to be cared for when I'm close to death. I asked for their belief and religions, background so that I can support them and communicate with relatives.
Sometimes you have strong relationships with some patients which is hard to avoid. You have a bond and connection with them. I was overwhelmed like I lost somebody.
Need time to learn how to balance the emotional boundary with the patients. But I don't want the patient to be only a patient number. It gives you a humane side but not the technical side. Reflect and know gradually to know where the boundary is set.
Need to behave slower and change a mindset while taking care of dying patients
A policy: going to a dying patient in pairs.
An intern or trainee will be present in the wards but only observing how it's to be done. To get a sense of how to get it done. Before going in, you already discussed and planned what you are gonna do.
I will go as least as needed to leave the moments to the families. Do not interrupt them.
Talking to colleagues is really helpful. Otherwise, you will take it home, that's not good.
The first thing to do after enter the room is quickly subconsciously observing how is the patient, comfortable? Anything different from your last visit? Then you know what you are supposed to do like they are in short of breath or have sounds in their throat. If the patient is in peace, I won't do what I planned to do, to move him/her that break the balance of this peaceful last phase of life, otherwise it will shock the family.
PTC supports a lot.
When I patient is dying, they move a lot and not in peace, restless, the hard thing is that it makes me feel uncomfortable. Really necessary to talk it off, otherwise you will take it home. Peers can recognize your down emotion and talk with you. It's a team effort. There is also professional backup to provide mental care and there is support for different religions of emotional cares.
Mainly learn on the spot and learn from previous cases (Hix system). Hix is used for doctors writing the conclusions and medical records. It provides all the information you need about the patients. Diagnose and treatment. Everyone has a certain prohibited area. File for every patient. There is also area you can look up for different solutions for situations of the dying phases. I searched there to know how to deal with certain cases in dying phases. It helps to remind me what to do. And I can leave what needs to be noticed for my next shift. Hix is used with a COW (computer on wheels). More useful than a laptop while typing. Shared device. 8 COW, shared with 15/16 people.

I don't feel heavy for this job, it's meaningful. Delirium patients is much harder case. It's really harmful to take care of them.
I've already experienced so no need of extra support. It can hit someone or upsetting them who is still a young trainee. You need to provide a trust area to them. In this setting it's very fragile. There is no need to push anyone of their limit. No: try a little bit harder. They need to feel comfortable about it.
In my first experience, an elderly nurse invited me to join a patient visit to observe. There is no need to push them. It's important for the trainees to keep up with their own boundaries.

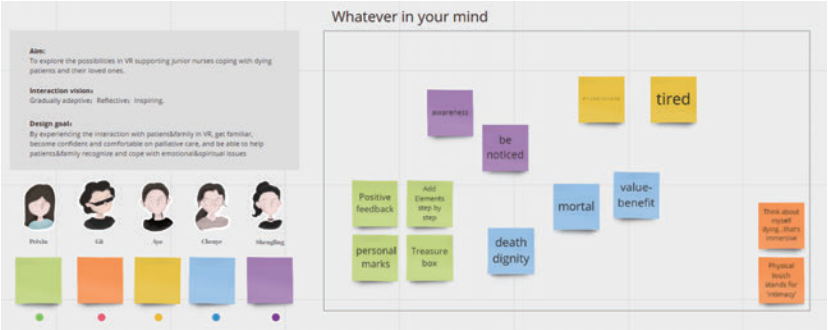
APPENDIX C. CREATIVE IDEATION SESSION

Participant preparation:
Laptop; iPad or drawing tablet; Snacks & Drinks; Comfortable workplace.

Participant setup instruction:
Zoom meeting; Miro; Jamboard
- For iPad user: Install the APP on iPad
- For drawing tablet user: Open the link through your own browser

Agenda:
1. Welcome passengers on board
2. Brief intro (10mins)
   Questions and notes (2mins)
3. Activate creativity (5mins guided meditation)
4. Warm-up and inspired- Opposite Thinking (10mins)
   - What if... (brainstorm on opposite and extreme scenarios) (5mins)
   - Corresponding solutions (5mins)
5. Warm-up and inspired- Analogy Thinking (10mins)
   - Everyone chooses two pics from two categories (VR and other things)
   - Observe and note down inspirations (5mins)
   - Share and discuss (5mins)
6. How to's brainstorming- Crazy 5's (30mins)
   3X5=15mins rounds, 10-15mins sharing
   - How to manifest/represent the experience in VR (in what forms)
   - How to enhance the feeling of reality for the experience
   - How to collect materials for creating contents of the virtual experience
   - How to evaluate the outcome of the virtual training
   - How to transfer the gained knowledge to the patients and family (how to make use of the knowledge on patients and family)
7. Idea shopping cart (20mins)
   - Vote for ideas (interaction vision)
   - Steal ideas and generate a concept each passenger and sketch it out (8mins)
   - Pitch (1min per passenger) and discussion (12mins)
8. Wrap-up (15mins)
   - 5mins meditation
   - 5mins Explorative talk on other potential choices or activities instead of VR
   - 5mins reflect on the session

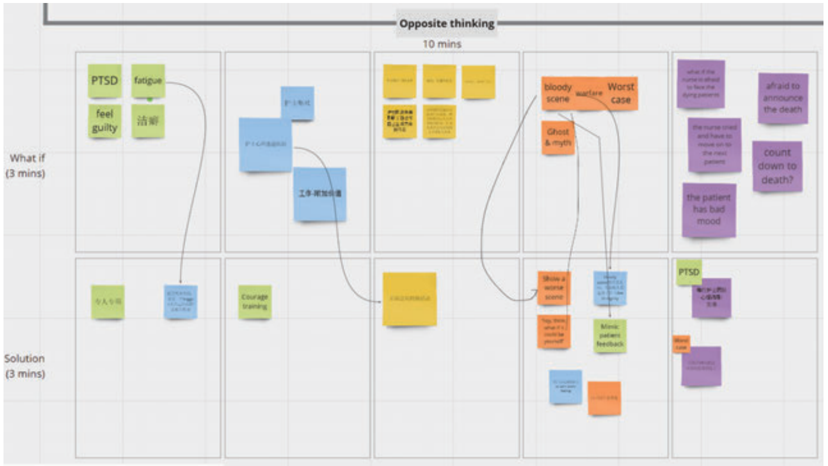
Introduce project brief and design goal

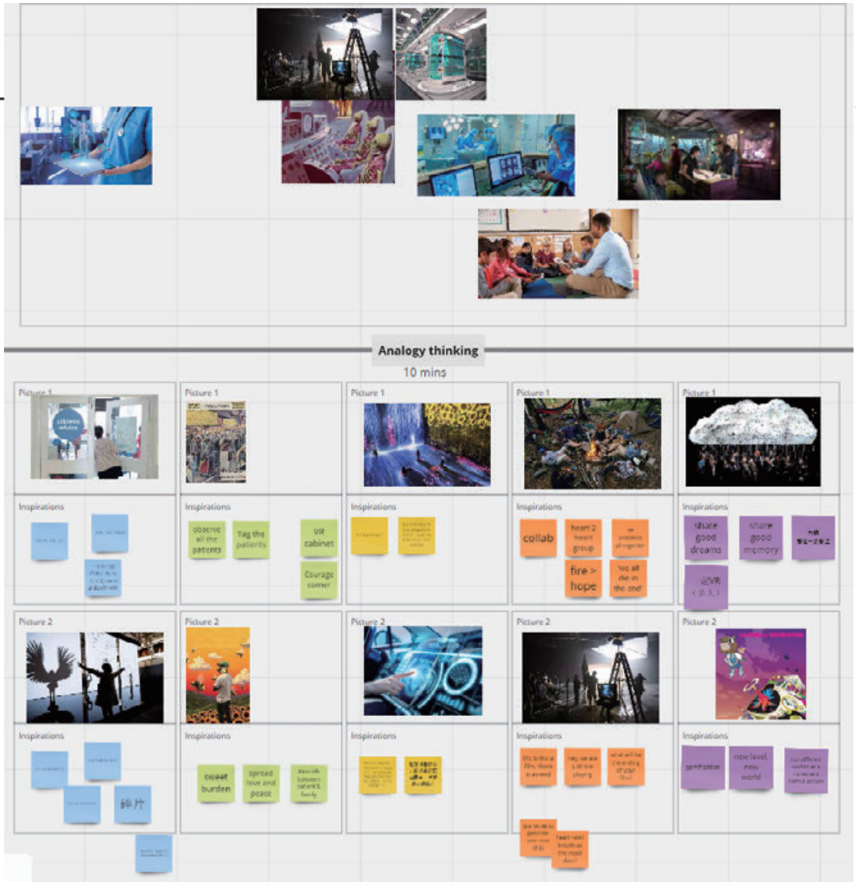


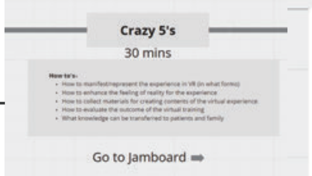
Aim:
To explore the possibilities in VR supporting junior nurses coping with dying patients and their loved ones.

Interaction vision:
Gradually adaptive; Reflective; Inspiring.

Design goal:
By experiencing the interaction with patiens&family in VR, get familiar, become confident and comfortable on palliative care, and be able to help patients&family recognize and cope with emotional&spiritual issues





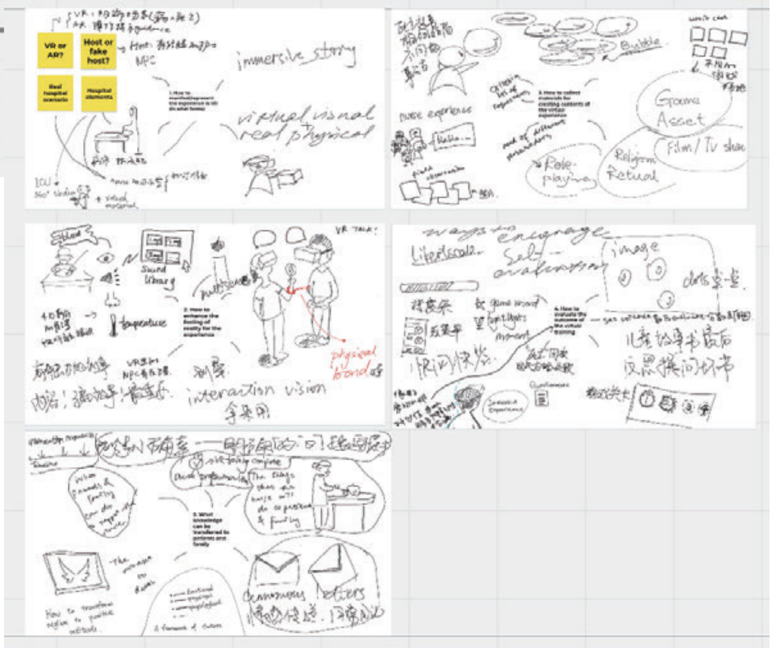


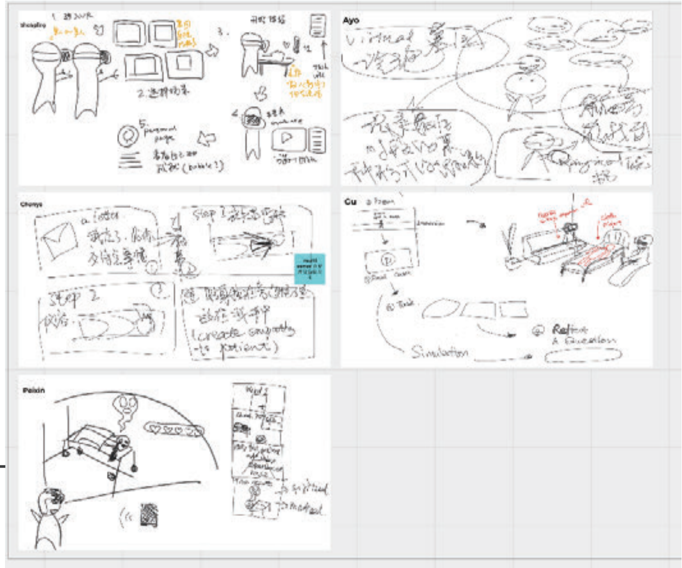
Crazy 5's

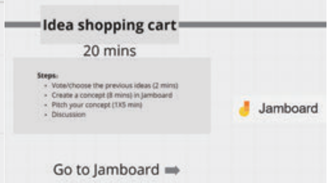
30 mins

How to's:
- How to manifest/represent the experience in VR (in what forms)
- How to enhance the feeling of reality for the experience
- How to collect materials for creating contents of the virtual experience
- How to evaluate the outcome of the virtual training
- What knowledge can be transferred to patients and family

Go to Jamboard ➡







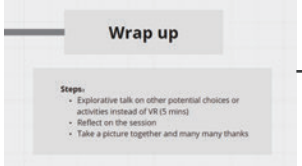
Idea shopping cart

20 mins

Steps:
- Vote/choose the previous ideas (2 mins)
- Create a concept (8 mins) in Jamboard
- Pitch your concept (1X5 min)
- Discussion

Jamboard

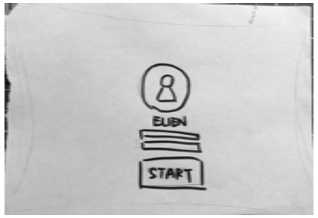
Go to Jamboard ➡

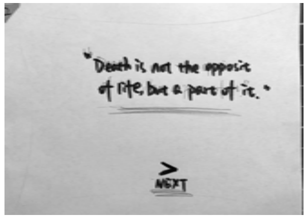


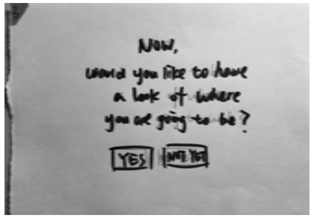
Wrap up

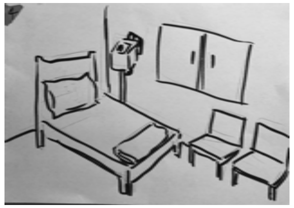
Steps:
- Explorative talk on other potential choices or activities instead of VR (5 mins)
- Reflect on the session
- Take a picture together and many many thanks

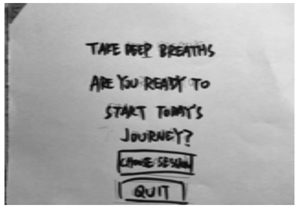
APPENDIX D. PAPER PROTOTYPE FOR DESIGN ITERATION

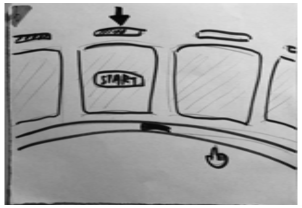


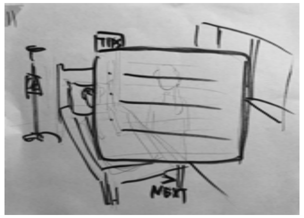


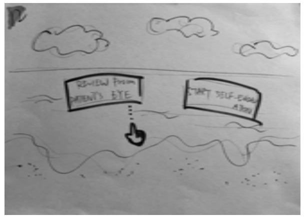


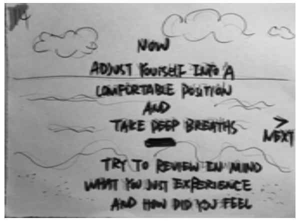


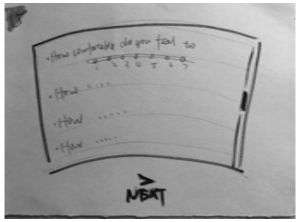


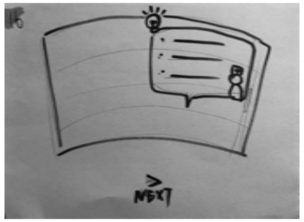


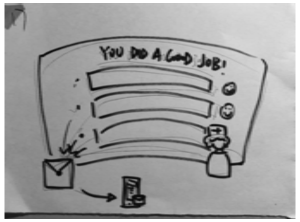


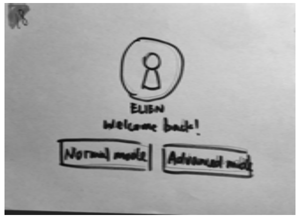


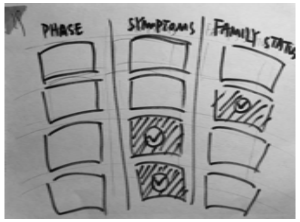


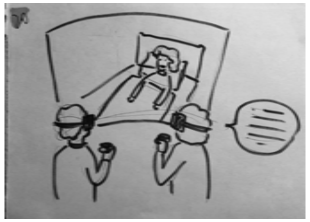


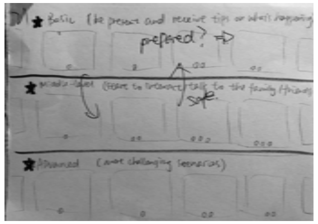


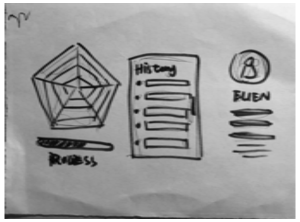




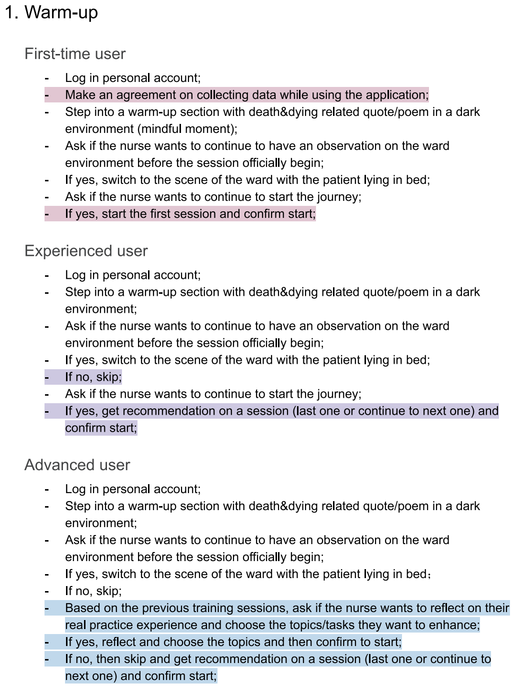








APPENDIX E. USER EXPERIENCE FLOW SCRIPTS



1. Warm-up

First-time user

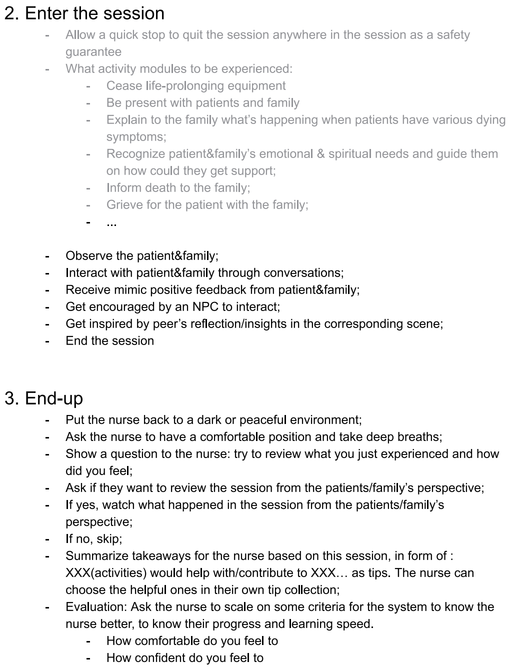
- Log in personal account;
- Make an agreement on collecting data while using the application;
- Step into a warm-up section with death&dying related quote/poem in a dark environment (mindful moment);
- Ask if the nurse wants to continue to have an observation on the ward environment before the session officially begin;
- If yes, switch to the scene of the ward with the patient lying in bed;
- Ask if the nurse wants to continue to start the journey;
- If yes, start the first session and confirm start;

Experienced user

- Log in personal account;
- Step into a warm-up section with death&dying related quote/poem in a dark environment;
- Ask if the nurse wants to continue to have an observation on the ward environment before the session officially begin;
- If yes, switch to the scene of the ward with the patient lying in bed;
- If no, skip;
- Ask if the nurse wants to continue to start the journey;
- If yes, get recommendation on a session (last one or continue to next one) and confirm start;

Advanced user

- Log in personal account;
- Step into a warm-up section with death&dying related quote/poem in a dark environment;
- Ask if the nurse wants to continue to have an observation on the ward environment before the session officially begin;
- If yes, switch to the scene of the ward with the patient lying in bed：
- If no, skip;
- Based on the previous training sessions, ask if the nurse wants to reflect on their real practice experience and choose the topics/tasks they want to enhance;
- If yes, reflect and choose the topics and then confirm to start;
- If no, then skip and get recommendation on a session (last one or continue to next one) and confirm start;



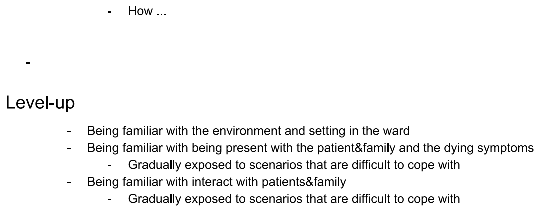
2. Enter the session

- Allow a quick stop to quit the session anywhere in the session as a safety guarantee
- What activity modules to be experienced:
    - Cease life-prolonging equipment
    - Be present with patients and family
    - Explain to the family what's happening when patients have various dying symptoms;
    - Recognize patient&family's emotional & spiritual needs and guide them on how could they get support;
    - Inform death to the family;
    - Grieve for the patient with the family;
    - ...

- Observe the patient&family;
- Interact with patient&family through conversations;
- Receive mimic positive feedback from patient&family;
- Get encouraged by an NPC to interact;
- Get inspired by peer's reflection/insights in the corresponding scene;
- End the session

3. End-up

- Put the nurse back to a dark or peaceful environment;
- Ask the nurse to have a comfortable position and take deep breaths;
- Show a question to the nurse: try to review what you just experienced and how did you feel;
- Ask if they want to review the session from the patients/family's perspective;
- If yes, watch what happened in the session from the patients/family's perspective;
- If no, skip;
- Summarize takeaways for the nurse based on this session, in form of : XXX(activities) would help with/contribute to XXX… as tips. The nurse can choose the helpful ones in their own tip collection;
- Evaluation: Ask the nurse to scale on some criteria for the system to know the nurse better, to know their progress and learning speed.
    - How comfortable do you feel to
    - How confident do you feel to



    - How ...

-

Level-up

- Being familiar with the environment and setting in the ward
- Being familiar with being present with the patient&family and the dying symptoms
    - Gradually exposed to scenarios that are difficult to cope with
- Being familiar with interact with patients&family
    - Gradually exposed to scenarios that are difficult to cope with

APPENDIX F. FINAL EVALUATION SETUP

Evaluation setup

Aim:

Based on the fact that the design focuses mainly on the users' experience flow and the structure of the application, but not the detailed interaction, there are two aspects that need to be tested: functional aspects and experience aspects.

- **Functional:** How users perceive the goal of the design that is shown to them, and where it matches or doesn't match with the original design goal
- **Experience:** Evaluate the effectiveness of the current interactive experience. Also, using the current interactions as a reference, find out users' preference on the detailed interaction style and format to lead to design recommendations.

Evaluation materials:

- VR demo with the main part of the designed interactions
  (The demo works for creating an immersive interactive experience for the users to experience the design directly, but to explain to the users, the current demo is not the optimized experience, but a reference for them to comment and give feedback on the design)
- Design brief slides as an elaboration
  (Support the design demo, help users get a clear overview of the design)
- Supplementary examples as comparison elements since the design demo didn't achieve the ideal interaction and multiple possibilities:
  - Information feeding (visual interface, voice…)
  - Interaction with NPC (positions and view, voice…)
  - Reflection setup (environment, inspirations…)

Protocol:

(40-60 min per participant)

Part 1. Introduce the evaluation agenda and the design brief (10 mins)
- Introduction slides

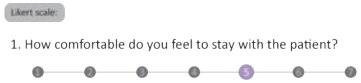
Part 2. Try on demo with the VR headset (5 mins)
- Nurse experience the demo

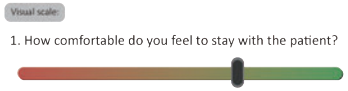
Part 3. Interview with supplementary examples (30 mins)

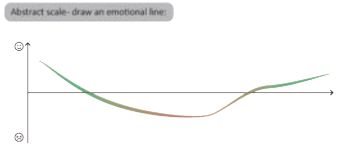
1) Starting stage:
    - Question: What do you think of/understand the purpose of this starting experience?
    - Explain the design goal of the starting stage to the nurse.
    - Discuss where it doesn't match and why.
    - Question: What do you like/dislike about it during your experience?
    - Show other possibilities with examples, choose preference and give reasons:
        - Other types of immersive and mindful environments
          (current: all dark; others: nature, universe....)
          (To gain insights on what environment can be considered if the environment can be tailored to personal preference)
        - Instead of seeing questions, start with a guided meditation section

2) Experiencing stage:
    - Question: What do you think of/understand the purpose of this interactive experience?
    - Explain the design goal of the experiencing stage to the nurse.
    - Discuss where it doesn't match and why.
    - Question: What do you like/dislike about it during your experience?
    - Show other possibilities with examples, choose preference and give reasons:
        - Interacting with the scene:
            - Clearer and more readable manual interface example
              https://www.youtube.com/watch?v=KdXsV2QUgpM
            - Hear the inspirational questions instead of seeing the text
            - More flexible view and positions
              (https://www.youtube.com/watch?time_continue=77&v=4om8g0u9a4M&feature=emb_logo)

3) Ending stage:
    - Question: What do you think of/understand the purpose of this ending experience?
    - Explain the design goal of the ending stage to the nurse.
    - Discuss where it doesn't match and why.
    - Question: What do you like/dislike about it during your experience?
    - Show other possibilities with examples, choose preference and give reasons:
        - Other types of environments that support reflection
          (current: all dark; others: nature, universe....)
          (To gain insights on what environment can be considered if the environment can be tailored to personal preference)
        - Other types of self-evaluation format shown in figure below:







4) The whole experience:
    - How much do you think the current design is adaptive from the starting to the experiencing stage?
      Scale 1-10 and give reasons.
    - How much do you think the current design is encouraging in terms of supporting you explore possibilities yourself?
      Scale 1-10 and give reasons.
    - How much do you think the current design is inspiring?
      Scale 1-10 and give reasons.
    - How much do you think the current design is able to support you reflect on your experience and feelings?
      Scale 1-10 and give reasons.
    - Final comments on the design and what do you hope to be there in the experience but not mentioned yet?