

# Preparing Patients for the Stage of Life Conversation:

A qualitative study in the Westelijke Mijnstreek in the  
Netherlands

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## **Abstract**

**Introduction.** The "Transmuraal Zorgpad Palliatieve Zorg" (TZPZ / Transmural Palliative Care Pathway) has come forward as an initiative that aims to improve palliative care in the southern regions of the Netherlands (Westelijke Mijnstreek). Positive results have already been established through the TZPZ, with patients timelier introduced to palliative care and assigned a more proactive role in their own care. However, improvements are still needed as patients and their families currently seem to be feeling overwhelmed by the questions that are asked during the stage of life conversation, which takes place a couple of days or weeks after the patient has received the news that he/she is in the palliative stage. Therefore, the present study aims to gather opinions from different members from a patient representative advisory group of palliative patients, to investigate how patients can be better prepared for the stage of life conversation. Moreover, the study investigates which existing conversational tools are already available to prepare patients for the stage of life conversation.

### **Methods:**

Scoping Review: A scoping review took place to provide a comprehensive overview of the conversational tools, available in the Netherlands, that can prepare patients for the stage of life conversation. Only tools from the Netherlands were considered. Moreover, only those tools were included which were specifically geared towards the patient (and his/her family)

Focus Group: 8 participants were selected to take part in the focus group. The participants consisted of members of a patient representative advisory group of palliative patients. Participants were selected through purposive sampling.

### **Results:**

Scoping Review: Several tools are available to prepare patients for the stage of life conversation, including guides, websites, E-books, games and apps, video-clips, and questionnaires. Most tools focus on providing practical medical information, whereas some tools also consider the social and psychological impact of being a palliative patient. 70% of these tools were focused on the patient and 30% of the tools also considered family members.

Focus Group: There seems to be a definite need for the use of conversational tools to prepare patients for the stage of life conversation. However, it should be left to the patients' choice which tool(s) he/she prefers to use, whom he/she would like to have the conversation with, and how much time he/she needs to prepare for the conversation.

**Recommendations:** The patient should be provided an overview of the conversational tools and a theme list with common discussion topics to prepare for the stage of life conversation. Further research should consider interviewing patients on the need for conversational tools to prepare for the stage of life conversation.

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# 1. Introduction

## 1.1 Palliative Care

Due to an aging population and a subsequent increase in non-communicable diseases on a global level, there is a rising need for palliative care (Connor & Sepulveda Bermedo, 2014). The World Health Organization (WHO) defines palliative care as:

“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2018, p.1).

Palliative care is the total care for patients that do not longer respond to curative treatment. It encompasses the patient, the family, and the community (Radbruch et al., 2009). It focusses on the avoidance or alleviation of suffering and on the creation of a support system for patients and their families, rather than prolonging life (WHO, 2018). During the illness or symptom stage, which are closely intertwined, palliative care mainly aims at optimizing the quality of life. In the stage nearing death, several days or hours before passing, palliative care should ideally be provided according to the needs of patients and their families to enhance the quality of dying. After the patient is deceased the family will usually receive aftercare (fig. 1) (Integraal Kankercentrum Nederland, 2014; Lynn & Adamson, 2003).

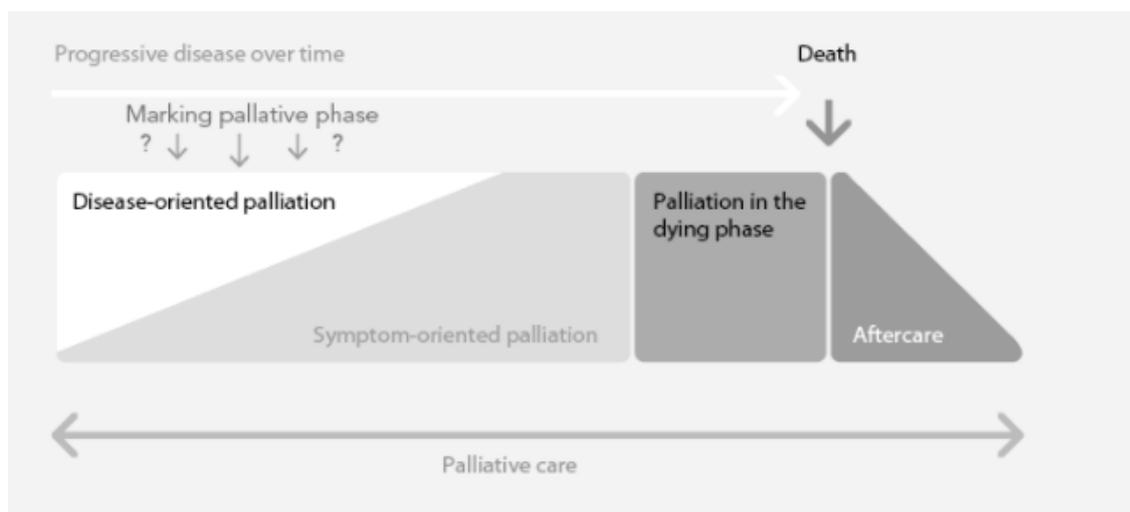


Figure 1. Palliative Care Model. Retrieved from Integraal Kankercentrum Nederland, 2014. Based on Lynn & Adamson (2003).

## **1.2 Palliative care developments in the Netherlands.**

In 2017, a quality framework has been developed in the Netherlands with the aim to improve the quality of palliative care based on the needs of the patient and his/her family. It considers the uniqueness of every person and it considers the personal, cultural, and spiritual values of the patient and their loved ones. Moreover, it describes that palliative care is based on mutual respect between care providers and patients and their families. According to this framework, the care provider should take into account the impact of the approaching end of life on the patient and the family (IKNL, 2017). The importance of these values such as autonomy, dignity, and collaboration and communication between the patient, family and, healthcare provider is widely acknowledged throughout European countries (Radbruch et al., 2009).

The "Transmuraal Zorgpad Palliatieve Zorg" (TZPZ / Transmural Palliative Care Pathway) is an initiative that aims to improve palliative care in the southern regions of the Netherlands (Westelijke Mijnstreek). The TZPZ is based upon different aspects described in the aforementioned quality framework. The goal of the TZPZ is to improve accessibility and continuity of care (Value Based Healthcare, 2017). The TZPZ focusses on the human as a whole while considering four domains of palliative care: the physical, psychological, social, and spiritual domain. Moreover, it captures the entire palliative process, including the symptom/illness stage and the stage nearing death (fig. 1), focusing on improving quality of life and quality of dying. It is an interdisciplinary pathway in which different healthcare professionals work together in intramural as well as transmural settings (Anders Beter, 2017).

Literature on advanced care planning, which involves increased collaboration and communication between patient, family, and healthcare professional, has indicated positive results regarding improved end-of-life care satisfaction and reduced levels of distress (Weathers et al., 2016). Positive results have also come forward since the introduction of the TZPZ, with patients timelier introduced to palliative care and being assigned a more proactive role in their own care. Consequently, patients and families have more time to prepare themselves for the end of life. An increased cooperation between the different healthcare professionals was also positively experienced by the patients (Anders Beter, 2017). According to the positive health theory of Magnert Huber et al. (2011), the capability to manage one's own disease or condition improves subjective well-being. Therefore, it seems important to timely and extensively involve patients in their own care process. Shared decision making seems an important concept related to pro-actively involving patients in their care process. Van de Pol et al. (2016) describe shared decision making as a dynamic and continuous process between patient

and the healthcare professional, in which the patients' values and goals of care are identified and taken into consideration when making care decisions.

While there are some positive outcomes as previously stated, there seems to be a need to further optimize the TZPZ to improve the quality of life and quality of dying. One of the major improvement points reflected by patients and their families is that they are currently feeling overwhelmed by the questions that are asked during the so-called stage of life conversation. This conversation takes place a couple of days or weeks after the patient has received the news that he/she is in the palliative stage. The stage of life conversation addresses the somatic, psychological, functional/care, and social needs of the patient during his/her last stage of life. To indicate when end of life care can be appropriately initiated, healthcare professional may use the surprise question ("Would I be surprised if this patient died in the next year?"). This indication is often used to determine the initiation of a stage of life conversation and is the first step in the TPZP (fig. 2) (Connor & Sepulveda Bermedo, 2014). Patients, however, seem to need more time to cope with the idea that the end of life is nearing and to deal with questions related to their nearing death (Anders Beter, 2017). Therefore, it is necessary to better prepare patients for the stage of life conversation. To date, little literature has focused on the need of preparing patients for the stage of life conversation. The majority of the literature, however, seems to focus on preparing the healthcare professionals for the stage of life conversation.

### **1.3 Research questions**

The present study will focus on how to better prepare patients for the stage of life conversation. Therefore, two main research questions are proposed. First, "Which tools are already available that may help patients to prepare themselves for the stage of life conversation?". And second, "What are the patients' preferences with regards to preparation for the stage of life conversation?" Answering these questions will provide an overview of existing conversational tools that are readily available for Dutch palliative patients. Moreover, it will provide insights in the specific needs of patients regarding the preparation for the stage of life conversation. These needs can subsequently be linked to the existing conversational tools.

### **1.4 Relevance**

The present study can help to gain insights into the needs of patients in preparation towards the stage of life conversation. From evaluations of the TZPZ it appeared that patients have a need to be prepared for the stage of life conversation to cope with the number of questions and issues they need to resolve in the final stage of their life (Anders Beter, 2017). The current research aims to investigate how patients can be

prepared for the stage of life conversation, so that their stress and anxiety concerning this evaluation are reduced, increasing quality of life and quality of dying. Moreover, currently there is no clear overview of conversational tools that can help prepare patients for the stage of life conversation. Establishing such an overview allows patients to more easily prepare for the stage of life conversation but also to maintain self-management and individual choice within their care process. Lastly, preparing early on for the palliative care process helps reduce unnecessary treatments and hospitalizations, which in turn is expected to reduce healthcare costs (Value Based Healthcare, 2017). Thereby, the relevance of the present study is reflected on a societal, scientific and political level.

## **2. Theory and Conceptual Framework**

Several concepts related to the research objective will now be elaborated in more detail, including palliative care and its bottlenecks, the Dutch quality framework for palliative care, conversational toolkits to discuss palliative care, and the transmural care pathway that was initiated in the Westelijke Mijnstreek area in the Netherlands.

### **2.1 Palliative Care**

Palliative care used to mainly focused on oncological care for cancer patients (Anders Beter, 2017; Connor & Sepulveda Bermedo, 2014). However, more recently palliative care for other chronic diseases has received increasing attention (Connor & Sepulveda Bermedo, 2014). Common diseases requiring palliative care among adults include cirrhosis of the liver, diabetes, kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, cardiovascular diseases, cerebrovascular diseases, neurodegenerative diseases such as dementia, chronic respiratory diseases, HIV/AIDS and drug-resistant tuberculosis. Worldwide, 69% of people in need of palliative care are adults over the age of 60 (Connor & Sepulveda Bermedo, 2014). Many people have a need for palliative care even before entering their last year of life (Connor & Sepulveda Bermedo, 2014). Early recognition of the moment when curative care is no longer possible seems to be crucial to avoid unnecessary treatments or hospitalizations (Meier, 2011). It also allows for patients and their families to prepare for the approaching end of life (Integraal Kankercentrum Nederland, 2014).

Within the Netherlands, palliative care is not considered a distinct medical specialty; it can be provided by any healthcare professional as is expected that all clinicians have primary palliative care skills. General palliative care is offered in hospitals, nursing- and care homes, and at home (Integraal Kankercentrum Nederland, 2014). Even though general palliative care is widely offered in the Netherlands, it is often initiated at a late stage with only less than 25% of the hospitals offering early palliative

care support to their patients (Brinkman-Stoppelenburg, Boddaert, Douma, & Van Der Heide, 2016). Approaching death and palliative care appear to be sensitive topics for both patients and healthcare professionals because they often appear to be associated with short-term death (Integraal Kankercentrum Nederland, 2014), possibly explaining the late initiation of palliative care. Even though there has been an increase in awareness and efforts to improve education, general knowledge of palliative care among healthcare professionals seems to be low (Brinkman-Stoppelenburg et al., 2016). Patients indicate that they are in need of better support and guidance to help them cope with anxiety, somberness, feelings of oppression, and to meet their psychological and spiritual needs (Integraal Kankercentrum Nederland, 2014). An obstacle for the dissemination of palliative knowledge and cooperation between healthcare professionals is that, currently, palliative consultation teams within hospitals operate mostly at an intramural level (Brinkman-Stoppelenburg et al., 2016). To continue preserving quality of care it is important that continuity of care is offered even when a patient is moving between settings (Vissers et al., 2013).

## **2.2 Quality Framework Palliative Care**

In the Netherlands, a framework has recently been developed to improve the quality of palliative care (IKNL, 2017). The definition of palliative care within this framework expands on the WHO definition, by adding concepts such as interdisciplinary teamwork, dignity, autonomy, access to information and decision making power;

“Palliative care is care that enhances the life of the patient and their loved ones that are facing a life-threatening condition or vulnerability, by preventing and alleviating suffering, by means of early recognition and a thorough assessment and treatment of the problems of physical, psychological, social, or spiritual nature. Throughout the course of the disease or vulnerability, palliative care considers autonomy, access to information, and choice” (IKNL 2017, p.8).

Continuity of care is an important aspect emphasized in this framework, including personal continuity and team continuity, as well as transmural continuity. Personal continuity refers to the inclusion of a fixed healthcare worker for a patient in every care setting. Team continuity entails the cooperation between healthcare providers within a care setting, whereas transmural continuity entails the cooperation between healthcare providers between different care settings (IKNL, 2017).

Effective communication, shared decision making, and proactive care planning are considered fundamental aspects of palliative care, in which the patient and his/her family play a central role. This is a continuous process in which the needs and values of patients

and their families are considered and the care plan is regularly adjusted to their changing needs (IKNL, 2017). Access to an actualized care plan is important for the patient to gain knowledge of his/her condition and to be able to actively participate in decision making and self-management of his/her own care. It also enables care providers to safeguard the continuity of care. (IKNL, 2017).

Moreover, palliative care is multidimensional because it focusses on four different dimensions of the individual, the physical, psychological, social, and spiritual nature. The multifaceted character of palliative care requires interdisciplinary collaboration and dynamic teamwork in cooperation with the patients and their loved ones. Early recognition of palliative care needs is considered instrumental in creating care that prioritizes quality of life and quality of dying. The surprise question could serve as an early recognition tool (IKNL, 2017)

### **2.3 Conversational Tools**

Several initiatives in the Netherlands have targeted the development of conversational tools for palliative patients. These tools aim to increase information provision, self-management, and decision making among these patients. Existing tools include guides, E-books, Websites, questionnaires, video-clips, and apps and games. These tools can help patients establish important topics and questions that need to be answered regarding their last stage of life. Moreover, these tools can help patients to start a conversation with a healthcare professional, loved-ones, or family members. These tools can also be useful in establishing important discussion topics for the stage of life conversation. However, for the time being, there seems to be no overview of these existing tools in the Netherlands.

### **2.4 Transmural Palliative Care Pathway**

Several bottlenecks related to palliative care were identified in the Westelijke Mijnstreek area in the Netherlands, including late consultation moments, late marking of the palliative stage, mediocre symptom control, insufficient knowledge of the desires of the patient, insufficient involvement of patients in end of life communication, and too much emphasis on oncological care. To tackle these challenges, the Transmural Palliative Care Pathway (Transmuraal Zorgpad Palliatieve Zorg/ TZPZ) has been developed in cooperation with different healthcare providers (Value-Based Health Care, 2017). Value-Based Health Care (2017) indicated that the TZPZ is based on eight principles, namely:

1. Early and proactive identification of palliative patients
2. Assessment at intake
3. A weekly multidisciplinary meeting

4. A Timely conversation about end of life wishes and needs resulting into a multidisciplinary care plan
5. A medication review
6. Intra- and extramural communication
7. Postmortem conversation with family
8. And continuous monitoring of outcomes

The head practitioner is responsible for initiating and executing the transmural palliative care pathway. The TZPZ marks the palliative stage early on (<1-year life expectancy) through the application of the surprise question by the healthcare professional: "Would you be surprised if the patient would pass away within a year?" Additional indicators to mark this stage include the RADPAC and the SPICT (Dijkstra 2017; Value- Based Healthcare, 2017). After this identification, an agreement between the GP and specialist is established on who will be the head practitioner and care coordinator. Subsequently, a life stage conversation will take place with the patient, including a semi-structured interview based on a questionnaire including the four domains of palliative care (physical, social, practical, spiritual) (Dijkstra 2017; Value- Based Healthcare, 2017). The outcomes of the conversation will be discussed within the Multidisciplinary Consultation (MDO) and the GP post will be informed of the inclusion and needs of the patient. The MDO will establish a palliative advice and written feedback will be given to the head practitioner. After the MDO a medication review will take place at the pharmacy of the patient in consultation with the head practitioner. The head practitioner will, subsequently, establish a proactive care plan that is discussed with the patient. The patient will be monitored and the care provided will be evaluated. If the head practitioner needs advice, there is a palliative advice team that can be consulted accordingly (fig.2) (Dijkstra, 2017; Value-Based Health Care, 2017).



Figure 2. Visualization of the Palliative Care Pathway. Retrieved from *Value-Based Health Care* (2017)

## 2.5 Conceptual Framework

The Ars Moriendi model by Leget (2007) will be used to establish an overview of the needs of the patients regarding the preparation for the stage of life conversation, to increase their self-management capacity (fig. 2). This theory is in line with the Positive Health theory of Huber, as it discusses autonomy and the decision-making power of the patient (Huber et al., 2011).

The Ars Morendi, or the art of dying, describes five temptations that a person has to deal with when facing death. It also describes a coping mechanism to deal with these temptations, named the inner space (fig. 2). Therein, inner space refers to an open-minded attitude involving both an emotional and a cognitive dimension. The emotional dimension allows for being aware of one's own emotions without being overthrown by them. The cognitive dimension enables one to find new interpretations of a particular situation. This allows for an atmosphere of confidence and trust between healthcare professionals, patients, and family (Leget, 2007). It moreover, may help to establish what a patients' needs are during the palliative stage and what his needs are in preparation for this stage.

The first temptation is related to autonomy; the relationship between oneself and others. It is about understanding our interrelatedness and interdependence. "[...] Inner space helps to listen to the patient with an open heart and an open mind the physician opens up the mind and heart of the old patient and the latter can begin to discover what [he]/she really wants." (Leget, 2007, p.4)

The second temptation concerns pain management and finding a way to deal with the tension between doing (medical intervention) and undergoing (refraining from further treatment). Finding a balance between both is applicable to all four dimensions of palliative care. Inner space can help to find this balance by accepting what is inevitable and by seeking for new solutions. (Leget, 2007).

The third temptation is the tension between holding on and letting go of physical abilities, health, your position in society, and family. Inner space is important because being aware of your own attachments is important for letting go (Leget, 2007).

The fourth temptation is the tension between forgiving and forgetting. Forgiving is important to find harmony within yourself, whereas forgetting is important when there is not enough time and energy for the process of forgiving. An attitude of inner space can help to accept the bad dimensions of the human soul to develop guilt and enable reconciliation with oneself or others (Leget, 2007).

The fifth and last tension is that between knowing and believing. Knowing are those things we can prove with evidence, whereas believing is about spiritual questions that cannot be answered by science. An attitude of inner space can help to be open-minded and to respect each other's moral convictions (Leget, 2007).

Addressing the needs that arise within the patient during each of the five stages may help to establish what a patient needs in order to feel prepared for the stage of life conversation.

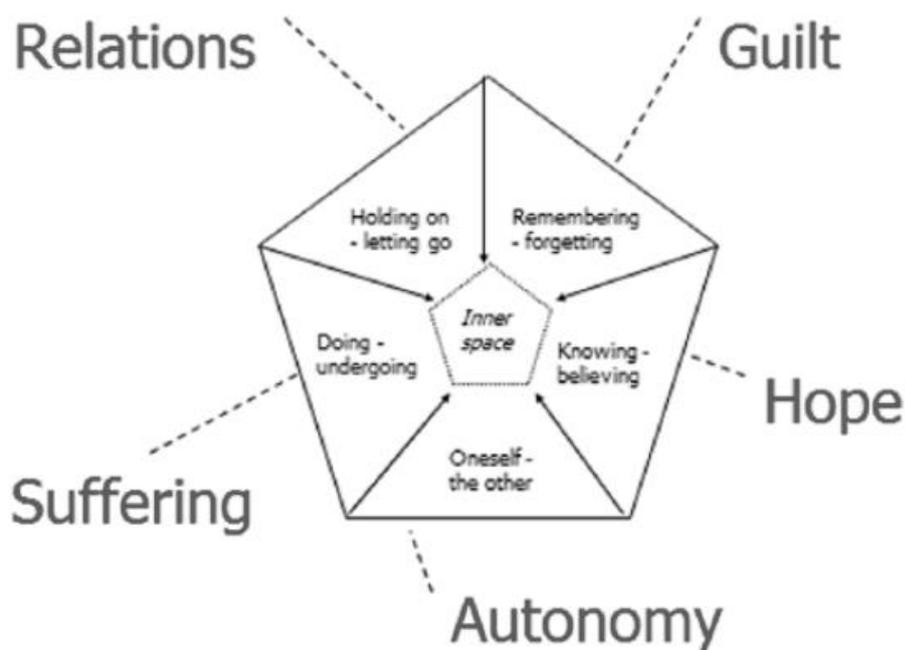


Figure 3. *Ars Moriendi* model. Retrieved from Leget (2016)

### 3. Methodology

The following section consists of two parts. First, the methodology of the scoping review, used to map out the existing conversational tools, will be described. Second, the methodology of the focus group that took place will be defined.

### 3.1 Scoping Review

The following section will give a detailed description of the research design, the study selection, and the data collection of the scoping review.

#### 3.1.1 Research nature, type and design

The scoping review was conducted from April 2018 until July 2018 as part of the Transmural Palliative Care Pathway that has been implemented in 2015. The aim of the scoping review is to provide a comprehensive overview of the conversational tools, available in the Netherlands, that can prepare patients (and their family) for the stage of life conversation. The overview can be distributed to patients by healthcare professionals and aid these patients in the preparation for the stage of life conversation.

#### 3.1.2 Study Selection

Several in- and exclusion criteria were taken into consideration for the scoping review. The TZPZ focusses on patients in the Westelijke Mijnstreek in the Netherlands and, therefore, only conversational tools from the Netherlands have been considered in this study. Moreover, only those tools were included which were specifically geared towards the patient (and his/her family). The tools did not necessarily need to be created as an instrument to prepare for a stage of life conversation; however, the patients should be able to use the tool for this purpose.

#### 3.1.3 Data Collection

Various sources were used for data collection, including governmental websites, academic and non-academic databases. Search terms included, "Conversational Tools", "End-of-life Conversation", "Preparation for the End of Life", "Palliative Assessment". These search terms were either used individually or combined to find meaningful sources. Subsequently, projects were grouped into different categories based on their type, target audience, main topics, and main aims (Table 1).

*Table 1. Categories for scoping review*

Type	<ul style="list-style-type: none"><li>• Websites</li><li>• Guides</li><li>• E-books</li><li>• Games/Apps</li><li>• Questionnaires</li><li>• Video-clips</li></ul>
Target Audience	<ul style="list-style-type: none"><li>• Patient</li><li>• Family</li></ul>
Main topics	<ul style="list-style-type: none"><li>• Medical Information</li></ul>

	<ul style="list-style-type: none"> <li>• Practical Information</li> <li>• Social impact</li> <li>• Psychological impact</li> </ul>
Main Aims	<ul style="list-style-type: none"> <li>• Informing</li> <li>• Conversation starter</li> <li>• Decision making</li> <li>• Establishing Health Goals/Priorities</li> <li>• Timely orientation towards passing</li> </ul>

### 3.1.4 Data Analysis

The tools were clustered into the different categories of table 1. The focus group was asked to review the different conversational tools and to provide feedback. If necessary, the feedback was used to make adjustments. An infographic and an overview table were created to visualize the outcomes. The infographic contains a comprehensive overview of all the conversational tools that are available in the Netherlands, whereas the table gives a more detailed overview of the target audience, aims, and main topics of the different tools.

## 3.2 Focus group

The following section will give a comprehensive overview of the design, the research population, the data collection, and the data analysis of the focus group that took place in the present study.

### 3.2.1 Research nature, type and design

Qualitative methods were used to investigate the main research question. The research was conducted from April 2018 up till July 2018 in cooperation with the Zuyderland Medical Centre in the Netherlands, as part of the Transmural Palliative Care Pathway project that has been implemented in 2015. The aim of the focus group was to establish the patients' preferences regarding the conversational tools that were found through the scoping review. A clear overview of these tools might help patients to be better prepared for the stage of life conversation, consequently reducing stress and anxiety associated with this conversation.

### 3.2.2 Research population

The study population consisted of eight members of the patient representative advisory group of palliative patients in the Zuyderland Medical Center. The group included members who either had a personal or occupational affinity with the topic of palliative care. This population was selected due to their personal experience with the topic of end of life care. An overview of the study population can be found in the results.

### 3.2.3 Data collection

To obtain data, a semi-structured interview was conducted within the focus group. This type of interview was applied to cover all the important topics but to still retain flexibility for new questions that emerged during the interview (Bourgeault et al. 2010). The interview guide was established based on the concepts such as autonomy and relations of the Ars Moriendi Model of Leget (2007) and on the information that was found on the conversational tools during the scoping review. First, the focus group members were asked about their general knowledge concerning the stage of life conversation. Subsequently, members were asked about their experiences with the preparation for the stage of life conversation. Then, they were presented with the conversational tools that had been found during the scoping review after which they were asked what their preferences would be with regards to the tools. Lastly, they were asked to which extent they considered these tools useful in starting a conversation with loved ones or family members on the stage of life conversation (Table 2).

*Table 2. Interview Structure*

Stage of life conversation	<ul style="list-style-type: none"> <li>- Is it clear what the stage of life conversation means?</li> <li>- Can you articulate this?</li> </ul>
Individual Preparation	<ul style="list-style-type: none"> <li>- How did you/How would you prepare for this conversation?</li> <li>- Were you offered any tools such as Guides, Websites, E-books, Apps, Games, Video-clips, or Questionnaires to prepare for the stage of life conversation?</li> </ul>
Conversational Tools	<ul style="list-style-type: none"> <li>- To what extent would you have considered it useful if you were offered these tools to prepare for the stage of life conversation?</li> <li>- Which of the tools would you prefer? (For example, Guides, Websites, E-books, Apps and Games, Video-clips, or questionnaires)</li> <li>- How much time do you think you need to prepare for the stage of life conversation?</li> </ul>
Family and Friends	<ul style="list-style-type: none"> <li>- What tool would you prefer to prepare yourself together with loved ones and family members' for the stage of life conversation? (For example, Guides, Websites, E-books, Apps and Games, Video-clips, or questionnaires)</li> </ul>

The interviews were conducted in Dutch with consent from the participants and were recorded after consent was given. Afterward, the recordings were transcribed verbatim for further analyses.

The sampling of the participants took place in a purposive manner. Purposive sampling is used to select participants that have knowledge regarding the topic that is investigated (Moule & Goodman, 2009).

### **3.2.4 Data analysis**

The interviews were audiotaped with the permission of the respondents. Subsequently, the interviews were transcribed and thematically analyzed to identify common themes. Nvivo version 11 was used to develop a coding scheme. Open coding was used to identify the main concepts and axial and selective coding will be used to sort the concepts into categories and networks (Böhm, 2004). An infographic was made to visualize the results (fig. 4).

### **3.3 Validity and reliability**

To ensure validity and reliability, triangulation took place by performing cross checks with fellow master students that are conducting research on the subject of palliative care (Leung, 2015). Moreover, the material will be well documented and audited for increased accuracy (Leung, 2015). The sampling method was selected according to the research paradigm and a wide scope of literature was reviewed to ensure validity and reliability (Leung, 2015).

### **3.4 Ethical Considerations**

Participants in the focus group were presented with an informed consent form before participating in the focus group (Appendix 2). The informed consent made sure that participants were knowledgeable about the nature of the study and their role within the study. It disclosed that the data would be handled anonymously and that personal details would be de-identified. Moreover, it informed them on the option to discontinue the study at any given time.

Recordings were destroyed after transcription to ensure the protection of personal data. Personal data in transcripts were de-identified.

## **4. Results**

Like the method section, the result section will also be divided into two different parts. First, the results will focus on the outcomes of the scoping review describing the different conversational tools that were found within the Netherlands. The second part of the results will focus on the outcome of the focus group interview concerning the preferences regarding the preparation for the stage of life conversation and the conversational tools that were found in the scoping review.

## 4.1 Conversational tools

Within the Netherlands, several initiatives have been taken concerning the development of conversational tools for palliative patients, their loved-ones, and their caregivers. Tools such as guides, websites, E-books, and apps have been developed for patients to help them establish the most important topics, related to end of life care, that need to be discussed with their loved ones and medical specialist.

These tools aim to timely introduce conversations on end of life care and enhance information provision, self-management, and decision making for palliative patients. An overview of these tools and the organizations that created these tools can be found in Table 3. It can be noted that the tools were all launched in the last 5 years, however for some tools the launch date unknown. Moreover, 29% (4) of the organizations are focused on providing palliative care, whereas the majority of the organizations, 57% (8), are more broadly aimed towards providing healthcare in general. An additional 14% (2) of the organizations are funeral companies. The different conversational tools will be described in more detail in the coming paragraphs.

*Table 3. Overview Projects and Organizations*

Project Name	Organizational Name	Organizational Details	Year the tool was developed	Where to find the tool
De Afscheidswijzer	De Afscheidswijzer	De Afscheidswijzer aims to encourage people to timely start a conversation about passing away by providing practical information concerning the last stage of life.	2014	<a href="http://www.afscheidswijzer.nl">www.afscheidswijzer.nl</a>
Onmisbare Informatie over het Einde v.h. leven	Unie KBO	KBO represents the interests of elderly citizens in the Netherlands.	2016	<a href="http://www.kbo.nl">www.kbo.nl</a>
Ik wil met je praten	Van Betekenis tot Einde	Van Betekenis tot Einde stimulates people to give more attention to their last stage of life and to discuss this with loved ones or family.	2016	<a href="http://www.ikwilmetjepraten.nu">www.ikwilmetjepraten.nu</a>
Drie Goede Vragen	-Patienten Federatie Nederland -Federatie Medisch	-Patienten Federatie Nederland aims to protect patient- and consumer organizations. It also helps people to make care related choices.	Unknown	<a href="http://www.3goedevragen.nl">www.3goedevragen.nl</a>

	Specialisten	- The Federatie Medisch Specialisten is a professional association of medical specialists that aims to improve the quality, safety and accessibility of care.		
Wat er toe doet	Harteraad	Harteraad is an organization for people with heart and coronary diseases which aims to increase safety and self-management of care.	Unknown	<a href="http://www.watertoedoet.info">www.watertoedoet.info</a>
Praat op Tijd over uw Levenseinde	-Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst (KNMG) - Nederlands Huisartsen Genootschap (NHG) -Patienten Federatie Nederland	- KNMG aims to increase the quality of the medical profession and the quality of population health. - NGHG provides guidelines for medical practitioners. -Patienten Federatie Nederland aims to protect patient- and consumer organizations. It also helps people to make care related choices.	2017	<a href="http://levenseinde.patientenfederatie.nl">http://levenseinde.patientenfederatie.nl</a>
Games that Matter	Bureau MORBidee	Bureau MORBidee has as mission to make dead a discussion topic for professionals as well as private persons.	Onbekend	<a href="http://www.gamesthatmatter.nl">www.gamesthatmatter.nl</a>
Raakvragen	Monuta	Monuta is a funeral company and funeral insurer in the Netherlands.	2013	Android and iOS Appstore
Before you Leave	DELA	DELA is a funeral company and funeral insurer in the Netherlands.	2017	Android and iOS Appstore
Praat Erover	Zorg voor Beter	Zorg voor Beter aims to increase information provision on elderly care.	2016	<a href="http://www.zorgvoorbeter.nl/palliatieve-zorg/filmjes">www.zorgvoorbeter.nl/palliatieve-zorg/filmjes</a>
Dela voor Elkaar	DELA	DELA is a funeral company and funeral insurer in the Netherlands.	Unknown	<a href="https://www.dela.nl/blog/voorelkaar/stilstaan/meeleven/video-wat-voor-moois-hebben-jullie-voor-het-laatste-tegen-elkaar-gezegd">https://www.dela.nl/blog/voorelkaar/stilstaan/meeleven/video-wat-voor-moois-hebben-jullie-voor-het-laatste-tegen-elkaar-gezegd</a>

Uitbehandeld maar niet Uitgepraat	Nederlandse Federatie van Kankerpatiënte n Organisaties (NFK)	The NFK exists of 19 cancer patient organizations and aims to increase the quality of life, the quality of care, and the accessibility to care.	2016	<a href="http://uitbehandeldmaarnietuitgepraat.nl">http://uitbehandeldmaarnietuitgepraat.nl</a>
USD-R	Netwerk Palliatieve Zorg Rotterdam en omstreken (NPZR)	The NPZR is an alliance of organizations that are concerned with providing palliative care.	Unkown	<a href="http://www.netwerkpalliatievezorg.nl/rotterdam/Zorgverleners/Palliatieve-Thuiszorg/PaTz-Tools/USD-R">http://www.netwerkpalliatievezorg.nl/rotterdam/Zorgverleners/Palliatieve-Thuiszorg/PaTz-Tools/USD-R</a>

#### 4.1.1 Guides

Two guides have been developed that mainly aim to inform the patient about important topics that can be considered related to the last stage of life. "De Afscheidswijzer" ("The Farewell Pointer") is a tool that helps palliative patients to timely orient towards their own passing and it helps people to orient towards the funeral or passing of a loved one. The tool is designed as a guide that aims to make people aware on why it is important to timely inform yourself about your own passing and everything that is associated with it. Themes within the guide are mainly related to medical care and practical information and in a lesser degree the social or psychological impact of being palliative. Main themes include, among others, organizing a funeral, grieving, establishing a testament and impact of having an incurable illness. The guide is specified for different areas in the Netherlands and detailed local information and contact details of institutions and organizations that deal with these topics are also included within the guide. In some guides, example questions that can help establish a conversation about the last stage of life are also included, such as "What is important to me in the last stage of life?", "How do I want to formalize my last phase of life?", and "What does the concept of quality of life mean to me?" (Afscheidswijzer, n.d; Afscheidswijzer, 2017). The guide can be downloaded online, or it can be retrieved in hard copy at one of the given locations on the website.

Another guide that helps people to establish important discussion topics related to the last stage of life is called "Onmisbare Informatie over het Einde van het Leven" ("Indispensable information on the end of life"). This guide discusses common topics and questions that palliative patients might have mainly related to medical care and self-management of medical care and in a lesser the psychological or social impact of being in the palliative stage. Example questions in the guide include; "Which role does the specialist have?" and "Do I want to consider euthanasia when suffering gets unbearable?". Moreover, it gives practical tips on which (medical) topics are useful to consider before starting a conversation with loved-ones or the GP. The guide also refers

to conversational groups existing of fellow palliative patients that can be joined to discuss the last stage of life and its implications for the patient and his/her loved-ones (KBO, n.d). The guide can be downloaded online or it can be bought as a hard copy.

In general, both guides seem to include a lot of practical medical information and information on local institutions or discussion groups that can help palliative patients coping with their last stage of life. However, detailed information on the social and psychological impact of the palliative stage is missing. Moreover, the guides are not scientifically verified.

#### **4.1.2 Websites**

Several websites have been established that discuss various topics related to the last stage of life. The coalition "Van Betekenis tot Einde" developed a website, named "Ik wil met je praten" (I want to talk to you) with tips to start an end-of-life conversation with loved ones with the aim to stimulate people to discuss their last stage of life early on with others. The website also refers to activities from different organizations that can help start a conversation. Moreover, it provides conversational topics that can guide the dialogue. The themes include medical care, practicalities, social impact, and psychological impact. Example questions are "What is important for you in the last stage of life", "What do you want your legacy to be?", and "Are there medical procedures that are (not) important to you at the moment?". The website also provides some video-clips on how to start a conversation with your specialist and how to talk to your loved ones. Lastly, it contains a tool in which example texts are generated that can help the patient starting a conversation. (Ik wil met je praten, n.d.)

"Drie goede vragen" ("Three good questions") is a tool that can be used by patients to get the information they need from the medical specialist to make informed decisions (concerning their last stage of life). This tool aims to enhance shared decision making between patient and doctor. This tool does not specifically apply to palliative patients, but can be used by all sorts of patients to make treatment-related decisions. For example, it can inform the patient about different treatment possibilities and about whether to continue or withdraw from further treatment. The three questions asked are: "What are my possibilities?", "What are the benefits and disadvantages of the possibilities?", and "What does that mean in my particular situation?". The questions are mainly related to medical care. (PatientenFederatie Nederland, n.d).

"Wat er toe doet" ("What Matters") is an initiative that aims to gain insights into important matters in the patient's life and into the patients' health goals. The tool exists of four questions that patients can answer in five minutes; "What is important to me in my life?", "What is important to me in my life right now"? "What do I want to be able to do?", and "What do I need to accomplish this?". The outcomes of these questions can be

discussed with loved-ones or caregivers and are expected to contribute to better understanding and more informed health-related choices (De Hart&Vaat Groep, n.d.). These questions mainly relate to medical care preferences, but also to social and psychological issues.

Taken together, the different websites offer insights into the medical, as well as the social and psychological impact, and more general practicalities. Especially the website "Van Betekenis tot Einde" seems to offer a broad array of questions. However, none of these websites are scientifically verified.

#### **4.1.3 E-books**

The E-book "Praat op tijd over uw levenseinde" ("Timely discuss your end of life") is developed as a tool for patients (and their loved ones) to help them start a conversation with their specialist about their (or their loved-ones') end of life. It can help the patient to establish what his/her preferences are in the last stage of life and what information he/she needs from the specialist. The E-book provides some conversational topics mainly related to medical care and practical issues that the patient can think about before seeing the specialist, including questions such as "What do you need to know from the specialist?", "What do you want to do when you're in a lot of pain", or "When does suffering become unbearable for you". The book furthermore provides some practical tips on how to prepare yourself for a conversation with your specialist, and tips on how to let the conversation run smoothly (KNMG, 2017). The E-book can be downloaded on the computer.

In general, the E-book is suitable to find practical and medical information but is not as suitable for finding information on the social and psychological impact of being a palliative patient. Moreover, the E-book is not scientifically verified.

#### **4.1.4 Games and Apps**

Some Apps and Games have been developed as an interactive way to discuss the end of life with loved ones, family members, or healthcare professionals. "Games that matter" is an initiative by Bureau MORBidee that designs unique games that can be used as conversation starters to discuss the topic of death at home, school or work. Whereas the games are mainly geared towards patients, they can also be used by professionals to learn to interactively communicate with their patients about topics related to the death. The topics are broad and include medical care, arranging practicalities, social impact and psychological impact. Example questions are "What/Who do you need to make life valuable?", "What do I need to know for certain when I'm taking care of you?", and "What is most important to you if little time is left?" What makes this tool unique is that

different games are available to suit dissimilar age categories and interests. The games can be bought online in various price categories. (Bureau MORBidee, 2018).

A funeral company, Monuta, has developed an app named "Raakvragen" ("Concise Questions") in which a patient can go through four different elements with his/her partner. The topics broadly include medical care, practicalities, social issues, and psychological impact. These elements contain surprising questions and difficult dilemma's which help the patient think about decisions relating to the last stage of life but also about good memories he/she may have. Questions include; "What is the most beautiful thing you experienced in your life", "What is the scariest thing you've ever done?", and "What was the nicest place in or around your parental home?". The answers to these questions are bundled together in a book that the patient can access through the app (Monuta, 2013). The app is accessible for free through Android.

Another funeral company, DELA, launched an app as well named "Before you leave". The app contains hundreds of questions regarding topics as medical care, practicalities, social issues, and psychological impact, with questions ranging from easy to more difficult topics such as "What is your nicest memory of our time together", or "What would you have done differently in your life". The conversations can be recorded and saved in order for them to be able to be used by informal caregivers or family to recall memories of their loved one. The recordings can also be used by healthcare professionals to understand the care needs of the patient. (Zorg Voor Beter, 2017). The app can be downloaded for free on iOS and Android.

Together, these apps and games contain a broad array of questions and dilemma's suitable for patients seeking information on medical and practical aspects but also for patients who want to look into the social and psychological impact of their state as a palliative patient. However, it must be noted that none of these apps and games are yet scientifically verified.

#### **4.1.5 Video-clips**

Several video-clips have been launched to raise awareness on starting an end of life conversation with loved ones and family members early on. The organization Agora, which is concerned with providing good palliative care in the Netherlands, developed several video clips to make patients aware to timely think about the decisions they need to make about their last stage of life. One of these video-clips "Praat Erover" ("Talk about it") encourages advanced care planning and inspires patients to discuss their care preferences early on with their family and caregivers and to translate these preferences to paper (Zorg Voor Beter, 2016). The videos are mostly geared towards medical care decisions. Questions include "Which treatments do/don't you want to receive?" and "What is valuable to you? Someone who listens, being at home etc.?".

The funeral company DELA launched a commercial, 'DELA voor elkaar' ("DELA for each other") that encourages people to talk to each other about important topics before it is too late. It encourages people to think about significant things that should be mentioned to loved ones when it is still possible. (DELA, n.d). The aim is raising awareness and starting a conversation.

The NFK also started a video campaign, "Uitbehandeld maar niet uitgepraat" ("Exhausted treatment options but not done talking"), that encourages people to keep talking with loved ones who are in their last stage of life. The website refers to some tools, flyers and, E-books that may be helpful to start a discussion. It also provides stories of people that are also going to the last stage of their life that can be used as support (NFK, 2016<sup>1</sup>; NFK, 2016<sup>2</sup>).

These video-clips mainly inform on the social impact of being classified as a palliative patient. The video-clip "Praat Erover" provides some additional information on medical care. Whereas these video-clips seem useful to help start a meaningful conversation, they are not scientifically verified.

#### **4.1.6 Questionnaires**

The USD-R (Utrecht Symptoom Dagboek-Rotterdam/Utrecht Symptom Diary-Rotterdam) is a questionnaire that helps to systematically and early on detect symptoms and complaints of patients. This questionnaire consists of several questions related to the different symptoms that the patient might experience. The patient can also indicate which symptoms are experienced as most bothersome. By applying this questionnaire regularly (once or twice a week) the medical specialist can set care priorities together with the patient (Netwerk Palliatieve zorg n.d.). The questionnaire is mainly medical oriented but also includes topics such as social impact and psychological impact. Questions include "In how much pain are you at the moment?", "How do you feel at the moment?", and "To what extent do you worry about your family?" The questionnaire is mainly provided through the healthcare professional but can also be downloaded online. It is unclear whether this questionnaire is scientifically verified, however, it is applied in different medical care settings in the Netherlands.

#### **4.1.7 Overview Conversational Tools**

In conclusion, there have been some promising initiatives regarding the development of conversational tools for palliative patients, their loved ones, and family in the Netherlands. An overview of the tools can be found in table 4. It must be noted that none of these tools seem to be scientifically verified. Moreover, it can be noticed that the larger majority of the tools seem to be geared towards medical and practical information

provision. Some tools, however, take a broader perspective also including practical information, and the social and psychological impact of being a palliative patient. The aim of the tools deviate between the different tools and also within the different type of groups vary from informing, to decision making tools, to conversation starters. The video-clips, however, can be assigned to be mainly conversation starters. Moreover, about 70% of the tools focus on the patient solely, whereas 30% of the tools also take the family into consideration as part of the preparation for the stage of life conversation.

*Table 4. Conversational Tools Scheme*

Tool Name	Type	Target Audience	Main Topics	Main Aims	Example Questions
De Afscheidswijzer	Guide	-Palliative -Patients Family	-Medical information -Practical information	-Timely orientation towards passing -Informing	"What is important to me in the last stage of life?" "How do I want to formalize my last phase of life?" "What does the concept of quality of life mean to me?"
Onmisbare Informatie over het Einde v.h. Leven	Guide	Palliative Patients	Medical Information	Informing	"Which role does the specialist have?" "Do I want to consider euthanasia when suffering gets unbearable?"
Ik wil met je praten	Website	Palliative Patients	-Medical information -Practical information -Social impact -Psychological impact	-Conversation starter -Informing	"What is important for you in the last stage of life", "What do you want your legacy to be?" "Are there medical procedures that are (not) important to you at the moment?"
Drie Goede Vragen	Website	(Palliative) Patients	Medical information	(Shared) decision making	What are my possibilities?" "What are the benefits and disadvantages of the possibilities?" "What does that mean in my particular situation?"
Wat er toe doet	Website	Palliative Patients	-Medical information -Social impact -Psychological impact	- Establish health goals/priorities	"What is important to me in life?" "What is important to me in life <u>right now</u> ?" "What do I want to be able to do?" "What do I need to accomplish this?"
Praat op Tijd over uw Levenseinde	E-book	-Palliative Patients -Family	-Medical information -Practical information	-Conversation starter -Informing	"What do you need to know from the specialist?" "What do you want to do when you're in a lot of pain" "When does suffering become unbearable for you".
Games that Matter	Game	Palliative Patients	-Medical information -Practical	Conversation starter	"What/Whom do you need to make life valuable?"

			information -Social impact -Psychological impact		"What do I need to know for certain when I'm taking care of you?" "What is most important to you if little time is left?"
Raakvragen	App	Palliative Patients	-Medical information -Practical information -Social impact -Psychological impact	-Decision Making -Informing	"What is the most beautiful thing you experienced in your life" "What is the scariest thing you've ever done?" "What was the nicest place in or around your parental home?"
Before you Leave	App	-Palliative Patients -Family	-Medical information -Practical information -Social impact -Psychological impact	-Conversation starter -Informing	"What is your nicest memory of our time together" "What would you have done differently in your life"
Praat Erover	Videoclip	Palliative Patients	Medical information	-Conversation starter -Timely orientation towards passing	"Which treatments do/don't you want to receive?" "What is valuable to you? Someone who listens, being at home etc.?"
Dela voor Elkaar	Videoclip	-Palliative Patients -Family	Social impact	Conversation starter	x
Uitbehandeld maar niet Uitgepraat	Videoclip	Palliative Patients	Social impact	Conversation starter	x
USD-R	Questionnaire	Patients	-Medical information -Social impact -Psychological impact	Establish health goals/priorities	"In how much pain are you at the moment?" "How do you feel at the moment?" "To what extent do you worry about your family?"

An infographic has been made to more clearly visualize the outcomes of the scoping review (Fig. 4). This infographic was presented to the focus group to help start the discussion on the different conversational tools.

## Conversational Tools that Help Prepare Patients for the Stage of Life Conversation



### Guides

- 1) De afscheidswijzer.  
[www.afscheidswijzer.nl](http://www.afscheidswijzer.nl)
- 2) Onmisbare informatie over het einde van het leven.  
[www.kbo.nl](http://www.kbo.nl)



### Websites

- 3) Ik wil met je praten.  
[www.ikwilmetjepraten.nu](http://www.ikwilmetjepraten.nu)
- 4) Drie goede vragen.  
[www.3goedevragen.nl](http://www.3goedevragen.nl)
- 5) Wat er toe doet.  
[www.watertoedoet.info](http://www.watertoedoet.info)



### E-books

- 6) Praat tijdig over het levenseinde.  
<http://levenseinde.patientenfederatie.nl>



### Games and Apps

- 7) Games that matter.  
[www.gamethatmatter.nl](http://www.gamethatmatter.nl)
- 8) Raakvragen App.  
Available for Free in Android and Apple Appstore
- 9) Before you leave App.  
Available for Free in Android and Apple Appstore



### Videoclips

- 10) Praat erover.  
<https://www.zorgvoorbeter.nl/palliatieve-zorg/filmpjes>
- 11) Dela voor elkaar.  
<https://www.dela.nl/blog/voorelkaar/stilstaan/meeleven/video-wat-voor-moois-hebben-jullie-voor-het-laatste-tegen-elkaar-gezegd>
- 12) Uitbehandeld maar niet uitgepraat.  
<https://uitbehandeldmaarnietuitgepraat.nl/>



### Questionnaire

- 13) USD-R  
<http://www.netwerkpalliatievezorg.nl/rotterdam/Zorgverleners/Palliatieve-Thuiszorg/PaTz-Tools/USD-R>

	Type	Target Audience	Main Aim	Example Questions
1)		Palliative patients and family	-Timely orientation towards passing -Informing.	"What is important to me in the last stage of life?" "How do I want to formalize my last phase of life?" "What does the concept of quality of life mean to me?"
2)		Palliative patients	Informing	"Which role does the specialist have?" "Do I want to consider euthanasia when suffering gets unbearable?"
3)		Palliative patients	- Conversation starter - Informing	"What is important for you in the last stage of life?" "What do you want your legacy to be?" "Are there medical procedures that are (not) important to you at the moment?"
4)		Patients	(Shared decision) making between	"What are my possibilities?" "What are the benefits and disadvantages of the possibilities?" "What does that mean in my particular situation?"
5)		Palliative patients	Establish health goals/priorities	"What is important to me in life?" "What is important to me in life right now?" "What do I want to be able to do?" "What do I need to accomplish this?"
6)		Palliative patients and family	-Conversation starter - Informing	"What do you need to know from the specialist?" "What do you want to do when you're in a lot of pain?" "When does suffering become unbearable for you?"
7)		Palliative Patients of all ages	Conversation starter	"What/Who do you need to make life valuable?" "What do I need to know for certain when I'm taking care of you?" "What is most important to you if little time is left?"
8)		Palliative patients	-Decision making -Informing	"What would you want to be great at?" "How many times have you been in love?"
9)		Patients, informal care givers, family and health care professionals	-Conversation starter -Informing	"What is your nicest memory of our time together?" "What would you have done different in your life?"
10)		Palliative patients	-Timely orient towards passing -Conversation starter	x
11)		Palliative patients and family	Conversation starter	x
12)		Palliative patients	Conversation starter	x
13)		Patients and healthcare professionals	Establishing health goals/priorities	"In how much pain are you at the moment?" "How do you feel at the moment?"

Figure 4. Infographic Conversational Tools

## 4.2 Focus group

This section of the results will focus on the outcome of the focus group regarding the preferences towards the stage of life conversation and the conversational tools that may aid in the preparation of this conversation. The focus group consisted of eight members from the patient representative advisory group of oncologic palliative patients in the Zuyderland Medical Center (table 5). 25%(2) of the interviewees were male and 75%(6) were female. All members had an affinity with the topic of palliative care either through their occupation or due to personal experiences.

Table 5. Focus Group Members

Male	Hospice Worker
Male	Hospice Worker
Female	Representative of a healthcare organization and funeral speaker
Female	Ex-employee of a healthcare organization and ex-member of the project Gewenste Zorg in de Laatste Levensfase
Female	Ex-representative of the elderly population
Female	Employee of the Toon Hermanshuis for oncology patients, their loved-ones, and family
Female	Representative of a volunteer association that helps people to participate in society
Female	Palliative Network coordinator and informal caregiver

First, the stage of life conversation will be discussed in general, followed by a discussion about the appropriateness of conversational tools for this conversation.

### 4.2.1 Stage of Life Conversation

A timely introduction to palliative care, which is one of the goals of the stage of life conversation, was positively received by the advisory board members, especially because palliative care is often initiated tardily according to the board members. This member states that initiating palliative care as early on as possible would be the optimal situation;

“That is what we just discussed, that the initiation of the palliative stage is often taking place very belated.” [“..”] To what extent could we give the patient population their own disease management?” [“..”] “You get diagnosed with dementia than you should speak up right away.” [Advisory member 8].

One of the members even states that the conversation should take place even before someone is classified palliative.

“[“..”] The question you could ask about these kinds of conversations is whether you have the horse behind the carriage. Shouldn't you get the horse in front of the carriage? That you start this kind of conversations when people are not yet in this stage?” [Advisory member 2].

Whether it is appropriate to start a conversation about palliative care before someone is classified as a palliative patient, or whether this care should start as soon as someone is classified palliative it seems clear that raising awareness early on about this topic is considered crucial by the board members.

The members also recognize that patients should be able to talk to a healthcare professional they feel comfortable with. Currently, the patients don't have a choice with whom they will have the conversation because the healthcare professional makes this decision unless the patient clearly states he doesn't feel comfortable with this professional.

“And do you give the client the choice [in which professional they choose?]. Or do you determine who conducts the conversation? Because there are also patients who never visit their GP.” [Advisory member 3].

Due to some patients not having a close bond with their GP the members seem to assign high importance to individual preferences when selecting a healthcare professional to have the stage of life conversation with, as the patient is the only one who can clarify whom he feels comfortable with.

Additionally, the board members indicate that the patient should be able to bring his own questions to the stage of life conversation instead of the healthcare professional deciding which questions will be asked;

“I think you should always start these conversations with [asking]: Do you have any questions yourself? Before you can really start the stage of life conversation and questionnaires.” [Advisory member 5]

However, the board members indicate that it is only possible for a patient to prepare these questions if sufficient time is given for this preparation. Currently, the healthcare professional decides when the stage of life conversation takes place. The advisory

members, however, argue that this decision should be made in consultation with the patient as the patient should be able to decide how much processing time he/she needs;

“Isn’t it a good idea to ask the patient himself/herself what he/she wants?”

[Advisory member 3].

“That’s where you start, I think. That’s what you start with, asking how much time do you think or how much time do you like.. And if that’s uncertain than you can say; Gee, should we say 14 days?” [Advisory member 5]

Some members even argue that one conversation might not be sufficient, as patients may be left with questions afterward. Therefore, according to this advisory member, it should be up to the patient to decide whether to have an additional conversation;

“I think you should always give them a chance. Like, if you have any more questions than you can reach me on my phone for sure.. Or something like that. And you can still say: Well you have so many questions, let’s get together again.”

[Advisory member 5]

Thus, regarding the life stage conversation, it became clear from the advisory board members that individual choice is deemed very important. The patients should be able to choose a professional they feel most comfortable with, they should be able to prepare their own questions for the conversation, and they should be able to decide how much time they need to prepare for the conversation.

The next part will focus on the use of conversational tools to prepare for the stage of life conversation.

#### **4.2.2 Conversational Tools as Preparation for the Stage of Life Conversation**

The advisory board members, having been handed the infographic of the conversation tools (fig. 4), do see the benefits of conversational tools as preparation for the stage of life conversation. This member states;

“[“..”] I think you can better prepare yourself [with a conversational tool]. [“..”]

And then you can say, study it at home or discuss it at home. If need be with a partner or I don’t know who. But write down.. Like I said, write down your own questions. Your own insecurities.” [Advisory member 5]

Thus, according to this advisory member, the conversational tools might help people to formulate their own questions in preparation for the stage of life conversation.

Additionally, the board members argue that it should be left to the patient which tool

he/she wants to use to prepare for the stage of life conversation. Some members, however, argued that apps would not be an appropriate tool for palliative patients;

“But is it considered if a client is.. a patient is ready for this? Or if he/she is engaged with this? Because basically, I think that the target audience that you approach are people that never worked with the internet before”. [Advisory Member 7]

Even though some objections were made against the use of apps, according to the members, it would not be appropriate for the professional to select a tool himself/herself for each patient;

“As a conversational partner, you would have to know all these websites very well to estimate which tool would be the right one for that patient.” [Advisory member 5]

“This would undermine self-management. I wouldn’t consider this method to be correct. I think you could hand it on an A4 sheet and the patient and family could find an own match.” [Advisory member 8]

To allow for self-management and individual choice, the board members argue to hand the patients the infographic to make an informed decision themselves on which tool to use. Moreover, the board members argue that the infographic should be more widely spread throughout the media to raise awareness for the topic of palliative care, as currently, according to the advisory board members, many people seem to be oblivious of this topic;

“You could by means of this [TZPZ] project propose these tools to the media as well. [“..”] People need to be made aware of the fact that life is finite. They know this, but they push this away. And if there is simple..” “Simple language [“..”]. The more response you will get in this kind of conversations” [Advisory member 2]

Thus, according to the board members, the TZPZ should broadcast the conversational tools to a wider part of society to raise additional awareness on palliative care. In addition to the infographic, the board members argue that it would be nice to have an additional preparation sheet for the patient with an overview of the most important and common themes that are discussed during this conversation. Currently, the healthcare professional has a standard questionnaire that is reiterated during the conversation,

however, this questionnaire is too complicated and elongated to be send to the patients. This member states;

“If you don’t want a questionnaire.. or if you say it is too complicated.. Too much input from the professional.. Couldn’t you also put in some kind of themes?”

[Advisory member 5]

Thus, the advisory members recommend to hand the patients the infographic and an overview of the most common themes which they can use to prepare for the stage of life conversation and in addition present them with a common theme list for this conversation. They also argue that patients should be made aware of the option of taking a notebook or recording device to the conversation to capture important aspects of the conversation. This advisory member states;

“That is important, that people write it down. They are still not doing this. If I talk to people who go to the GP, I always tell them to make notes. Because you are sitting there and then they ask you questions, and later on you forget them. I think this is important in this stage because you, of course, have hundreds of questions when you are in that kind of position” [Advisory member 5]

Concluding, it seems that the advisory members see a definite need for conversational tools as a preparation method for the stage of life conversation, however, they argue that not one tool is preferred over another and that the patient should be left to make his/her own decision regarding which tool to use. Moreover, the board members advise for a theme list to be handed to the patient with an overview of the most important topics that are discussed during the stage of life conversation.

## **5. Discussion**

The discussion will provide the main conclusion of the study, the limitations, and the recommendations for practice and for further research.

### **5.1 Conclusion**

There have been some promising initiatives regarding the development of conversational tools for palliative patients in the Netherlands. A total amount of 13 tools have been found to prepare patients for the stage of life conversation. However, the larger majority of the tools seem to be geared towards informing about medical care. Some tools, however, take a broader perspective also including practical information, and the social and psychological impact of being a palliative patient. The psychological of being a palliative patient is huge, with mood disorders having a prevalence of 29% and

depression having a prevalence of 24.6% (Mitchell et al., 2011). Therefore, it is important for organizations to keep creating tools that consider the psychological impact of being a palliative patient as well.

The advisory members that were included in the focus group seem to see a definite need for conversational tools as a preparation method for the stage of life conversation. Literature indicates as well that advanced care planning (ACP) is important for palliative patients to increase shared decision making and to give them the feeling that their needs are recognized (Waldrop & Meeker, 2012). Moreover, ACP for palliative patients seems to reduce stress, anxiety, and depression within the patients itself but also for the family (Detering, Hancock, Reade, & Sylvester, 2012). It seems important to include the family aspect as well in these tools as they experience a strong need for social support after the death of a loved-one (Benkel, Wijk, & Molander, 2009). Therefore, it is important to start creating more tools for family members, as they currently only make up 30% of the total amount of tools.

As previously stated, the advisory board members in the focus group acknowledged a need for the use of these conversational tools as a preparation for the stage of life conversation. They also argued that the patient should be left with the choice of which tool to use to prepare for the conversation. On the other hand, some members argued that an app would not be popular because palliative patients often wouldn't know how to use this technology. This contradicts their previous statement made about individual choice as they make the assumption that patients will not use an app. It seems that assumptions about what is the best way to provide care for a patient are easily made. However, it is important to keep on considering the needs of the patient at any given time.

The present study is, to my knowledge, the first that has presented an overview of the available conversational tools in the Netherlands to prepare palliative patients for the stage of life conversation. The study reveals that there is a promising amount of conversational tools available at the moment varying from guides and E-books to apps and games. There is a need to spread these tools among healthcare professionals and raise awareness on their existence to actually make use of these tools. Literature indicates that there seem to be different technologies on the market for patients to help them prepare for their last stage of life, however, they are often not utilized due to poor professional to patient communication (Waldrop & Meeker, 2012). Therefore, appropriate training for professionals on end-of-life communication seems to be crucial to spread the awareness on the conversational tools.

## **5.2 Limitations**

The major limitation of this study is that due to ethical difficulties and due to the limited time in which the study was conducted, it was not possible to interview any palliative patients themselves. Therefore, some information might not be applicable to the current situation that patients experience. Therefore, it is recommended for future studies to investigate the opinions of patients on the matter of the stage of life conversation

## **5.3 Recommendations**

Based on the results several recommendations will be made for the TZPZ in specific. These recommendations can be applied to other settings as well. Moreover, recommendations for further research will also be made.

- Let the patient take initiative in the stage of life conversation by allowing him/her to ask his/her own questions.
- Let the patient decide how much time he/she needs to prepare for the stage of life conversation.
- Let the patient decide which healthcare professional he/she wants as conversation partner.
- Provide the patient with the infographic to help him/her prepare for the stage of life conversation.
- Provide the patient with the theme list to give him/her an overview of the most important topics to consider for the stage of life conversation. To foresee in the need for a theme list that has been proposed by the focus group a document has been created based on the existing questionnaire that the GP currently uses during the stage of life conversation, and based on a questionnaire with important questions related to the last stage of life that was created by the focus group (fig. 5).

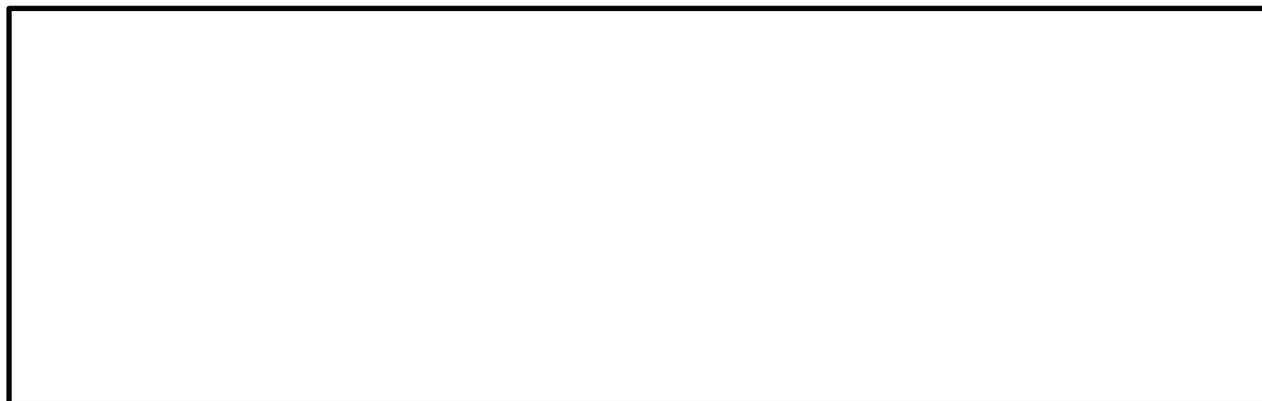
A visualization of these recommendations for the TZPZ can be found in figure 6.

## Themes to consider as preparation for the stage of life conversation

The following topics can be considered as a preparation for the stage of life conversation. You can also select one or more topics that you consider as most important or you can add additional topics if you wish to do so.

- Medical treatments: (Which treatments do I still want to receive & which (life sustaining) treatments do I not want to receive anymore).
- Location: (Where do/don't I want to spend my last stage of life)
- Funeral arrangements: (What are my wishes concerning my funeral)
- Testament and financial information: (Do I want to arrange a testament & who takes care of my financial matters)
- Practical issues: (Do I experience issues with the care for my children, my accommodation, transportation, work/school/study, finances, or insurance)
- Social issues: (Do I experience issues in the relationship with my partner, children, and/or family)
- Emotional/psychological issues: (Do I experience guilt, shame, anxiety, anger etc.?)
- Religious/spiritual issues: (Do I experience issues with my trust in faith/God?)
- Physical issues: (Which physical issues do I experience?)
- Valuable activities: (Which activities do I still want to do or which experiences do I still want to have.)

Space for additional topics and notes



Note:

- Feel free to discuss these topics with family members and loved-ones.
- It is possible to make notes during the stage of life conversation. Feel free to take a notebook or recording device with you. You can also ask the healthcare professional for assistance in making notes.

Figure 5. Theme list

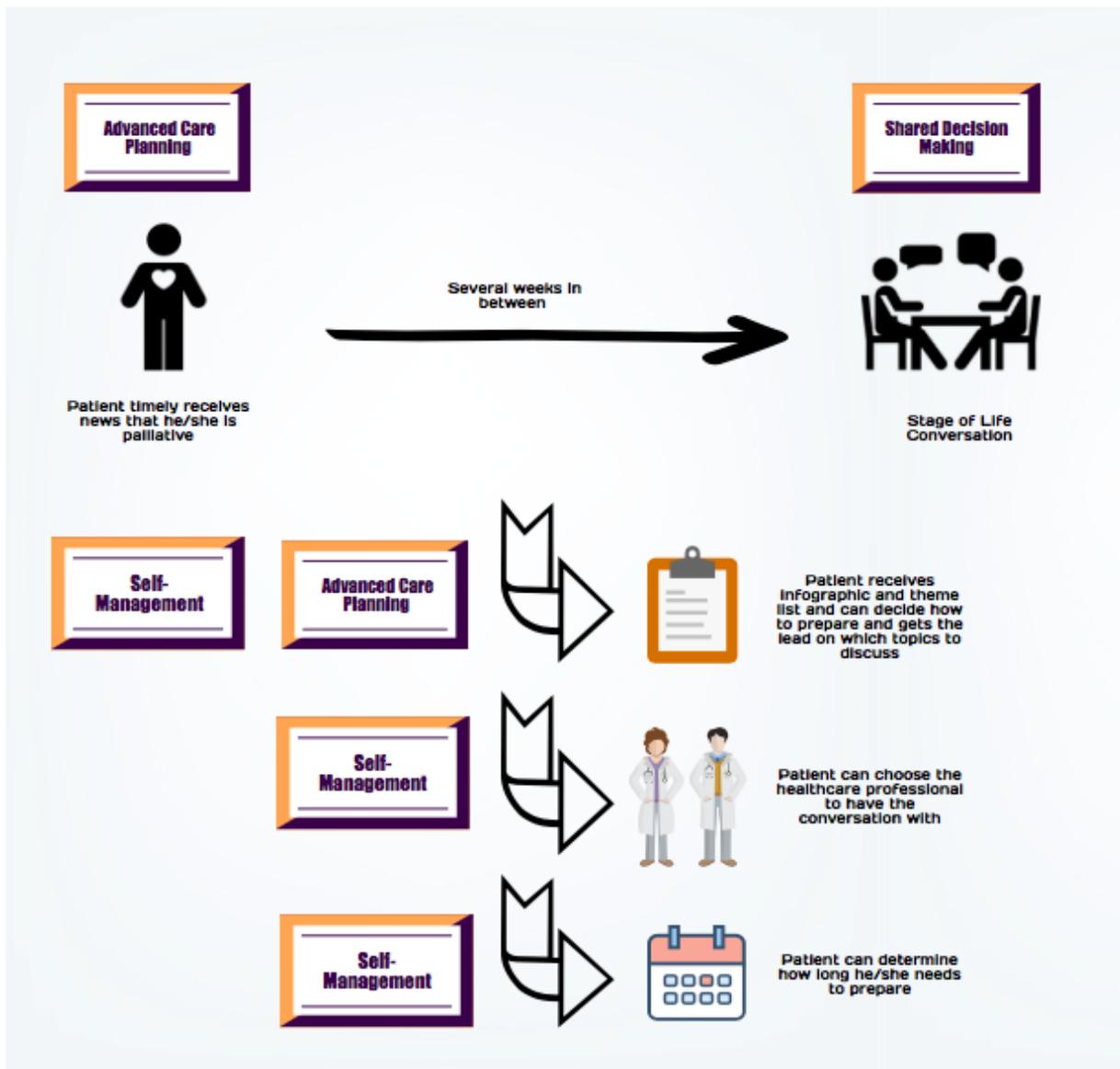


Figure 6. Infographic Recommendations TZPZ

Moreover, some recommendations for future research will be proposed;

- There is a need to investigate the ability to create more tools geared towards the family members of palliative patients.
- There is a need to conduct interviews with palliative patients on the demand of conversational tools as a preparation for the stage of life conversation

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## **Appendix 1: Interview guide focus group**

### **Introductie:**

Mijn naam is Anne Neumann, ik ben master student aan de universiteit van Maastricht en voor mijn afstudeerstage doe ik onderzoek naar hoe je mensen het beste voor kunt bereiden op het levensfase gesprek (voorheen palliatief assessment). Het levensfase gesprek is een gesprek waarin de wensen voor de laatste levensfase in kaart worden gebracht. Er zijn verschillende manieren waarop mensen voorbereid kunnen worden voor een levensfase gesprek, maar wij horen graag welke benadering uw voorkeur zou hebben gehad.

Hierover zou ik u graag een aantal vragen willen stellen. Uw ervaring draagt positief bij aan de verbetering van de kwaliteit van zorg voor palliatieve patiënten en het zorgt ervoor dat mensen meer eigen regie kunnen behouden in hun laatste levensfase. Uw deelname is volledig anoniem en uw naam zal niet vermeld worden in de studie. Uw deelname is volledig vrijwillig. U mag op ieder moment kiezen om te stoppen. Als u vragen heeft over de studie of over uw deelname aan de studie kunt u altijd contact met me opnemen. Voor een correcte documentatie van dit interview zou ik graag met uw toestemming een geluidsopname maken. De opname wordt vernietigd na afloop van de studie. Vindt u dat goed?

### **Inleidende vraag:**

**Q1:** Is het voor u duidelijk wat het levensfase gesprek is?

Zo ja: Kunt u dit onder woorden brengen?

**Q2:** Hoe lang geleden heeft u dit gesprek gehad?

### **Individuele voorbereiding**

**Q3:** Hoe heeft u zichzelf voorbereid op dit gesprek?

**Q4:** In hoeverre heeft u middelen zoals gidsen, E-books, Apps, spellen, of video's... aangereikt gekregen die u hielpen in de voorbereiding op het levensfase gesprek?

**Q3:** In hoeverre voelde u zich overvallen door de vragen die werden gesteld tijdens het levensfase gesprek?

**Q5:** In hoeverre zou u het prettig vinden als u deze middelen aangeboden had gekregen ter voorbereiding?

**Q6:** Wat voor een middel zou u voorkeur hebben met betrekking op de voorbereiding op het levensfase gesprek en uw zorgbehoeften? (bijvoorbeeld: Gids, E-book, App, Spel, Video).

**Q7:** Hoe veel tijd denkt u dat er voor nodig is om iemand goed voor te bereiden op het levensfasegesprek?

**Q8:** Wat zou in u ogen de meerwaarde zijn van deze voorbereiding?

**Q9:** Is er iets wat u verder gemist heeft tijdens de voorbereiding op het levensfase gesprek?

### **Familie en vrienden**

**Q10:** In hoeverre werden uw familie en vrienden betrokken bij de voorbereiding op het levensfase gesprek?

**Q11:** Heeft u middelen aangereikt gekregen die u hebben geholpen om met familie en vrienden een gesprek aan te gaan?

**Q12:** In hoeverre zou u het prettig hebben gevonden als u middelen aangeboden had gekregen om uw familie of vrienden te betrekken bij de voorbereiding op het levensfase gesprek?

**Q13:** Wat voor een middel zou u voorkeur hebben met betrekking op de voorbereiding op het levensfase met uw familie en/of vrienden (bijvoorbeeld: Gids, E-book, App, Spel, Video).

### **Overige:**

**Q14:** Heeft u nog andere opmerkingen wat betreft het levensfase gesprek of de voorbereiding die nog niet genoemd zijn?

### **Reflectie**

**Q15:** Hoe heeft u dit gesprek vandaag ervaren? Heeft u nog suggesties of opmerkingen wat betreft dit gesprek vandaag?

## Appendix 2: Informed Consent

### Formulier voor toestemmingsverklaring

**Titel onderzoek:** Kwalitatief onderzoek naar het voorbereiden van patiënten op het levensfase gesprek

**Verantwoordelijke onderzoeker:** Anne Neumann

*In te vullen door de deelnemer*

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en belasting van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Mijn vragen zijn naar tevredenheid beantwoord.

Ik begrijp dat geluidsopnamen of de bewerking daarvan uitsluitend voor analyse zal worden gebruikt.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgave van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam ..... deelnemer:  
.....

Datum: ..... Handtekening ..... deelnemer:  
.....