

Retrospective Evaluation of Treatment Passports that Support Advance Care Planning

A Secondary Data Analysis of Qualitative and Quantitative Information



J.M.A. Biesmans - I6262484

Thesis MSc Healthcare Policy, Innovation and Management

1st Supervisor: Dr. J.M.M. Meijers

2nd Supervisor: Drs. S.R. Bolt

Organisational Supervisor: Drs. I. Jochem

Internship Organisation: MCC Omnes,
Milaanstraat 100 Sittard

April – July 2021

Faculty of Health, Medicine and Life Sciences

Maastricht University

Date of submission: 02-07-2021

Acknowledgments

Foremost, I would like to express my gratitude to my thesis supervisors Judith Meijers and Sascha Bolt for their support during my research period. Without your clear feedback, motivation and enthusiasm, I would not be able to develop myself to the point where I am now. I really enjoyed working with you and hope to meet you again during my professional career.

In addition, I want to thank my organisational supervisor, Inge Jochem. I appreciated your encouraging words and guidance throughout the thesis period. You motivated me to provide a real contribution to this project. Hopefully we will meet again.

Further, my sincere gratitude to the coordinators of Burgerkracht Limburg, the Palliative Care Network and the Dementia Support Network. Els, Nicole, Marja and Jolanda, thank you for your feedback and support during the writing of my thesis.

Likewise, I would like to thank my family. My father, whose advices and freshly-made orange juice in the morning helped me to keep going. My sister, who expressed her interest by designing the title page. Lastly, my girlfriend. We supported and advised each other while working on our graduation projects. To all, my deepest gratitude for your support and interest.

To close, this work is dedicated to my mother, who experienced a difficult time fighting cancer during the thesis period. Your energy and drive provided me with motivation to gain the best result possible and continue to work towards my goals. Thank you for everything.

Abstract

Background: The number of people with a chronic disease is rising in the Netherlands. A chronic disease is a disease that cannot be fully healed or cured anymore. Palliative care can be used in these situations. It is becoming increasingly important that preferences and wishes for the end of life (EOL) are timely communicated between the care recipient and involved healthcare professionals. Advance Care Planning (ACP) is an intervention that attempts to timely think and discuss the wishes and preferences before a person becomes limited. The treatment Passport (Dutch: Behandelpaspoort) is a new tool that assists persons to think and discuss their (treatment) wishes and preferences for the last EOL.

Aim of the study: This study aims to evaluate the experiences of older persons and their involved care professionals with the usage of the Treatment Passport during the ACP-processes (i.e. thinking, discussing and documenting about wishes and preferences for EOL). The study is conducted in two regions of Limburg: Westelijke Mijnstreek and Oost-Zuid Limburg.

Methods: A secondary data analysis was conducted with the use of questionnaires. The questionnaires were distributed to the eligible care professionals (N=30) and care recipients (N=80). To analyse the qualitative data, Directed Content Analysis was conducted. Quantitative data provided an illustration of the categorical questions. Triangulation of the analysis was applied with the organisational supervisor and involved coordinators of the research.

Results: Care professionals saw the passport as an opportunity to start talking about (treatment) wishes and the end of life (EOL). Additionally, the passport was considered a practical tool that provided guidance during ACP. However, some professionals did not experience the passport as an added value. Care recipients considered the passport as a contributing tool to think, discuss and document (treatment) wishes for the end of life (EOL). The simplicity, tangibility and content were contributing to the ACP-processes.

Conclusion: From the experiences of professionals and care recipients, the treatment passport can be considered a facilitating tool for the thinking-, discussing- and documenting process during ACP. Participants who found the passport of limited added value mostly had their own methods for thinking and discussing the EOL or already documented their wishes and preferences.

Table of Contents

Chapter 1: Introduction.....	1
1.1 Problem statement, Research Objective and Research Question.....	2
1.2 Approach Outlining.....	3
Chapter 2: Theory and Concept Model.....	4
2.1 Patient-Centered Care	4
2.2 Shared Decision-Making.....	5
2.3 Advance Care Planning	6
2.4 Palliative Care Quality Framework	6
2.5 Concept model	8
Chapter 3: Methodology	9
3.1 Research Type and Design	9
3.2 Population and Recruitment.....	9
3.3 Data Collection and Procedures.....	11
3.4 Data Analysis	14
3.5 Reliability & Validity	14
3.6 Ethical Considerations	15
Chapter 4: Results.....	17
4.1 Results of the Care Professionals.....	17
4.2 Results of the Care Recipients	26
4.3 Comparison of the Sample Populations	32
Chapter 5: Discussion	33
5.1 Strengths and Limitations	36
5.2 Advice for Further Research	37
5.3 Implications for Practice.....	38
5.4 Conclusion	38
References.....	39
Appendix 1: Complete Questionnaire for Healthcare Professionals	45
Appendix 2: Complete Questionnaire for Care Recipients	48
Appendix 3: Instruction Form for General Practitioners.....	53
Appendix 4: Instruction Form for Advisory Nurses & Specialised Palliative Care Nurses	56
Appendix 5: Instruction Form for Dementia Case Managers	59
Appendix 6: Coding Tree Care Recipient	62
Appendix 7: Coding Tree Care Professional	71

Chapter 1: Introduction

The number of people with chronic diseases is rising in the Netherlands (RIVM, 2021). Populations become older and scientific advancements contribute to prevention and alleviation of acute diseases (Van Oostrom, et al., 2016). A chronic disease is a disease that no longer can completely be cured or healed (Volksgezondheid en Zorg, 2021). In such situations, palliative care can provide helpful methods to improve the situation of the care recipient (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014; IKNL/Palliactief, 2017; Stjernswärd, Foley & Ferris, 2007). Palliative care aims to provide the most suitable care for patients, so that the quality of living can be improved in the last phases of life (Brinkman-Stoppelenburg et al., 2014). Palliative care not only focuses on a patient, but also the family of the patient is included in the care process, for example when making treatment decisions (Brinkman-Stoppelenburg et al., 2014; IKNL/Palliactief, 2017). Within the field of palliative care, Advance Care Planning (ACP) is an intervention to timely discuss and document a person's wishes and preferences for later stages of life (Rietjens et al., 2017). Not only people diagnosed with a disease can take advantage of ACP, but also (vital) older people may benefit from discussing preferences for later life (Lum, Sudore & Bekelman, 2015). ACP-processes (i.e. discussing and documentation of the wishes and preferences) are carried out before persons become limited in their physical- and communicational capacities, to prevent that their preferences and thoughts cannot be properly documented (Brinkman-Stoppelenburg et al., 2014). The person's preferences, wishes and values are important to use in Shared Decision-Making (SDM). SDM is a method to make decisions regarding treatments or medical actions that are in consent with the family, care recipient and care providers (Fleuren, Depla, Janssen, Huisman & Hertogh, 2020).

Using ACP can have advantages for the care recipient, family and care professionals (Fleuren et al., 2020). As primary advantages, it provides the care recipient with the power to make the decisions regarding treatments, so that in the future the person can fall back on his stated (treatment) wishes and maintain autonomy during the last phases of life (Fleuren et al., 2020). Decision-making for the last phases of life can be an unpleasant experience. Therefore, ACP aims structure and ease the decision-making processes, which can result in decreased stress for the involved relatives (Fleuren et al., 2020). Family and care recipient can optimally spend time together, which can bring peace and relief, and strengthen the relationships of care recipient and family (Fleuren et al., 2020). Increased personal attention for the family can also improve grieving processes, which may lead to decreased psychological problems (Fleuren et al., 2020). For the involved interdisciplinary

professionals, ACP can also be beneficial. By collectively aiming to use the stated preferences and wishes as the working grounds for conducting a treatment, more effective collaboration between the disciplines can be established, leading to improved quality of care (Fleuren et al., 2020; Jimenez, Tan, Virk, Low, Car & Ho, 2018). An additional advantage for the healthcare setting is that overtreatment may be prevented (Lum et al., 2015). Since the persons already documented what they require from a treatment, no other possible treatments have to be explored (Lum et al., 2015). This can save resources and lower healthcare expenditures (Lum et al., 2015).

However, there might be challenges when discussing treatment preferences and the end-of-life (EOL) situation (Bloomer, Tan & Lee, 2010; Fleuren et al., 2020). ACP-conversations can be confronting and emotional, making it difficult to discuss the last phase of life (Bloomer et al., 2010). A second hurdle is that the severity and complications of palliative diseases can be unpredictable, possibly causing that the person's preferences cannot be aligned with the professionals' treatment options (Fleuren et al., 2020). For example, when the disease rapidly decreases communicational abilities of the patient, it might not be fully clear to the professionals what the preferred treatment from the patient might be. Lastly, the preferences of a person regarding treatment might change overtime. Therefore, it is important to continuously communicate the preferences and wishes of care recipients and family so that the healthcare workers can take suitable actions. One of the tools created to improve the communication between professionals, care recipients and family is called the 'treatment passport'. The central goal of the passports is to facilitate users with a tool to think and timely communicate their treatment preferences and wishes, so that these can be easily discussed with the involved healthcare workers (Behandelpaspoort, 2021).

1.1 Problem statement, Research Objective and Research Question

The Ministry of Health, Welfare and Sport made 45.000 treatment passports available across the Netherlands during the COVID-19 pandemic (Bertholet, 2020). The usage of the passports can be of important value to enhance ACP-processes during the current, unpredictable circumstances: Good communication between (vulnerable) persons, family and professionals is necessary to (quickly) assess a person's needs (Reja, Naik & Parikh, 2020). The experiences of using the treatment passports can help to improve ACP-processes and palliative care. Therefore, the experiences of using the treatment passport during ACP need to be evaluated. While medical professionals provided feedback in the developmental phase of the passport, an evaluation about the current user experiences is becoming increasingly important (Nyst, 2020). An evaluation by Bertholet (2020) described how care workers experienced the usage of the passport (Bertholet, 2020). However, limited evidence takes into account both the perspectives of the older

persons/care recipients *and* the care professionals regarding the use of the passport in ACP-processes. This information is not only important to improve the quality of the treatment passport, but also the quality of ACP-processes and care provision could be improved as well. The aim of this study is therefore to evaluate the care recipients' and care providers' experiences with treatment passport usage during ACP-processes. The research questions that will be addressed are stated as follows:

- *What are the experiences of the care professionals with treatment passport usage in the ACP-process?*
- *What are the experiences of older persons, with usage of the treatment passport in the ACP-process?*
- *What are the differences and similarities between the two groups with regard to the experiences?*

1.2 Approach Outlining

A mixed-methods study was conducted using questionnaires that are completed by the target groups (i.e. (frail) older persons, chronically-ill persons and involved care professionals). The data from the questionnaires is analysed and used to draw conclusions regarding the experiences of using the treatment passports.

Chapter 2: Theory and Concept Model

Theoretical backgrounds provided relevant information and frameworks that were used over the course of the study. The explained theories and models are: Patient-Centered Care, Shared Decision-Making, Advance Care Planning and the Palliative Care Quality Framework. Lastly, a concept model is presented, which links the described theories in one central model.

2.1 Patient-Centered Care

Patient-centered care (also referred to as person-centered care) revolves around the notion that patients should be seen as experts of the disease that they carry (Brummel-Smith et al., 2016; Hudon, Fortin, Haggerty, Loignon, Lambert & Poitras, 2012). Figure 1 indicates the core characteristics of patient-centered care in chronic disease treatment: Create a personalized care plan, provide accessible care, continuously improve the care provision, provide and support resources for selfcare, etc. (Brummel-Smith et al., 2016; Hudon et al., 2012). In addition, informing the patient about realistic situations that could happen due to the burden of disease is a major aspect of patient-centered care in the context of chronic disease management (Hudon et al., 2012). Lastly, the expectations and needs of the patient might change over time. Therefore, it is important to regularly discuss difficulties or struggles that might have occurred due to the development of the disease (Hudon et al., 2012). ACP utilizes the principles of patient-centered care to discuss the care recipient's and families' treatment preferences and values, so that the treatment is narrowed down to these stated preferences (Ferguson, 2008; Fleuren et al., 2020; Williams, 2017).

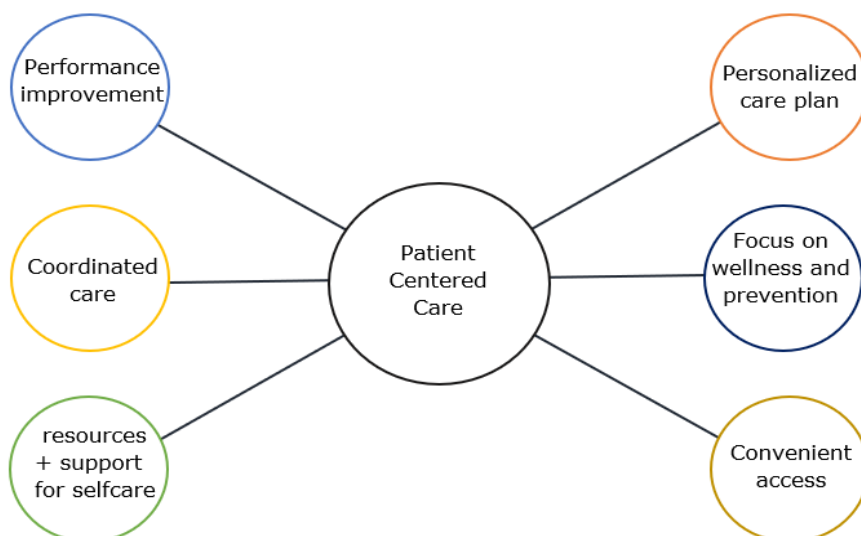


Figure 1. Concepts of patient centered care (Brummel-Smith et al., 2016).

2.2 Shared Decision-Making

Healthcare professionals are increasingly including care recipients in the provision healthcare or improving the patient's medical situation (Entwistle & Watt, 2006; Makoul & Clayman, 2006). In more classical views on healthcare, medical professionals were the ones making decisions related to a patients' treatment (Hoving, Visser, Mullen & Van den Borne, 2010). Today, it is the patient and family who are in control when making medical decisions or establishing a treatment plan (Hoving et al., 2010; IKNL/Palliactief, 2017). Therefore, Shared Decision-Making (SDM) became an important method in healthcare to reach consensus about treatment options between the care provider and care recipient (Dy & Purnell, 2012; IKNL/Palliactief, 2017). Figure 2 describes that within SDM-processes, the patient and professional should transparently and continuously share relevant information regarding treatment, so that shared decisions can be conducted more easily (Elwyn et al., 2017; IKNL/Palliactief, 2017; Makoul & Clayman, 2006). By encouraging patients to make their own decisions based on preferences and wishes, the feelings of autonomy and control of the patient can improve (Fleuren et al., 2020; Hoving et al., 2010). The control and autonomy over the last phases of life can be a contributing factor to improve the quality of life in the last phase (Elwyn, et al., 2012; Fleuren et al., 2020). Moreover, for the involved professional team SDM offers the possibility to align the amount of resources that are needed for (palliative) care provision (Kay Frank, 2009). This explains that SDM is an important tool to use in ACP-processes.

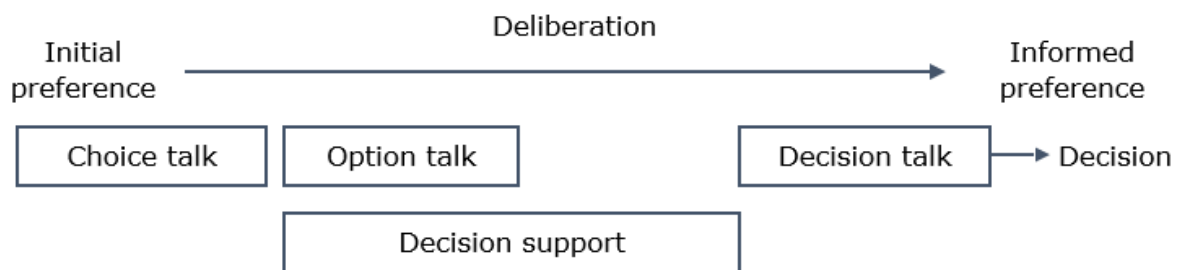


Figure 2. The Three-talk model of SDM (Elwyn et al., 2017).

2.3 Advance Care Planning

ACP is the method used to timely discuss a person's and involved relatives' preferences, wishes and values regarding treatment in the last phases of life, so that the treatment plan can be aligned to the stated preferences of the patient and his relatives (Fleuren et al., 2020; IKNL/Palliactief, 2017; Rietjens et al., 2017). ACP does not necessarily have to be used when a person is diagnosed with a palliative disease (IKNL/Palliactief, 2017; Lum et al., 2015). Instead, it can also be used to discuss the future of treatment and life of older persons that are currently healthy (Lum et al., 2015). Diseases can limit a person in one's capabilities to express their ideas and thoughts. ACP tries to anticipate on this situation by discussing the person's treatment preferences and wishes before the disease limits the patient's physical or cognitive capacities (Fleuren et al., 2020). The ACP-approach is thus a tool to make shared decisions (SDM) and overlaps with the principles of Patient-centered care: the care recipient's and relative's perspectives on treatment, such as the wishes and preferences are highly prioritized and used when creating a treatment plan (Fleuren et al., 2020). By using ACP, the person can feel more autonomous about his life, even in the phases where limits in the physical or cognitive possibilities start to occur (IKNL/Palliactief, 2017; Jimenez et al., 2018). Additionally, ACP can enhance the relationships between family and care recipient, by taking out the burden of making stressful decisions (Fleuren et al., 2020; IKNL/Palliactief, 2017). Subsequently, more attention can be directed at the care for the family and care recipient. They can feel more satisfied about the EOL when the care recipient is treated with dignity and respect, which can set the basis for a peaceful grieving process (IKNL/Palliactief, 2017). Overall, ACP covers a various amount of goals that could bring beneficial effects for the care recipient, family and healthcare professionals in the last phases of life.

2.4 Palliative Care Quality Framework

The palliative quality framework provided a set of guidelines to improve the quality of palliative care in the Netherlands (IKNL/Palliactief, 2017). The framework describes ten areas that lay the basis for improved quality of palliative care for the patient, involved relatives and healthcare workers (IKNL/Palliactief, 2017). Specific information, rules and criteria about these areas is provided in the framework, which gives the care provider a supportive grip to improve their own actions when delivering care (IKNL/Palliactief, 2017). This can improve the quality of palliative care. In Table 1. the ten domains of the palliative care framework are explained.

Table 1. Domains of the Palliative Care Quality Framework (IKNL/Palliactief, 2017).

○ Core principles of palliative care: Guidelines that elaborate on the most important topics of palliative care, such as: Patient safety, respect, confidentiality, continuity and communication.
○ Structure and process: Provides stepwise explanations to (1) timely identify if palliative care is appropriate, (2) make shared decisions (SDM), (3) be constantly involved in the care process of the patient to make adjustments, (4) create a personalised care plan with the stated preferences and wishes, (5) provide interdisciplinary care, etc.
○ Physical dimension: Criteria that emphasize how physical wellbeing of patient or vulnerable persons can be improved. For example, by alleviating complaints on the body.
○ Psychological dimension: Guidelines are given to provide attention to the psychological well-doing of a person. Continuous assessment of the care recipient's psychological needs and perspective on the last phases of life is important.
○ Social dimension: The nearing EOL can have implications for the social environment of the patient and relatives. The principles of this domain describe how care workers can support and discuss wishes and values of the patient and involved loved ones.
○ Spiritual dimension: Guidelines to recognize and discuss the spiritual needs and thought of the patient and family. This can bring peace and relief in the lives of the involved persons.
○ Phase of dying: Factors that indicate the dying-phase of the patient are described. Increased emphasis on the 4 dimensions and preferences, feelings and wishes of family and patient.
○ Bereavement and grief: Importance of a good farewell is described and how care professionals can anticipate on grieving processes of family. Increased attention and support for the grieving relatives and friends is indicated.
○ Culture: Cultural backgrounds could influence the preferences, values and wishes of patients and family. Instructions on how to combine cultural background and palliative care given in this domain.
○ Ethical and legal: Capabilities of healthcare workers to take ethically- and morally responsible decisions are important criteria in palliative care. Ethical topics, such as organ donation and sedation of the patient are also described.

2.5 Concept model

To summarize, the theories indicated that (palliative) treatments and medical decisions should always happen in consent with the patient. This not only applies for the current situation, but also for the prospective circumstances of the patient and relatives. The ACP-approach and the beforenamed theories share the core principles that the patients' decision-making power must be acknowledged and that continuous communication about preferences, wishes and values is important to specify a suitable treatment for the patient and relatives in the last phases of life (Fleuren et al., 2020; IKNL/Palliactief, 2017; Joren, de Veer, de Groot & Francke, 2020). The treatment passport is used as a tool to communicate preferences, wishes and values between care recipients, involved family and professionals within the process of ACP and palliative care. From these iterative processes, preferred treatment can be provided to the care recipient. Figure 3. illustrates the interrelatedness of the theories, ACP processes and the use of the treatment passport.

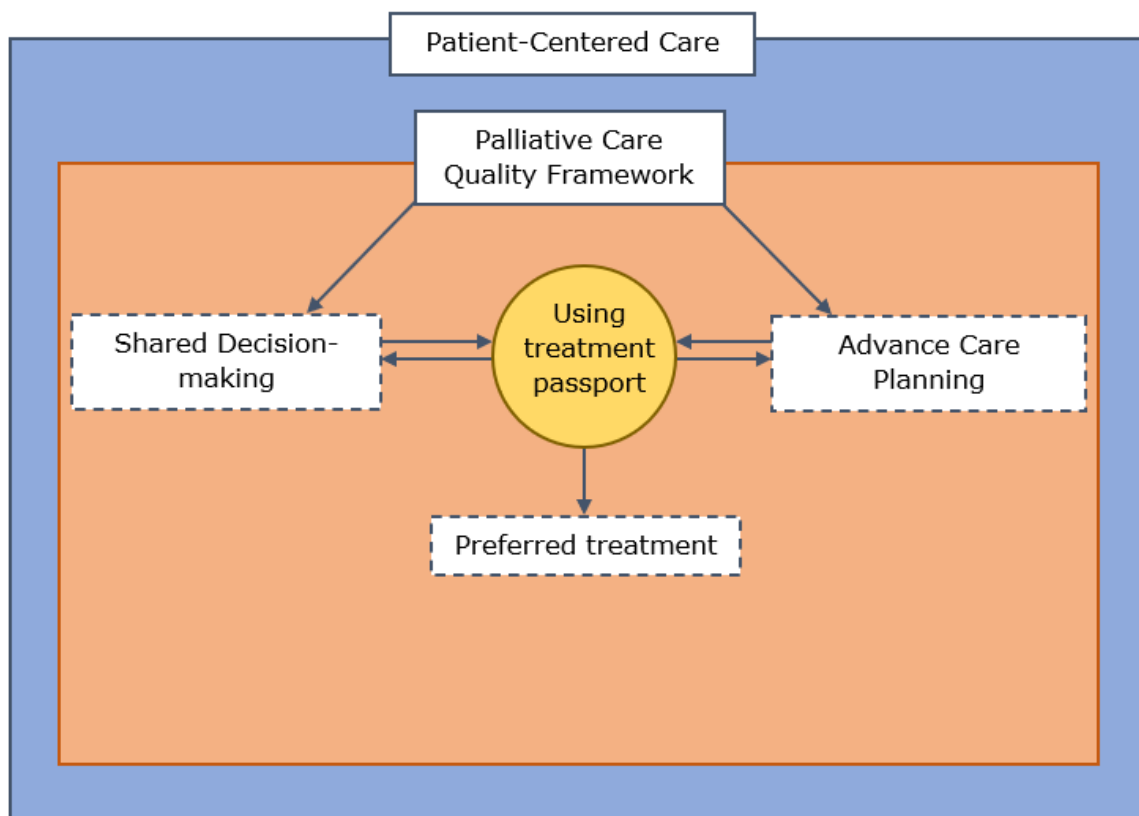


Figure 3. Concept model of palliative care, including treatment passport usage.

Chapter 3: Methodology

In the methodology chapter, the used research design, data collection methods and sampling methods are discussed. In addition, the data analysis strategy, ethical considerations, validity and reliability are explained in the context of the study.

3.1 Research Type and Design

A secondary data analysis was conducted with the use of qualitative and quantitative cross-sectional data (Kesmodel, 2018; Thomas, 2006). Questionnaires were used to collect experiences and personal perspectives of two included sample groups. The collected data were used to describe the experiences of using the treatment passport, making this a descriptive study (Nassaji, 2015).

3.2 Population and Recruitment

Our study addressed both the perspective of the professional and the care recipient regarding treatment passport usage. Thus, the selected population for this study consisted of two groups. The first group of participants were the professionals that provided care for the care recipients. The care professionals were recruited in two regions of Limburg: 'Westelijke Mijnstreek' and 'Oost Zuid-Limburg'. They were approached to participate in the study by the pilot organisations (i.e. the Palliative Care Network, the Dementia Support Network and Burgerkracht Limburg). The inclusion criteria for the professionals to be enrolled in the study were:

1. The care professionals must have direct contact with their care recipients in order to optimally assess if the care recipient met the inclusion requirements to participate in the study.
2. The care professionals should be educated or have knowledge about (social)geriatric-, or palliative care provision. The pilot organisations used their care network to select care professionals that met this requirement. By specifying the knowledge and abilities of the care professionals, they can optimally recruit care recipients or older people to participate in this study.

The sample of professionals consisted of various disciplines. Subsequently, the included professionals were asked to recruit care recipients for the research. Figure 4. visualises the distribution of the treatment passports and questionnaires from care professionals to care recipients. The professionals were given an instruction sheet from the pilot organisations to correctly distribute the treatment passports and explain the purpose of the study to the care recipients (consult Appendices 3, 4 and 5 for the instruction forms). Judgemental sampling was used to select care recipients that could be included in the study (Etikan & Bala, 2017). This sampling technique offered the opportunity for the professional to 'judge' if a care recipient was eligible to participate (Etikan & Bala, 2017). Clinical reasoning was used to select the care recipients. Moreover, care recipients had to meet the following inclusion criteria:

1. Within the sample group of older people, two groups were included: (1) older persons who have become frail due to age or illness and (2) older persons that are currently in a vital condition of life.
2. The person needs to understand and be able to correctly use the passport and questionnaire. Additionally, they should be able to express thoughts, opinions and experiences regarding treatment passport usage. Therefore, professionals should use valid measuring instruments to assess the cognitive state of the care recipient and indicate if they were eligible to participate.

In order to assess if a care recipient was eligible to participate, the Minimal Mental State Examination (MMSE) was standardly conducted by Dementia casemanagers (Woodford & George, 2007). General practitioners and physicians used the Groninger Frailty Index (GFI) and medical records of the patient to assess the cognitive condition of the care recipient. In general, the professionals were instructed to use their own preferred assessment methods to select the participants. The clinical reasoning process and test results of the care recipient were unknown to the researchers, since every professional has their own preferred assessment methods and this research was anonymously conducted.

3.3 Data Collection and Procedures

Questionnaires were used to collect the data. The questionnaires were created by a multidisciplinary team. This team consisted of members of the pilot organisations and the developers of the treatment passport. Two kinds of questionnaires were created:

1. The questionnaire for the perspective of **care professionals**: This questionnaire contained 17 questions, of which 12 were open-ended and 5 were closed.
2. The questionnaire for the perspective of **care recipient**: This questionnaire contained 20 questions, of which 9 were open-ended and the remaining 11 questions were closed.

Both questionnaires contained a combination of open-ended questions and categorical questions. A number of the open-ended questions enquired the participants to describe their personal perspective and experiences regarding usage of the treatment passport (Maxwell, 2008; Stockemer, 2019). In the questionnaire for both the care professionals and care recipients, a number of key concepts were addressed. For example, if the treatment passport contributed to improve or enhance the thinking process for the next phases of life, if the passport was applicable to initiate conversations about treatment wishes and preferences and if the passport was user-friendly. The categorical and closed questions aimed to acquire factual and demographic information from the professionals, like: discipline, working area and if they conducted conversations with their patients about the last phases of life (Maxwell, 2008; Stockemer, 2019). The care recipients were asked to provide their age, residence, illness (if applicable), date of receiving the treatment passport and if the treatment passport was a suitable tool for them. The categorical data were used to draw numbers and percentages regarding the participants' findings. For example, the amount of participants that indicated that the treatment passport had beneficial values for them. No scales or scoring methods were used in the questionnaires (consult Appendices 1 and 2 for the complete questionnaires). Although most questions in the survey aimed to gain insight into the experiences of using the treatment passports, several questions asked information that was not relevant for the study. For example, questions regarding where the treatment passport was stored by the care recipients or where the professional registered the information. In order to adequately answer the research questions of this study, a specific set of questions were selected, analysed and used to describe the results. Table 2. presents the selected questions. Selecting the questions was discussed and in consent with the involved pilot organisations.

Table 2. Selected open and closed questions.

Selected open-ended questions for care professionals

1. Is there, in your opinion, an adding value of the treatment passport for your patients?
2. In which way did the treatment passport help you to start the conversation with the patient regarding treatment wishes?
3. Do you have an advice for your colleagues regarding handing out the treatment passport?
4. Would you like to continue the use of the treatment passport yourself? Please provide an explanation.

Selected closed questions for the care professionals

1. To which groups of patients do you hand out the treatment passport?
2. Do you conduct conversations when handing out the treatment passport?
3. Do you feel qualified to conduct the conversations this theme/treatment passport and the distribution of this?
4. Did handing out the treatment passport provide reasons for follow-up conversations with the care recipient?
5. Did the care recipient share information from the treatment passport with you as professional?
6. Would you like to continue the use of the treatment passport yourself?

Selected open-ended questions for care recipients

1. Does the treatment passport have adding values for you? Please provide an explanation
2. Did the treatment passport help you to think about treatment wishes?
3. Would you recommend the treatment passport to other persons?
4. Do you miss certain aspects in the treatment passport or would you like to change certain things?

Selected closed questions for care recipients

1. Does the treatment passport have adding values for you?
 2. Would you recommend the treatment passport to other persons?
 3. Did the treatment passport help you to think about treatment wishes?
 4. Have you ever documented or discussed the information before?
 5. After receiving the treatment passport, did you (already) talk to someone about this topic?
-

The pilot organisations distributed the treatment passports and questionnaires to the care professionals that were invited to participate. Thereafter, the care professionals allocated the treatment passport to eligible care recipients. During a period of three to four weeks, the care recipients were asked to write down their wishes and preferences in the passport. When the care recipient had gained experience with the usage of the treatment passport, the care professional invited the care recipient to have a conversation regarding their preferences and wishes. During the conversation, the care recipient was given a questionnaire and was asked to voluntarily fill in this questionnaire. Then, the completed form was returned to the Palliative Care Network or Dementia Support Network by e-mail or postal service. It is important to emphasize that the patient can be aided by family or trusted persons when completing the treatment passport and questionnaires. The total amount of returned questionnaires depended on the response rate of the care recipients, since completing the questionnaire and using the treatment passport was on full voluntary basis. Figure 4. illustrates the distribution and returning of the passports and questionnaires.

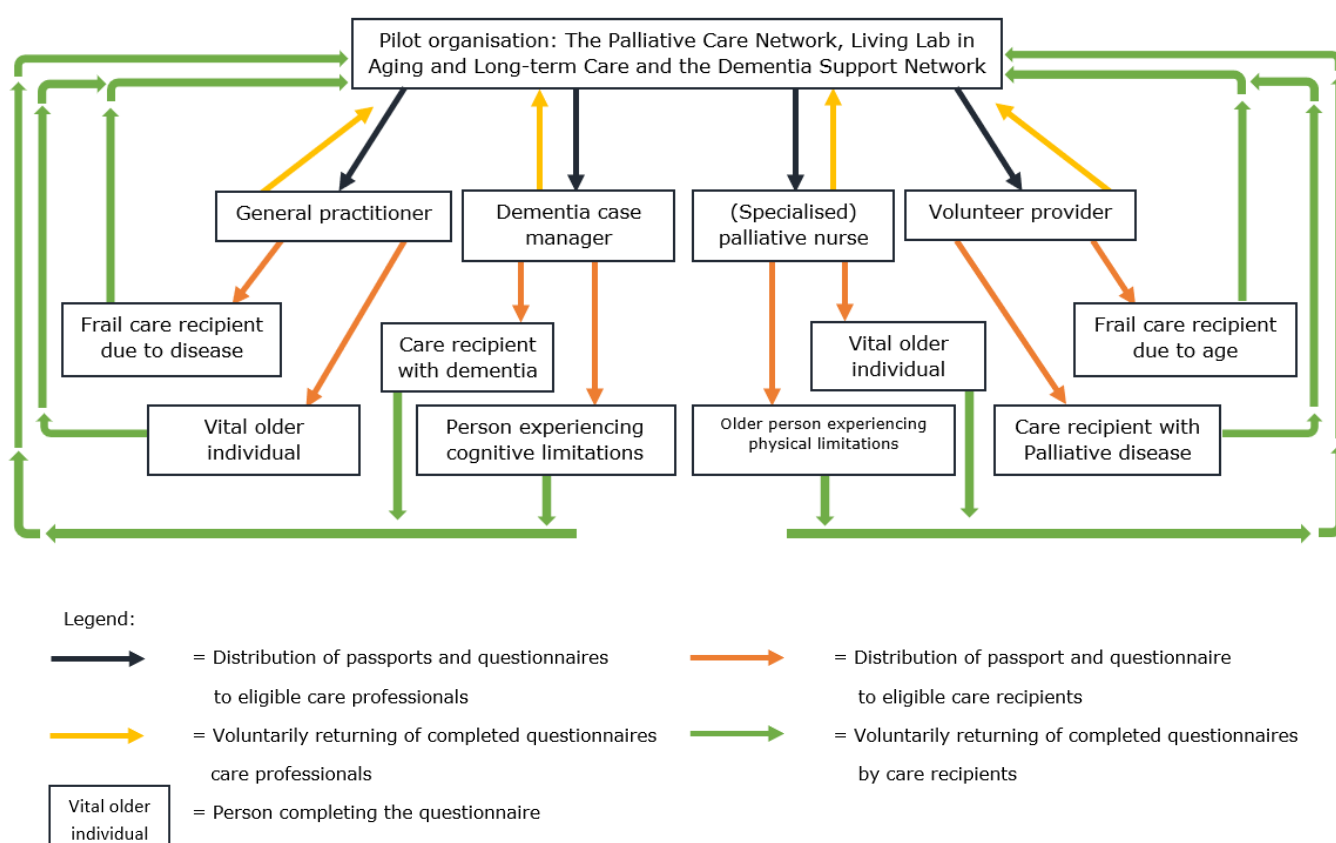


Figure 4. Visualisation of possible passport and questionnaire distribution among care professionals.

3.4 Data Analysis

Directed Content Analysis (DCA) was used to analyse the qualitative data (Hsieh & Shannon, 2005). In DCA-analysis, the collected data is combined with the existing theories and frameworks (Hsieh & Shannon, 2005). Thus, the results from the analysis were deductively coupled to the existing information and literature of ACP, SDM and other relevant information. The first step of DCA-analysis entailed an inductive approach. The qualitative data from the respondents were used to create open codes, which indicated important aspects in the compiled data (Hsieh & Shannon, 2005; Mortelmans, 2017). Then, axial coding was executed to merge open codes consisting of common important topics (Mortelmans, 2017). The last step was to use selective coding to interconnect the most important axial codes with the existing theories and literature (Mortelmans, 2017). Figure 5. visualises the steps of the coding process. With this approach, the information was structurally analysed and coupled to the already-existing information. (Hsieh & Shannon, 2005). NVivo software was used to organise the data and to code important topics, which subsequently were used to describe the results. Quantitative information was organised using an Excel spreadsheet, in which categorical and quantitative information was analysed and visualised.

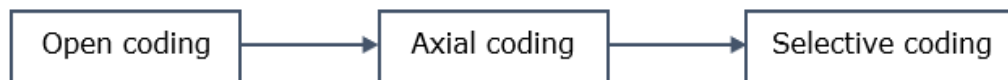


Figure 5. Schematic coding process.

3.5 Reliability & Validity

Being able to reproduce the conducted research is one of the most important aspects to ensure reliability (Heale & Twycross, 2015). To increase the reproducibility of the study, sampling criteria were established for both the professionals and the care recipients. Furthermore, to ensure that data from the returned questionnaires is trustworthy, critical assessment of the care recipient's cognitive condition was required with the use of clinical reasoning of the professional. However, the clinical reasoning process was not transparent for the researchers. During the data analysis phase of the research, triangulation has been applied (Carter, Bryant-Lukosius, DiCenso, Blythe & Neville, 2014). The overarching coordinator of the research extensively reviewed the coding methods and provided feedback if certain data needed recoding or clarification. In addition, multiple meetings with all present coordinators from the pilot organisations was conducted. During this session, the analysis was discussed and feedback provided to the primary researcher. Using multiple analysts increased the objectivity of the research and made the coding process and results description more reliable (Heale & Twycross, 2015).

The validity in qualitative research refers to accurately measuring what should be measured so that the research question can be answered (Taherdoost, 2016). To ensure a degree of internal validity in the research, care professionals were provided with a standardised information sheet to inform the care recipient about the usage of the passports. By providing information about the function of the treatment passport, it was clarified how the care recipients can use the passport. With this information, the care recipients can submit the experiences that they had while using the passport in the questionnaires (consult Appendices 3, 4 and 5 for the instruction forms) (Taherdoost, 2016). In addition, during the creation of the questionnaires the internal validity was also taken into regard. The questionnaires were constructed by the coordinators and experts of the Palliative Care Network, the Dementia Support Network, Living Lab for Ageing and Long-Term Care and the initial creator of the treatment passport. During two online group sessions, input and feedback from the involved coordinators and experts were used to construct and critically review the content of the questionnaires (Taherdoost, 2016). The sample group is not specified to a certain disease or age, which makes the study more representative to the whole (older) population, rather than being representative for a specified group of people. Professionals recruited care recipients that they considered eligible, which could lead to an increased inclusion of specific groups of people while other people were less frequently included. For example, Dementia casemanagers recruited more people with dementia than people with other forms of illness. This could have caused a selection bias that might hurdle the external validity of the research (Berk, 1983). Data saturation refers to the point where little or no new information comes from the data in the study (Moser & Korstjens, 2018). By including a large group of professionals, saturation could be more easily recognized in the data.

3.6 Ethical Considerations

All information from this research has been privately stored and transferred throughout the research process. The study does not apply for a permission statement by the Dutch Government, since this study is not eligible for the status of medical research involving humans (Dutch: Niet-WMO) (Overheid Wettenbank, 2021). The FMHLREC-form was submitted, which specifies the relevant ethical considerations regarding participants' safety and information sharing. Additional clarification was required from the board, since it was not clearly defined that this study was anonymous and voluntary for the participants. After clarifying these aspects, the FHML-REC board approved the study. Furthermore, the Dutch law regarding patient safety indicates that research subjects should not be exposed to any forms of harm in not-WMO research (Overheid Wettenbank, 2021). The eligible care recipients were invited to participate in the research by an explanation of their care

provider. At first, the treatment passport was provided as a complementary tool to think about the wishes and preferences they had for healthcare provision. After a period of three to four weeks, the questionnaire was provided. It was explicitly mentioned that filling in the questionnaire was completely voluntary and anonymous. Limited personal data was enquired from the patient, such as age and disease. The questionnaires did not contain any questions or means which could lead to reidentification of the person. To add, the care recipients were able to choose if they wanted to participate and submit their findings. The care recipient could quit completion of the questionnaire without accountability. Instructions for the care recipient were provided to the healthcare professionals with the use of an instruction paper (consult Appendices 3, 4, and 5).

Chapter 4: Results

In total, 30 care professionals and 80 care recipients completed and submitted the questionnaires. The chapter is divided into two sections. First, the results from the perspective of the care givers are discussed. Thereafter, the results of the care recipients are given. In order to establish a structure in the result sections, a coding tree was made (consult Appendix 6 and 7 for the Dutch coding trees of the professionals and care recipients). In addition, relevant quantitative information is visualised in the results.

4.1 Results of the Care Professionals

The results of the care professionals are divided into six themes. Table 3. provides demographic details about the participants.

Table 3. Demographic information of the care professionals.

Demographic categories	N	Percentage
Gender		
Male	4	13,3%
Female	26	86,7%
Discipline		
Dementia Casemanager	25	83,4%
Practice assistant GP	1	3,3%
District nurse or home care nurse	1	3,3%
General practitioner	3	10,0%

Theme 1: The process of using the treatment passport

From the perspective of the care professional, usage of the treatment passport was accompanied with a number of steps that needed to be taken. For example, the process of carefully selecting care recipients and communicating with them so that their stated preferences can updated and evaluated. Since ACP is a continuous process, these aspects were from importance to optimise the usage of the treatment passport. Three subtopics are described.

I use the treatment passport for specific groups of people

Several care professionals not only provided the passport to persons with an illness, but also used it with older persons that were in a vital condition. They used the treatment passport for care recipients that have beginning stages of Dementia or other forms of frailty. Another professional said that the treatment passport is not only applicable for

patients in the last phases of life, but more for vital groups of people. Figure 6 illustrates for which situations the professionals handed out the treatment passport.

"I should not only give the passport to patients in the last phases of life."

"Use the passport for frail older people or other vulnerable groups."

"Use the passport for clients that have beginning Dementia and where there is little to no suspiciousness."

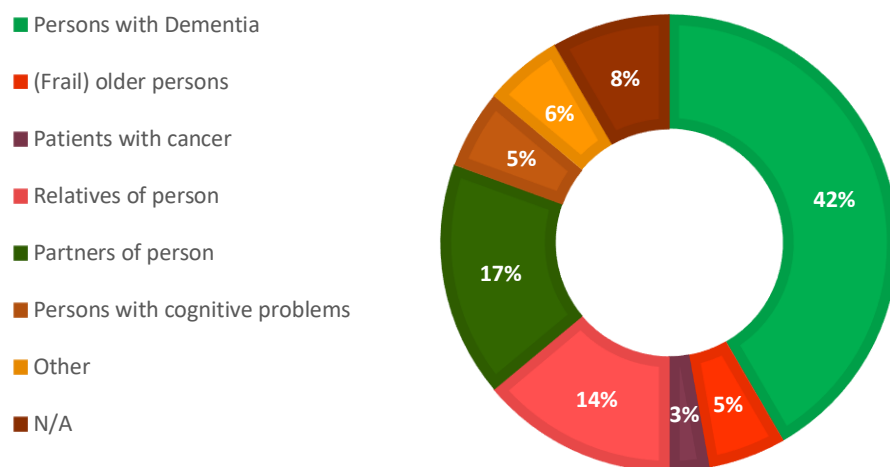


Figure 6. Groups to which the treatment passport was handed out by professionals (N=30).

Openness for using the passport

Care professionals indicated that the treatment passport is not suitable for every patient or care recipient. Instead, it should be carefully assessed if care recipients are ready to use it. Several professionals stated that the relationship between professional and care recipient must be strong and trustful in order to investigate if the treatment passport is a suitable tool for the care recipient to. Thus, the passport could be provided to care recipients that trust their caregivers and relatives in the care process. Furthermore, it was indicated that the introduction of the treatment passport to the patient required large amounts of time. It should be introduced with different conversations, in which the professional carefully assesses if the care recipient and relatives are open to talk about the EOL and treatment wishes.

"You firstly need to know the persons and build up trust."

"First investigate if the client/family is open for the topic."

"It is not about giving the passport, but about the conversation that comes with it"

Professionals said that, even though the treatment passport might facilitate the thinking process of the care recipient about EOL and treatment wishes, it is a sensitive topic and some care recipients do not want to think about EOL.

"I think it is valuable, but I notice that it is a neglected topic. When other problems or things are going on in people's lives, this topic is often denied"

Usage of the treatment passport can be impractical

While the professionals indicated that the treatment passport could have adding values, six professionals provided information about impracticalities surrounding the usage of the treatment passport. One professionals said that the passport is too small, which makes it hard to write things down in the passport. Furthermore, one care provider stated that is sensitive for privacy-related issues. In the treatment passport, people write personal information and their signature. The professionals clarified that the passport could be simply taken or stolen. Other professionals said that their care recipients experienced the passport as an unclear document. Lastly, professionals indicated that some care recipients lose the passport or throw it away, never to be looked at again.

"Yes, a too small format, you have to scribble everything which makes it hard to read"

"It was indicated that it is not completely safe because people can put their signature in the passport, but people can in fact just take the passport"

"No, because for the patients it is too unclear what to do with it"

"No, because the experience is that people throw it in their closet/lose it and do not use it anymore"

Theme 2: The added value of the treatment passport

The majority of the professionals stated that the treatment passport had several beneficial aspects. Topics that emerged from the data mostly described that de treatment passport is practical, small and understandable. Hereafter, the added values are discussed.

Check and evaluate information, wishes and preferences

A number participants stated that the treatment passport can be used as a reference book, in which the care recipient and care professional can check if the wishes that they stated earlier were still correct or do not have to be changed. For example, one professional said that the care recipient can look into the treatment passport at a later stage and evaluate if the information is correct or needs alteration.

'They can later review and reread this with their relatives and helps with the topics to think about'

The tangibility of the treatment passport

Tangibility was regularly discussed by the participating professionals. They stated that the physical aspect of the treatment passport was experienced as very pleasant by the care recipients. Following the tangibility of the treatment passport, a few participants said that the treatment passport was useful for care recipients to carry it with them and help them in dire situations, for example emergencies.

'They find the treatment passport an added value to have something that they can carry along with them'

'Clients like to have something in their hands and see it for themselves'

'Because it is a physical booklet in which preferences can be captured'

'Yes, you provide people with something tangible which they can fall back on'

Practical, clear and handy to use

One of the last added values of the treatment passport was the practical usage. Participating professionals stated that the treatment passport was very clear and compact. This connects to the practical usage of the passport. A number of professionals stated that the passport was handy and pleasant to use. The clarity of the passport was considered another added value. Three care professionals said that the treatment passport provided oversight.

'Yes, because it is practical, all wishes together'

'Yes absolutely, a nice and handy document to discuss together with the patient'

'Very pleasant and clear document to work with'

'The treatment passport makes it less abstract for the client'

The treatment passport provides clarity for professionals and relatives

A few professionals stated that the treatment passport created clarity for the professionals. For example, regarding which treatments a persons want or which not. Other professionals said that the information in the treatment passport also provided clarity for relatives regarding the (treatment)wishes and preferences for the last phases of life.

'Yes, because it is practical, all wishes together. Also for family/medical contacts it is clear what the person wants'.

'It is a nice tool to make their wishes known for themselves, care providers and family'

'Yes, discussing the treatment policies provide the caregivers with the notion that they do not have to decide on these matters alone'

Theme 3: Thinking and talking about the EOL and (treatment)wishes

The first step in ACP-processes is thinking about the EOL. Afterwards, the professional and care recipients can talk about the topic. Five important topics emerged.

Opens a window to think and talk about EOL and (treatment)wishes

The majority of the care professionals indicated that the treatment passport helped the care recipient to think about treatment preferences and wishes. The information in the passport not only provided an opportunity for the care recipient to think about the last phases of life and wishes , but also it opened a window for the professionals to schedule conversations with the care recipient and document the information. A large amount of professionals used the treatment passport to start conversations about the topic. For most professionals, talking about EOL and treatment wishes was considered very important, but sometimes also very hard. The treatment passport provided an opening and reasons to discuss this topic with patients or clients. The majority of the professionals indicated that the treatment passport facilitated the conversations. Figure 7 and 8 provide quantitative information regarding the conversations with care recipients.

'People are given the chance to think about it. Apart from the fact that they want to do anything with it'

'The treatment passport motivates to think about the topic'

'It provides an opening to discuss treatment wishes and wishes regarding the end of life'

'The treatment passport can be an opening for the conversation about the last wishes'

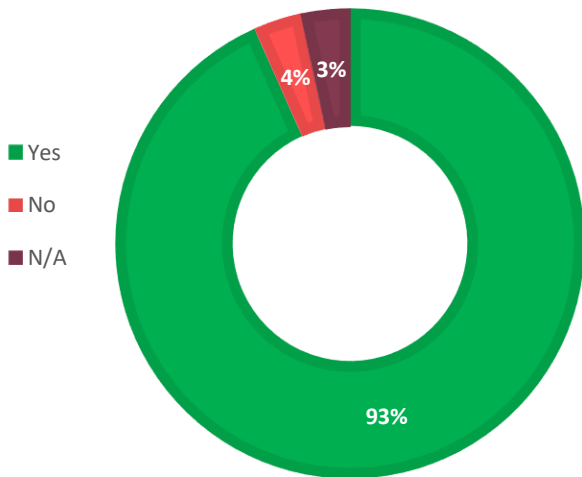


Figure 7. Do you conduct conversations with the care recipient when handing out the treatment passport? (N=30).

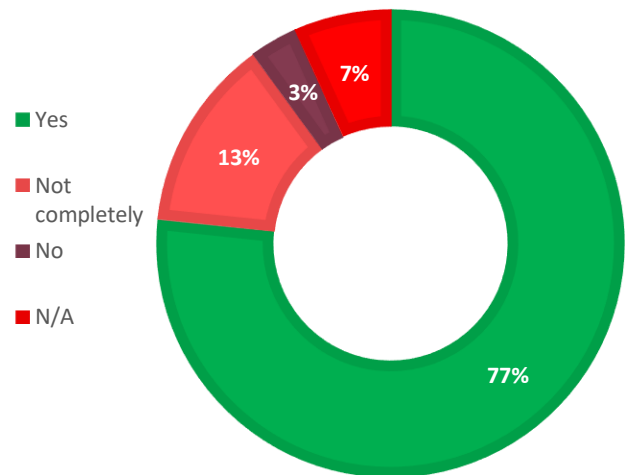


Figure 8. Do you feel qualified to conduct the conversations regarding this theme/treatment passport and the distribution of this? (N=30).

The treatment passport makes it easier talk about EOL with the care recipient
 EOL and palliative care can be sensitive topics. A number of professionals indicated this in the questionnaire. Thus, discussing these topics can be hard. The professionals said that the treatment passport eases the topic and makes it possible to discuss it.

"Yes, it eases the conversation and makes the conversation less loaded"

"It makes the conversation about the topic more easy"

"It has added values for partners who do not dare to start talking about it or when the client does not want to talk about it. Then it is a tool"

The treatment passport helps to structure the conversation

Another important aspect that facilitated conversations was the structure of the treatment passport. The majority of the professionals said that the content and structure of the passport was useful for both the care professionals and care recipients while talking about the topic.

"Yes, it can be a support while conducting the conversation or documenting the conversation"

"It literally provides handles to -after discussing the topic with me- make an appointment with the general practitioner and use the passport for the conversation, so that this also can be documented in the medical dossiers"

The treatment passport was not always the tool for the conversation

While a large amount of professionals saw the treatment passport as a facilitating tool for having conversations, others answered that the treatment passport was not from added value during the conversation. Mostly because they had their own structure for the conversation or because their client or patients already had these kinds of conversations with the general practitioner or Dementia casemanager. Figure 9 indicates that follow-up conversations regularly happened with the use of the treatment passport, while Figure 10 states that more than fifty percent of the care professionals indicates that the care receiver did not share information from the treatment passport (yet).

'The treatment passport did not provide help for the conversation''

'I also heard that they discussed and documented everything with their Dementia casemanager and general practitioner''

'I already started the conversation with clients and relatives about treatment wishes and the importance of documenting this''

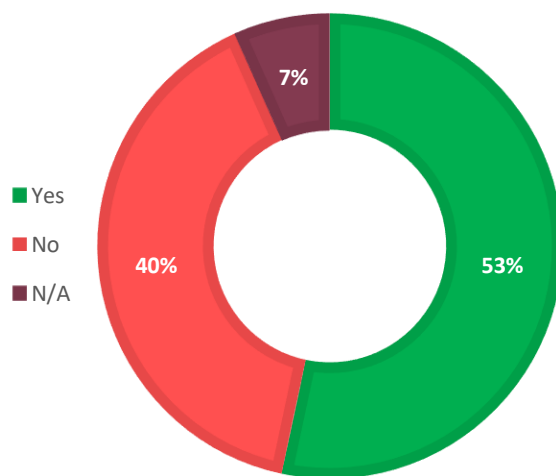


Figure 9. Did handing out the treatment passport provide reasons for follow-up conversations with the care recipient? (N=30).

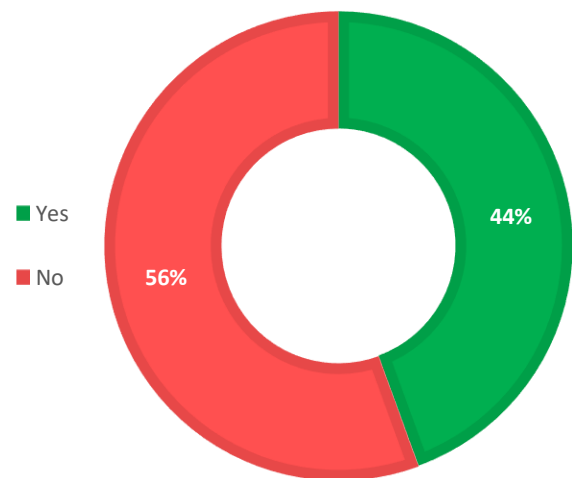


Figure 10. Did the care recipient share information from the treatment passport with you as professional? (N=30).

Theme 4: Documenting (treatment)wishes with the treatment passport

Thinking and talking about the EOL and (treatment) wishes are two subsequent steps that ultimately result in the documentation of these wishes and preferences. Therefore, the next results focus on the documentation and decision-making with the use of the treatment passport. Figure 9 says that approximately half of the respondents stated that the treatment passport provided the opportunity for follow-up conversations, in which it was possible to document information or make wishes known. On the other hand, a number of professionals said that the documentation has already been done without the treatment passport.

A tool to document (treatment)wishes and preferences

A number of professionals provided information regarding the decision-making and documentation processes. Namely, that the treatment passport is a suitable tool to facilitate decision-making and write these choices down in the passport. When the information is written down in the treatment passport, it could also provide a structure for conversations, which was an important topic from the perspective of the professional.

'It literally provides handles to -after discussing the topic with me- make an appointment with the general practitioner and use the passport for the conversation, so that this also can be documented in the medical dossiers'

'Because the added value for the client is to clarify their wishes and to prepare themselves for an ACP-conversation with the general practitioner'

Information transfer between professionals

Transferring information from the treatment passport to the involved care professionals was indicated as another important process-based topic. The general practitioner is responsible for documenting the patient's treatment preferences and wishes in the will of the care recipient. Therefore, a number of professionals stated that the general practitioner should be closely involved in the process of decision-making and documenting the stated information from in the treatment passport into a declaration of will or euthanasia statement.

'Eventually, these things have to be documented by the general practitioner. It is more clear for the clients as well when the initiative to think about the topic comes from there.'

Clients and patients already documented their information

Four participating professionals have patients or clients who already documented the (treatment)wishes and preferences in a declaration of will or euthanasia declaration.

'The information was already documented at several places''

'There were people who have arranged this themselves''

'The clients approached by me do not see the values from it. The ones that were really interested often have a life statement or have spoken with family/caregivers an general practitioners often as well''

To close the result section of the care professionals, the participants were enquired if they wanted to continue the use of the treatment passport in the future. More than fifty percent wants to keep using the passport.

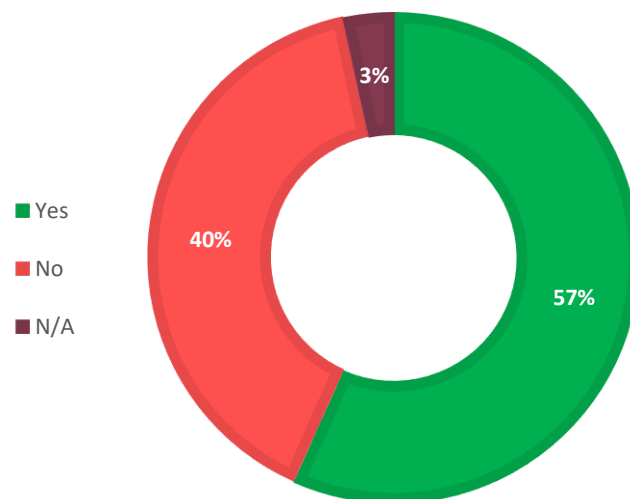


Figure 11. Would you like to continue to use the treatment passport yourself? (N=30).

4.2 Results of the Care Recipients

Both the perspective of the care professional and care recipient are from importance in this study. Therefore the qualitative and quantitative data from the sample of care recipients was analysed as well. Table 4. provides a demographic oversight of the included participants.

Table 4. Demographic information of the care recipients.

Demographic categories	N	Percentage
Gender		
Male	28	35,0%
Female	52	65,0%
Age		
Mean age	75.3	
Highest age	93	
Lowest age	59	
Disease		
Yes	52	65,0%
No	28	35,0%
Living situation		
Living alone	27	33,8%
Living with others	53	66,2%
Total	80	

Theme 1: The added value of the treatment passport

From the perspective of the care recipient, usage of the treatment passport entailed several added values.

The treatment passport is clear and practical

Several participants indicated that the treatment passport is clear and simple. In addition, the care recipients find it pleasant that the document was compact. Figure 12. and 13. provide a quantitative illustration regarding the added value of the passport and if the added values related to the recommendation of the treatment passport.

"Handy, practical and clear"

"Everything in a nutshell, easy to use"

"A clear document"

The treatment passport helps me to check my information

Just as a number of professionals indicated, two care recipients also stated that the treatment passport was useful to check and confirm the information that they stated in a declaration of will or an euthanasia declaration.

"To check the things that were described at my notary"

"It confirmed what I already wanted"

The treatment passport provides me with insight into the treatment options

A number of care recipients found the passport an added value in terms of insight into the treatment options that are available and which choices the care recipient can make.

"Important information for orientating on the topic"

"More insight into possibilities that are available"

"Which choices are available"

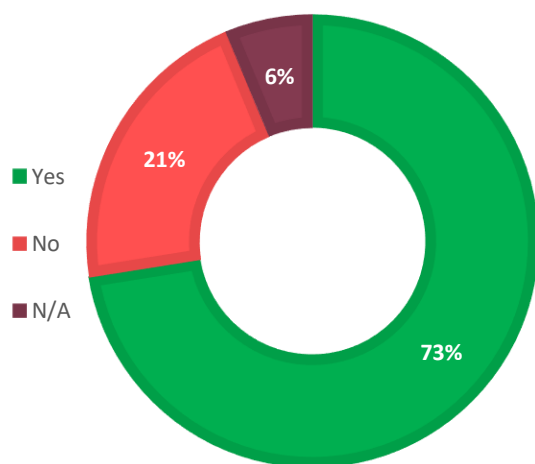


Figure 12. Does the treatment passport have adding values for you? (N=80).

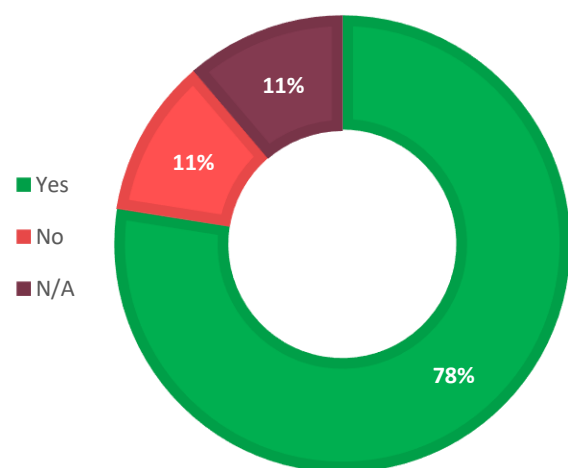


Figure 13. Would you recommend the treatment passport to other persons? (N=80).

Theme 2: Thinking about the topic and (treatment)wishes

A large group of care recipients that participated said that thinking about the EOL and treatment wishes was very important for them. The acquired data indicated that the care recipients find the treatment passport a helpful tool to think about these topics. Moreover, the majority of the participants said that this is an important topic to think about while it is still possible. Figure 14. indicates that the treatment passport helped to think about the treatment wishes and EOL. On the other hand, a number of persons stated that they do not want to think about it yet.

The passport is a tool for me to think about my (treatment) wishes and future

The majority of the participants said that the treatment passport was a tool for them to think about their own treatment wishes. The passport was helpful to become more conscious about these choices and take responsible decisions. Thinking about treatment

wishes is one of the most frequent codes to be assigned to the qualitative data of the care recipients. Some care recipients stated that the passport helped to think about how they wanted to continue in life or how they want their future to look like.

"It provides insight and something to think about"

"It triggers to think about the future"

"You start thinking about it work towards something"

I think EOL and (treatment) wishes is an important topic to think about

A third group of participants indicated that they find the topic important to think about. Circa ten persons stated the treatment passport helped to think about the importance of the topic.

"It is important at our age"

"It is practical and important information"

"Important to think about"

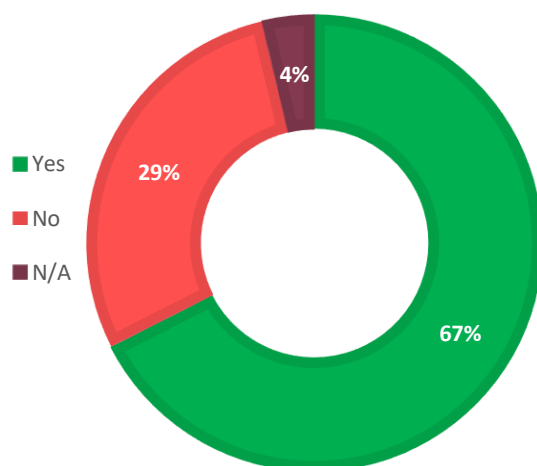


Figure 14. Did the treatment passport help you to think about treatment wishes? (N=80).

I do not need or want to think about this topic yet

While a large number of participant said that the treatment passport was a tool to think about the EOL or (treatment) wishes, another group of persons stated that the treatment passport was not from value in the thinking process. Mostly because persons were not ready to talk or think about it, or because their medical situation is currently good. One care recipients explained that there were treatment options missing in the treatment passport. The participant said that he/she could not think about the topic adequately and that therefore, the treatment passport did not provide added value.

'At this moment I am healthy and do not want to be concerned with this topic'

'It did not completely help me. I specifically miss the topic about Dementia. That would be an exception for me to discontinue living'

I already thought about the topic

Some participants indicated that the treatment passport did not provide added values when thinking about the topic. This was mostly the case because people already thought about the topic before the treatment passport was introduced.

'I already thought about it and will keep thinking about it'

'This has been thoroughly discussed and thought about'

Theme 3: A tool to stimulate conversations about the topic and (treatment) wishes

Having conversations was another important topic that emerged from the data. Participants thought that the treatment passport was a tool to talk about the treatment wishes. The treatment passport plays a role in the clarification of the wishes towards relatives and professionals. This was one of the most frequently coded pieces of information found in the qualitative data. Figure 15. illustrates that almost fifty percent of the participants already talked about the topic or documented the information without the use of the treatment passport. On the other hand, Figure 16. states that the majority of the care recipients indicated that they have talked to a care professional or relative after receiving the treatment passport.

The treatment passport helped me to talk about my (treatment) wishes and make my wishes known

Some participants explained that the treatment passport helped them to talk about their treatment wishes with relatives or their care professional. The majority of participant stated that the treatment passport was a suitable tool to make their wishes known to their family and care professionals. From the data it became clear that the care recipients used the treatment passports to express their choices. Making the (treatment) wishes known was the most frequent occurring open code that emerged from the data.

'My wishes are known when I cannot indicate them myself anymore'

'After this conversation I have chosen my treatment wishes'

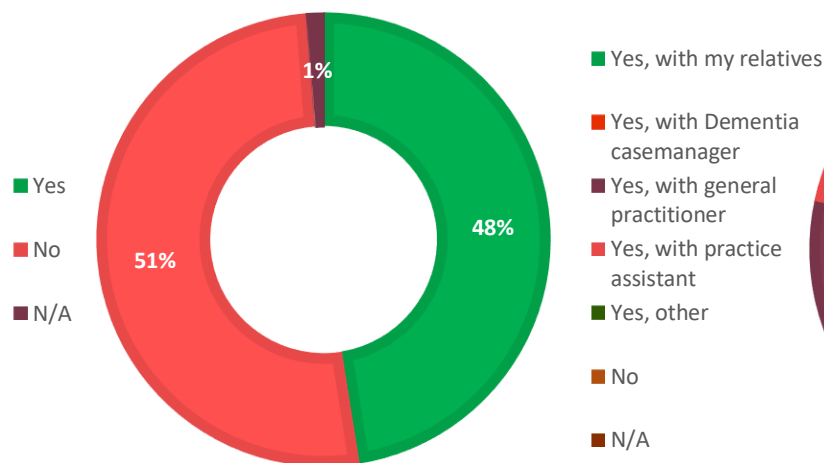


Figure 15. Have you ever documented or discussed the information before? (N=80).

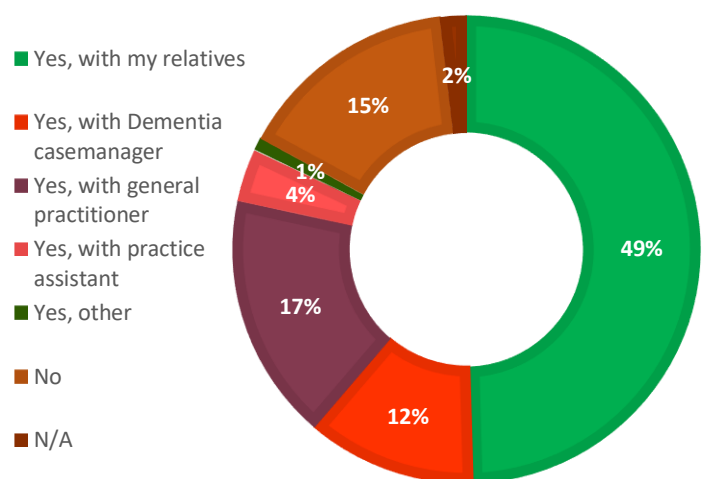


Figure 16. After receiving the treatment passport, did you (already) talk to someone about this topic? (N=80).

It gives me peace that my (treatment) wishes are shared and documented

Within the topic of creating clarity regarding (treatment) wishes, eight participants stated that sharing and documentation of the information provided peace and rest.

"It is a nice feeling to know that your wishes are documented"

"It provides some clarity/peace that it is put on paper"

The treatment passport provides clarity for myself regarding (treatment) wishes

While the passport provides peace for certain care recipients, it also provides them with structure for themselves. It is known to persons and relatives what will happen to them in the future or what they will have to do in the future. One participant stated that he has to take care of his wife when something happens. This is also a form of clarity for the persons.

"Clarity in the process"

"Clear indications of what I want"

The passport provides clarity for relatives and professionals about my (treatment) wishes

The majority of the participants indicated that the treatment passport was useful to create a concrete image regarding (treatment) wishes for the relatives and professionals. In the passport, the care recipient stated information that could be of importance for the decision making by family, relatives and professionals in the last phases of life.

'I can indicate what I want towards my family''

'Yes! To fulfil my wishes and save my family from difficult decisions''

'If something acute happens, it is known what I want''

'Clear decisions for the people who have to make decisions''

I already talked about my (treatment) wishes

Several care recipients responded that they have already talked to someone about the wishes and preferences. Figure 15. indicates that almost half of the participants already talked about (treatment) wishes and the EOL. Often it was said that the care recipients already documented the information the same way as they talked about it. Most persons indicated that they have already documented their wishes in a declaration of life or euthanasia statement.

'I thought and expressed this already many years ago''

'I already talked about it with my general practitioner in an euthanasia statement''

'My treatment wishes are already documented in a will and life statement''

Theme 4: Disadvantages of the treatment passport

A small amount of care recipients said that the treatment passport had some disadvantages. One person said that it was sensitive to privacy issues. Another person said that the treatment passport was not clear. Lastly, one participant stated the passport was unpractical to carry.

'I do not understand it at all''

'And always carry that passport with me? I do not like that. How do I accomplish that?''

4.3 Comparison of the Sample Populations

From the data of both the care professionals and care recipients, three themes emerged that shared common grounds. These themes were about the added values of the treatment passport and thinking and discussing about the EOL and (treatment) wishes. Firstly, more than half of both sample groups found the treatment passport a practical document to work with and additionally would like to continue to use it for the conversations and to facilitate the thinking process. Both groups indicated that the content and structure of treatment passport provided the most support during the thinking and talking processes. Talking about the EOL was experienced as a difficult task. The passport gave a reason to talk about the topic and structure this conversation.

Thinking and talking about EOL and (treatment) wishes eventually could lead to the documentation of the wishes and preferences. The documentation phase was experienced different for care recipients than for care professionals. From the perspective of the care recipient, the conversation about the treatment wishes (with the use of the treatment passport) was a way to document these preferences and wishes. For example, during a conversation with the Dementia casemanager, the care recipients made their wishes known and could be documented during this exact moment. However, a number of professionals indicated that the documentation of wishes and preferences should happen at the general practitioner, since they mostly have (official) documents, for instance an euthanasia statement.

Continuing the usage of the treatment passport was another difference that emerged from the quantitative data. The majorities of both care recipients and care professional said that they wanted to continue the use of the treatment passport, but there are differences in the amounts of participants who want to keep using the passport. Figure 11. indicated that 57% of the professionals want to continue using the passport while 40% does not want to keep using it. The care recipients were more positive about the usage of the treatment passport: Figure 12. illustrated that 73% of the care recipients found the passport having added values. Similarly, Figure 13. stated that 78% percent would recommend the treatment passport to others. This could mean that approximately 20-30% would not like to continue using the passport. This might indicate that the care recipients are more likely to keep using the passport than the professionals.

Chapter 5: Discussion

The overall aim of the study was to gain insight into the experiences of the care professionals and care recipient when using the treatment passport during ACP-processes. The majority of the professionals stated that they found it difficult to initiate the conversations about the EOL and that the treatment passport provided an opening to motivate or trigger the care recipient to start thinking and discussing wishes and preferences for EOL. In addition, the treatment passport structured the conversations so that the thoughts, wishes and preferences could be discussed and shared decisions could be made. The simplicity, tangibility and practical usage were experienced as contributing factors to the thinking-, discussing- and documenting processes. Furthermore, professionals indicated that it was important that there was a trustful relationship between the care recipient and the professionals, so that the EOL and (treatment) wishes could be adequately thought about and discussed. While the majority of the participating professionals found the treatment passport from beneficial value during ACP-processes, some said that the passport did not have adding values. This was mainly because some professionals had their own methods or used other tools or that the care recipients already expressed or documented their wishes and preferences for EOL. More than half of the professionals wanted to continue using the passport.

From the viewpoint of the care recipients the content and structure of the treatment passport motivated and helped the care recipients to think about the treatment options that were available, about their own future and about their wishes for EOL. Most care recipients stated that the treatment passport helped to making the (treatment) wishes known to professionals and relatives with the use of the treatment passport. After receiving the treatment passport, more than eighty percent of the care recipients used it to talk about the EOL and (treatment) wishes, while half of the participants already discussed or documented wishes without the passport. This emphasizes that the passport makes the care recipient conscious to rethink or review their (stated) wishes and preferences for EOL. More than sixty percent of the included care recipients said that the passport helped them to think about EOL and (treatment) wishes. On the other hand, some care recipients already discussed or documented their wishes with relatives or professionals. For this group, the treatment passport had limited added values.

The limited functionality of the treatment passport could be (partially) explained by the fact that it is a recently-introduced new tool and by the influences of the COVID-19 situation. The pandemic has severe influences on global healthcare systems (Fadul, Elsayem & Bruera, 2021). To add, people from different kind of ages are increasingly confronted with the consequences of COVID-19 (Heitzman, 2020; Radbruch, Knaul, de Lima, de Joncheere & Bhadelia, 2020). Therefore, more persons already thought, discussed and conducted SDM about their (treatment) wishes and preferences for the EOL (Fadul et al., 2021; Radbruch et al., 2021). This could possibly provide an explanation why the treatment passport had limited adding values for certain care professionals and care recipients.

For the care professionals, the results of the current study indicated that the structure, content and practical use of the treatment passport made it a helpful tool to start and provide structure during the ACP-processes. Literature describes that ACP-processes can be divided into two kinds: systematic and ad hoc approaches (Glaudemans, van Charante, Oosterink & Willems, 2018). These ACP-approaches share some similarities with the treatment passport. During a systematic approach, structured and fixed topics are used to let the care recipient think and discuss the topics of ACP and the EOL (Glaudemans et al., 2018). Ad hoc approaches depend on the situation and needs of the care recipients (Glaudemans et al., 2018). The results indicated that the treatment passport mostly uses a systematic approach since the content and information provided a structure to think, discuss and document the (treatment) wishes for EOL. Our results also showed that the treatment passport structured the thinking-, discussing- and documenting processes during the dynamic and abrupt COVID-19 situation, in which a flexible tool might be important to adequately respond to a person's needs and wishes. Therefore, the passport could also be suitable in an ad hoc approach. Thus, this literature links the treatment passport to ACP by indicating that treatment passport might be integrated in both structured and ad hoc ACP-approaches. The professionals experienced difficulties to initiate the conversations about the topics of EOL and treatment wishes because every person is different and has different needs (Smeenk, Schrijver, van Bavel & van de Laar, 2017). The passport gave the professional the possibility to start a conversation regarding this topic. In the analysis of Bertholet (2020) healthcare professionals also expressed that the treatment passport provided an opening to talk about the topic, which is similar to the findings of our current study (Bertholet 2020). Moreover, Fleuren et al. (2020) indicated it can be of important value that thinking phases and conversations are initiated early in the care process, making the treatment passport a valuable and practical addition to timely start the ACP-processes (Fleuren et al., 2020). From the study of Bertholet (2020) it also

emerged that professionals found the passport practical to bundle all information in one booklet. Other results were that the passport was user-friendly and the tangibility of the passport contributed to the practical usage (Bertholet, 2020). This aligned with the results found in our study. The current research also yielded that the relationship between care professional and care recipients is an important condition to work with the treatment passport. Literature indicates that knowing the care recipient and having a trustworthy relationship is important during palliative care (Bolt, van der Steen, Schols, Zwakhalen, Pieters & Meijers, 2019; Smeenk, et al., 2017; Vanderhaeghen, Bossuyt, Menten & Rober, 2020).

For the care recipients, the treatment passport was also contributing to ACP. Recent literature from Janssen et al. (2020) indicated that tools for thinking, discussing and documenting (treatment) wishes and preferences for EOL should meet specific characteristics and requirements in order to be supportive during the processes of ACP (Janssen et al., 2020). ACP-tools should –among other things– be (1) personalised for the care recipient, (2) presented as a checklist or predefined set of questions, (3) proactively guiding to identify the needs of the patient and (4) need to be functional for both professionals and care recipients (Janssen et al., 2020). There is a linkage between the literature and the results from our research. Namely, the results indicated that treatment passport mostly integrates the aspects of Janssen et al. (2020) into practical usage. For example, the passport provided free space for the care recipient to write down detailed information about EOL and treatment wishes, emphasising that the personal perspectives are central (Fleuren et al., 2020; Janssen et al., 2020). In addition, the care recipients found the content and structure of the passport facilitating to make their wishes known, while professionals found the structure helpful to initiate and guide the ACP-processes. Thus, the passport is a tool that is not only functional for the care recipient, but also for the professionals. This refers back to the aspects that the passport should entail a predefined structure and be functional for both professionals and care recipients (Janssen et al., 2020). Further, older persons or persons with an illness can experience difficulties in expressing their wishes and preferences (Bolt et al. 2019). The results of our study showed that the majority of the care recipients found the simplistic and clear information of the passport supportive to make their wishes known. Evidence suggests that simple language, appealing looks and tangibility can assist palliative care recipients to think and talk about the EOL and (treatment) wishes (Roodbeen, et al., 2020). This might explain that persons who received the passport were motivated to take action regarding ACP. On the other hand, some persons did not understand the goals or content of the passport. It should therefore be mentioned that good communication between the care recipient,

professionals and relatives is a key element in these ACP-processes (Norals & Smith, 2015). The conversation about ACP and the usage of the treatment passport is from utmost importance during the usage of the treatment passport (Fleuren et al., 2020; Hartog & Michl, 2021; Norals & Smith, 2015). From our results it repeatedly became clear that the treatment passport is useful tool for professionals to guide these discussions. Moreover, the EOL and (treatment) wishes were considered very important by the majority of the care recipients. They wanted to timely make their wishes known, not only for themselves, but also for their relatives and professionals. This provided peace and clarity for the future. During the usage of the treatment passport, the care recipients were given the opportunity and structure to think and talk about their wishes, which subsequently can facilitate SDM and helps to conduct ACP (Elwyn et al., 2017).

This study primarily adds to the current body of literature by revealing the experiences that professionals and care recipients had while using the treatment passport in ACP-processes. An earlier study of Bertholet (2020) regarding the treatment passport only addressed the perspective of the care professionals, while this study taken into account both perspectives. When reflecting on the results, it can be seen that more than half of the professionals and care recipients found the treatment passport useful during ACP. However, it should be emphasized not all persons found the passport of added value. Mainly the group of professionals were critical about continuing to use the passport. The experiences were mainly that care recipients did not want to talk about the EOL or already documented their wishes and preferences. In these situations, the passport did not contribute much to the ACP-processes. The same applied for care recipients. Some stated that the passport was of no value because they already documented wishes and preferences. Overall, it can be indicated that the treatment passport can be helpful during ACP, but might have no or limited added value for persons who have already taken action regarding their wishes and preferences for the EOL.

5.1 Strengths and Limitations

The strengths and limitations should be taken into consideration while interpreting the results and concluding from this study. One of the strengths of the research was that a variety of participants were included which makes the study more representative for the total population and reduces the probability of selection biases. The group of care professionals consisted of Dementia casemanagers, general practitioners, nurses etc. In addition, the care recipients were also highly varied, from people with (chronic) diseases to vital older persons. Varying perspectives on the use of the treatment passport were shown, as can be seen in the results. Moreover, due to the large sample size, data saturation in the qualitative data could be identified, which strengthens the

representativeness of the research. To improve the trustworthiness of the research, the coding process was discussed with the organisational and university supervisors. Thereafter, the codes were presented to other involved coordinators and professionals of the passport working group, consisting of the Network Palliative Care and Dementia case coordinators, which provided feedback if applicable.

A possible limitation were the instructions for the professionals to select care recipients that could be included in the study. Limited guidelines or assessment protocols were established for the professionals to assess if the care recipient was able to use the passport. Instead, the professionals could select their own assessment methods and clinical reasoning. For example, the MMSE and GFI were used by physicians and Dementia casemanagers, but for other professionals, no specific guidelines or reasoning methods were selected. While this could cause an inconsistent way of assessing the patient, it is very important that the sampling process did not fully depend on standardized tests only. Every person is different and requires a suitable clinical assessment. Intuitive reasoning is the most important part of a clinical reasoning process and the use of valid measurements is important, but complementary (Pelaccia, Tardif, Tribby & Charlin, 2011). Therefore, by only using valid assessments, an incomplete image of the person and their capabilities might emerge.

A second limitation of the study could be that the treatment passport is a recently-introduced tool and that the effects of the treatment passport were studied on a timespan of approximately two to three months. It could be possible that the given time was too short for professionals and care recipients to fully use the passport. The participants might had to get acquainted with the use of the passport. COVID-19 could have also influenced the current situation. Since an increasing amount of persons might already have documented their wishes for the EOL and treatments, it could give a distorted image of the thoughts and opinions regarding the functionality and usage of the treatment passport.

5.2 Advice for Further Research

Further studies regarding the treatment passport should focus on the experiences of the treatment passport while using it for a longer period of time. For example, a longitudinal study might reveal different outcomes. Cohort studies should be conducted to statistically indicate if the treatment passport improves the thinking, talking and documenting phases of the treatment passport. In addition, there might be a difference in the functionality of the treatment passport for persons who are in a vital condition of life or who are bearing a disease. For instance, the passport can be more suitable for persons with an illness, but this has to be investigated in further research.

5.3 Implications for Practice

The results described several aspects that might make the treatment passport a contributing tool during ACP-practices. For the professionals, the treatment passport gave an opening to talk about the EOL and (treatment) wishes. Starting the thinking- and discussion processes was experienced as a hard task by the professionals. By handing out the treatment passport, thinking and talking about the EOL might be initiated earlier, which could also prevent that wishes and preferences cannot be documented before a person gets limited physically or cognitively. Furthermore, the results also indicated that the clear structure and content of the passport provided guidance for both care professional and care recipient to think and discuss the EOL and (treatment) wishes. The treatment passport mainly functions as a guiding and facilitating tool during ACP-practices. By facilitating the thinking- and discussion phases, more well-considered and timely decisions can be made for the EOL.

5.4 Conclusion

The experiences of care recipients and care professionals were mainly positive regarding the usage of the treatment passport. More than fifty percent of the participants experienced the treatment passport as an added value during ACP. For both groups, the passport provided structure and guidance during ACP-processes. The passport gave an opening to talk about the EOL and the discussion was less weighted. The practical aspects, such as the clarity of the content, the format of the document and that it can reviewed were experienced as pleasant by the participants. Some of the participants did not find the passport of added value. This was mostly because they had their own methods of thinking and talking about (treatment) wishes for the EOL or did not want to think about it. Thinking and talking about the EOL can be difficult and sensitive. Just as ever person is different, so is their way they want to think and talk about the EOL. Therefore, other approaches that are more preferred by a person to discuss the EOL should not be neglected, but encouraged.

References

- Barlow, J. (2017). *Managing innovation in healthcare*. New Jersey, USA: World Scientific.
- Berk, R. A. (1983). An Introduction to sample Selection Bias in Sociological Data. *American Sociological Review*, 48(3), 386-398. Retrieved from <https://www.jstor.org/stable/2095230>
- Bernard, H. R. (2013). *Social research methods: Qualitative and quantitative approaches* (2 ed.). Thousand Oaks, USA: SAGE Publications
- Bertholet, E. (2021). Behandelpaspoort. Retrieved from <https://www.behandelpaspoort.nl/>
- Bertholet, E. (2020). *Evaluatie vragenlijsten ten behoeve van het Behandelpaspoort*. Retrieved from <https://www.behandelpaspoort.nl/wp-content/uploads/Evaluatie-Online-Vragenlijstendef.pdf>
- Bertholet, E. (2020). Het Behandelpaspoort. *Huisarts en Wetenschap*, 63(12), 71. <https://doi.org/10.1007/s1244502009269>
- Bloomer, M., Tan, H., & Lee, S. (2010). End of life care: The importance of advance care planning. *Australian family physician*, 39(10), 734-737. Retrieved from <http://hdl.handle.net/10536/DRO/DU:30081921>
- Bolt, S. R., van der Steen, J. T., Schols, J. M., Zwakhalen, S. M., Pieters, S., & Meijers, J. M.M. (2019). Nursing staff needs in providing palliative care for people with dementia at home or in long-term care facilities: A scoping review. *International journal of nursing studies*, 96, 143-521. <https://doi.org/10.1016/j.ijnurstu.2018.12.011>
- Brinkman-Stoppelenburg, A., Rietjens, J.A.C., & van der Heide, A. (2014). The effects of advance care planning on end-of-life care: A systematic review. *Palliative medicine*, 28(8), 1000-1025. <https://doi.org/10.1177/0269216314526272>
- Brummel-Smith, K., Butler, D., Frieder, M., Gibbs, N., Henry, M., ... & Vladeck, B. C. (2016). Person-centered care: A definition and essential elements. *Journal of the American Geriatrics Society*, 64(1), 15-18. <https://doi.org/10.1111/jgs.13866>
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J. & Neville, J. A. (2014). The Use of Triangulation in Qualitative Research. *Methods and Meanings*, 41(5), 1-3. <https://doi:10.1188/14.ONF.545-547>
- Dy, S.M., & Purnell, T. S. (2011). Key concepts relevant to quality of complex and shared decision-making in health care: A literature review. *Social Science & medicine*, 74(4), 582-587. <https://doi.org/10.1016/j.socscimed.2011.11.015>

- Elwyn, G., Durand, M.A., Song, J., Aarts, J., Barry, P.J., ... & Van der Weijden, T. (2017). A three-talk model for shared decision making: Multistage consultation process. *BMJ*, 359. <https://doi.org/10.1136/bmj.j4891>
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., ... & Barry, M. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal of general internal medicine*, 27(10), 1361-1367. <https://doi.org/10.1007/s11606-012-2077-6>
- Entwistle, V. A., & Watt, I.S. (2006). Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient education and counselling*, 63(3), 268-278. <https://doi.org/10.1016/j.pec.2006.05.002>
- Etikan, I., & Bala, K. (2017). Sampling and sampling methods. *Biometrics & biostatistics International Journal*, 5(6), 215-217. <https://doi.org/10.15406/bbij.2017.05.00149>
- Fadul, N., Elsayem, A. F., & Bruera, E. (2021). Integration of palliative care into COVID-19 pandemic planning. *BMJ supportive & palliative care*, 11(1), 40-44. <http://dx.doi.org/10.1136/bmjspcare-2020-002364>
- Ferguson, T. (2008). E-Patients: How They Can Help Us Heal Healthcare. In K. Birtcher (Ed.), *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care* (pp. 93-150). Sudbury, USA: Jones and Bartlett Publishers.
- Fleuren N., Depla, M. F. I. A., Janssen, D.J.A., Huisman, M., & Hertogh, C.M.P.M. (2020). Underlying goals of advance care planning (ACP): a qualitative analysis of the literature. *BMC Palliative Care*, 19(27), 1-15. <https://doi.org/10.1186/s12904-020-0535-1>
- Glaudemans, J. J., van Charante, E. M., Wind, J., Oosterink, J. J., & Willems, D. L. (2018). Experiences with approaches to advance care planning with older people: a qualitative study among Dutch general practitioners. *BMJ Open*, 8, 1-8. <http://dx.doi.org/10.1136/bmjopen-2018-024762>
- Hartog, C. S., & Michl, S. (2021). Advance care planning in critical care: Potential and requirements. *Medizinische Klinik, Intensivmedizin und Notfallmedizin*, 116(3), 198-204. <https://dio.org/10.1007/s00063-021-00799-z>
- Heale, R., & Twycross, A. (2015). Validity and reliability in quantitative studies. *Evidence-based nursing*, 18(3), 66-67. <http://dx.doi.org/10.1136/eb-2015-102129>
- Hesse-Biber, S. (2015). Mixed methods research: The "thing-ness" problem. *Qualitative Health Research*, 25(6), 775-788. <https://dio.org/10.1177/1049732315580558>
- Heitzman, J. (2020). Impact of COVID-19 pandemic on mental health. *Psychiatr. Pol.*, 54(2), 187-198. <https://doi.org/10.12740/PP/120373>

- Hoving, C., Visser, A., Mullen, P. D., & Van den Borne, B. (2010). A history of patient education by health professionals in Europe and North America: From authority to shared decision making education. *Patient education and counselling*, 78(3), 275-281. <https://doi.org/10.1177/0825859720938583>
- Hudon, C., Fortin, M., Haggerty, J., Loignon, C., Lambert, M., & Poitras, M. E. (2012). Patient-centered care in chronic disease management: A thematic analysis of the literature in family medicine. *Patient education and counselling*, 88(2), 170-176. <https://doi.org/10.1016/j.pec.2012.01.009>
- Hui, D., De La Cruz, M., Mori, M., Parsons, H. A., Kwon, J. H., Torres-Vigil, I., ... & Bruera, E. (2013). Concepts and definitions for "supportive care", "best supportive care", "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Supportive Care in Cancer*, 21(3), 659-685. <https://doi.org/10.1007/s00520-012-1564-y>
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. <https://doi.org/10.1177/1049732305276687>
- Janssen, D. J., Ament, S. M., Boyne, J., Schols, J. M., Rocca, H. P. B. L., Maessen, J. M., & van den Beuken-van Everdingen, M. H. (2020). Characteristics for a tool for timely identification of palliative needs in heart failure: the views of Dutch patients, their families and healthcare professionals. *European Journal of Cardiovascular Nursing*, 19(8), 711-720. <https://doi.org/10.1177/1474515120918962>
- Jimenez, G., Tan, W. S., Virk, A. K., Low, C. K., Car, J., & Ho, A. H. Y. (2018). Overview of systematic reviews of advance care planning: summary of evidence and global lessons. *Journal of Pain and Symptom Management*, 56(3), 436-459. <https://doi.org/10.1016/j.jpainsymman.2018.05.016>
- Joren, C., Veer, A. de, Groot, K. de, Francke, A. (2020). Kwaliteitskader palliatieve zorg goede leidraad voor zorgverleners. Retrieved from <https://www.nivel.nl/nl/publicatie/kwaliteitskader-palliatieve-zorg-goede-leidraad-voor-zorgverleners>
- Kay Frank, R. (2013). Shared decision making and its role in end of life care. *British Journal of Nursing*, 18(10), 612-618. <https://doi.org/10.12968/bjon.2009.18.10.42466>
- Kesmodel, U. S. (2018). Cross-sectional studies - what are they good for? *Acta obstetricia et gynecologica Scandinavica*, 97(4), 388-393. <https://doi.org/10.1111/aogs.13331>

- Kuebler, K. K., Davis, M. P., & Moore, C. D. (2005). *Palliative practices: An interdisciplinary approach*: Elsevier Health sciences.
- Kwaliteitskader palliatieve zorg Nederland, IKNL/Palliactief, 2017.
- Lum, H. D., Brungardt, A., Jordan, S. R., Phimphasone-Brady, P., Schilling, L. M., Lin, C. T., & Kutner, J. S. (2019). Design and implementation of patient portal-based advance care planning tools. *Journal of pain and symptom management*, 57(1), 112-117. <https://doi.org/10.1016/j.jpainsymman.2018.10.500>
- Lum, H. D., Sudore, R. L., & Bekelman, D. B. (2015). Advance care planning in the elderly. *Medical Clinics*, 99(2), 391-403. <https://doi.org/10.1016/j.mcna.2014.11.010>
- Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient education and counselling*, 60(3), 301-312. <https://doi.org/10.1016/j.pec.2005.06.010>
- Maxwell, J. A. (2008). Designing a qualitative study. *The SAGE handbook of Applied Social Research Methods* (2 ed., pp. 214-253): SAGE Publications.
- Mortelmans, D. (2017). Kwalitatieve analyse met NVivo (2 ed.): Acco Leuven/Den Haag
- Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *European Journal of General Practice*, 24(1), 9-18. <https://doi.org/10.1080/13814788.2017.1375091>
- Murad, M. H., Katabi, A., Benkhadra, R., & Montori, V. M. (2018). External validity, generalisability, applicability and directness: a brief primer. *BMJ evidence-based medicine*, 23(1), 17. <https://doi.org/10.1136/ebmed-2017-110800>
- Nassaji, H. (2015). Qualitative and descriptive research: Data type versus data analysis. *Language Teaching Research*, 19(2), 129-132. <https://doi.org/10.1177/1362168815572747>
- Norals, T. E., & Smith, T. J. (2015). Advance care planning discussions: why they should happen, why they Don't, and how we can facilitate the process. *Oncology*, 29(8), 567-567.
- Nyst, E. (2020). *Behandelpaspoort moet patiënt helpen en kosten besparen*. Retrieved from <https://www.medischcontact.nl/nieuws/laatste-nieuws/nieuwsartikel/behandelpaspoort-moet-patient-helpen-en-kosten-besparen-.html>
- Overheid Wettenbank. (2021). Wet medisch-wetenschappelijk onderzoek met mensen. Retrieved from <https://wetten.overheid.nl/BWBR0009408/2020-01-01>

- Pelaccia, T., Tardif, J., Tribby, E., & Charlin, B. (2011). An analysis of clinical reasoning through a recent and comprehensive approach: the dual-process theory. *Medical education online*, 16(1), 1-9. <https://doi.org/10.3402/meo.v16i0.5890>
- Radbruch, L., Knäul, F. M., de Lima, L., de Jongheere, C., & Bhadelia, A. (2020). The key role of palliative care in response to the COVID-19 tsunami of suffering. *The Lancet*, 395(10235), 1467-1469. [https://doi.org/10.1016/S0140-6736\(20\)30964-8](https://doi.org/10.1016/S0140-6736(20)30964-8)
- Reja, M., Naik, J., & Parikh, P. . (2020). COVID-19: Implications for advanced care planning and end-of-life care. *Western Journal of Emergency Medicine*, 21(5), 1046-1047. <https://doi.org/10.5811/westjem.2020.6.48049>
- Rietjens, J. A., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., ... & I. J., Korfage. (2017). Definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care. *The Lancet Oncology*, 18(9), 543-551. [https://doi.org/10.1016/S1470-2045\(17\)30582-X](https://doi.org/10.1016/S1470-2045(17)30582-X)
- RIVM. (2021). Chronische Ziekten. Retrieved from <https://www.rivm.nl/rivm/kennis-en-kunde/expertisevelden/chronische-ziekten>
- Roodbeen, R., Vreke, A., Boland, G., Rademakers, J., van den Muijsenbergh, M., Noordman, J., & van Dulmen, S. (2020). Communication and shared decision-making with patients with limited health literacy; helpful strategies, barriers and suggestions for improvement reported by hospital-based palliative care providers. *PloS ONE*, 15(6), 1-20. <https://doi.org/10.1371/journal.pone.0234926>
- Smeenk, F. W., Schrijver, L. A., van Bavel, H. C., & van de Laar, E. F. (2017). Talking about end-of-life care in a timely manner. *Breathe*, 13(4), 95-102. <https://doi.org/10.1183/20734735.013717>
- Stjernswärd, J., Foley, K. M., & Ferris, F. D. (2007). Integrating palliative care into national policies. *Journal of Pain and Symptom Management*, 33(5), 514-520. <https://doi.org/10.1016/j.jpainsymman.2007.02.031>
- Stockemer, D. (2019). *Quantitative methods for the social sciences: A Practical Introduction with Examples in SPSS and Stata* (1 ed.): Springer International Publishing.
- Taherdoost, H. (2016). Validity and reliability of the research instrument; how to test the validation of a questionnaire/survey in a research. *International Journal of Academic Research in Management*, 5(3), 28-36. <https://dx.doi.org/10.2139/ssrn.3205040>

- Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American journal of evaluation*, 27(2), 237-246.
<https://doi.org/10.1177/1098214005283748>
- Vanderhaeghen, B., Bossuyt, I., Menten, J., & Rober, P. (2020). What is good advance care planning according to hospitalized palliative patients and their families? An explorative study. *Journal of Palliative Care*, 35(4), 236-242.
<https://doi.org/10.1177/0825859720938583>
- Van Oostrom, S. H., Gijzen, R., Stirbu, I., Korevaar, J. C., Schellevis, F. G., Picavet, , & S. J., H., N. (2016). Time Trends in Prevalence of Chronic Diseases and Multimorbidity Not Only due to Aging: Data from General Practices and Health Surveys. *PLoS ONE*, 1-14. <https://doi.org/10.1371/journal.pone.0160264>
- Volksgezondheid en Zorg. (2021). Chronische aandoeningen en Multimorbiditeit. Retrieved from <https://www.volksgezondheidenzorg.info/onderwerp/chronische-aandoeningen-en-multimorbiditeit/cijfers-context/huidige-situatie#definitie--node-wat-een-chronische-aandoening>
- Williams, N. J. (2017). *Defining Shared Values in Patient-Centered Care: A Case Study*. St. John Fisher College.
- Woodford, H. J., & George, J. (2007). Cognitive assessment in the elderly: a review of clinical methods. *QJM: An International Journal of Medicine*, 100(8), 469-484.
<https://doi.org/10.1093/qjmed/hcm051>

Appendix 1: Complete Questionnaire for Healthcare Professionals

Period of January-May 2021

Dear care provider/healthcare professional,

You have indicated to participate in the pilot for the treatment passports. Again, we would like to thank you for your participation. Herewith, we send you a short questionnaire to study if the treatment passports, whether or not in its current form, can contribute to the self-determination of people regarding their treatment preferences, values and wishes.

Please fill out the questions in the form and return it to us by email or the postal service

Thank you in advance!

Demographic information

1) Gender ☐ Man or ☐ Woman ☐ Other

2) Age ... Years

3) Profession

- ☐ General practitioner
- ☐ Practice nurse/assistant of the general practitioner
- ☐ (District) nurse or home care provider
- ☐ Case manager Dementia
- ☐ Otherwise:

4) Work location/ municipality:

Questions regarding the Treatment Passport

5) **How** did you distribute the treatment passports?

a. To which kind of patients;
.....

b. With or without conversation;

.....
.....

6) Is there, in your opinion, a **beneficial value** to the use of the treatment passport? If so, which benefits?

.....
.....

7) In which way did the treatment passport **helped** you to have a conversation with the patient regarding treatment preferences, values or wishes?

.....
.....

8) Do you feel **qualified to have** conversations about this theme/the treatment passport and the distribution of the treatment passport?

- ☐ Yes
- ☐ Not entirely
- ☐ No

9) When a conversation regarding treatment preferences has to be done, **who executes this task** in your practice?

- ☐ General practitioner
- ☐ Practice nurse/assistant of the general practitioner
- ☐ Case manager Dementia
- ☐ Nurse
- ☐ Other:

10) Have you **received and processed** the information from the returned treatment passports in your medical dossiers?

- a. If yes, how did you receive the passports: and how did you process the information:
- b. No

11) Do you have advice for your colleagues **when giving the patient** a treatment passport? (E.g. To whom, at which moment, by whom)

.....
.....
.....

12) Would you **recommend** the treatment passport to other people? Why would you do so? Or why not?

.....
.....

13) Do you **miss anything** in the treatment passport or would you like something to be changed?

☐ Yes, description:

.....
.....

☐ No

14) Do you have **tips/advice** regarding the treatment passport?

.....
.....
.....

Thank you very much for completing this questionnaire

We would like to receive your response via:

Email: ingejochem@mcc-omnes.nl

Appendix 2: Complete Questionnaire for Care Recipients

Period of January-May 2021

Dear Sir/Madam,

Recently, you received a treatment passport from your care provider. This treatment passport offers you the possibility to think about your wishes for the future of your health. In this booklet you can document and show your own wishes and preferences to others.

Currently, we are curious about your opinion about the treatment passports and if you think it is useful to think about health-related decisions.

Therefore we would kindly like to ask you to fill out the next questions and send this questionnaire back to us. You can return this survey by email or postal service, by using the provided envelope. In addition, you can ask the person who gave you the passport to help you to return the questionnaire.

Thank you very much

General questions

- | | |
|--------------------|---|
| 1) I am a | <input type="radio"/> Man
<input type="radio"/> Woman
<input type="radio"/> Other |
| 2) My age is | years |
| 3) I live | <input type="radio"/> With other people
<input type="radio"/> Alone |
| 4) My residence is | |

- 5) I have a disease ☐ No
 ☐ Yes, namely,

Questions regarding the treatment passport

6) **From whom** did you receive the treatment passport?

- ☐ General practitioner
- ☐ Practice nurse/assistant of the general practitioner
- ☐ Casemanager Dementia
- ☐ Nurse
- ☐ Other:

.....

7) Did you find it **logical** that you received the treatment passport from this person?
Or did you expect it from someone different?

- ☐ Yes, I expected it from this person
- ☐ No, I expected that it would be from someone differently, namely:

.....

8) **When** did you receive the treatment passport?

..... (month) (year)

9) Does the treatment passport have **beneficial values** for you?

- ☐ If yes, which;
- ☐ If no, why not;

10) Did the treatment passport **help you** to think about your wishes and preferences regarding treatment?

- ☐ Yes, namely:
- ☐ No, because:

11) Did you formulate treatment wishes or preferences?

- ☐ Yes, namely:
 - ☐ Always all options
 - ☐ Some treatment are no longer necessary
 - ☐ No CPR

- No admission to an intensive care unit
 - Preferably no hospitalization anymore
 - Other, namely:.....
 - No treatment anymore
 - No
- 12) Did you **know** what the different treatment options entailed? (acute aid, CPR, palliative care or sedation) ?
- Yes
 - No; What was new for you?
- 13) Were options **missing** for you?
- If yes, which;.....
 - No
- 14) Have you ever documented or discussed the information **before the current one**?
- O Yes
- And do you currently have other information or opinions?
- What is different than before?
- O No
- 15) After you received the treatment passport, did you discuss the treatment preferences and wishes with **someone**?
- Yes, with:
 - My relatives
 - General practitioner
 - Practice nurse/assistant of the general practitioner
 - Case manager Dementia
 - Other, namely.....
 - No
- 16) If you have not discussed the content of the treatment passport yet, are you **planning to do so**?
- Yes; with.....
 - No; why not:

17) Did you submit the information that you filled out to **a healthcare professional**?

- If yes, to whom?
 - General practitioner
 - Practice nurse/assistant of the general practitioner
 - Case manager Dementia
 - Nurse
 - Other:
- No, why not:

18) Where do you **store** the treatment passport?

- In my bag or purse
- At home,
- Somewhere else, namely:

19) When or **why** did you fill out the treatment passport at this moment?

- Interest, it seems important
- I recently got diagnosed
- On request of others
- Other, namely:

20) Would you **recommend** the treatment passport to others?

If yes, why?.....

If no, why not?.....

21) **Do you miss anything** in the treatment passport or would you like something to be changed?

- Yes, namely:
- No

Thank you very much for your help! We would like to receive the questionnaire via:

Email: ingejochem@mcc-omnes.nl or

Post: Pilot Behandelpaspoort

J. Middelburg, Hulp bij Dementie

Bussiness reply number 4034

6400 VC HEERLEN

Appendix 3: Instruction Form for General Practitioners



Thank you very much for your participation in the pilot for the 'Treatment Passport'!

Besides the advancements for Advance Care Planning (ACP) by healthcare professionals in the regions of south-eastern Limburg and the region of the 'Westelijke Mijnstreek', it has become important to let the civilians take control about their treatment preferences, wishes and values for the last phases of life.

With the Treatment Passport, developed by Esther Bertholet, a tool has become available for civilians to timely think, discuss and document their treatment preferences in the last phases of life. When a civilian or care recipient cannot express his/her own thoughts or wishes anymore, the best prospective medical action can be taken according to the documented information in the Treatment Passport.

Therefore, a pilot of five months has been initiated in January 2021, which consists of the distribution of the Treatment Passports and a questionnaire to inventory the impact of the Treatment Passport from the perspective of the civilian or care recipient. The focus lays on the older population in a vulnerable position, for example due to the burden of disease. In addition, the focus lays on people where the first conversation for the beginning of the palliative phase of life took (recently) place.

What is your role in the pilot?

As general practitioner (and practices) you contribute to the distribution and allocation of the (free-of-charge) Treatment Passports and the questionnaires in the regions of the Mijnstreek. The filled out questionnaires will be collected, processed and analysed at a central organisation of the pilot.

You will receive approximately 10 Treatment Passports and questionnaires to distribute to patients in your own practice between the months of January and May 2021.

As general practitioner, you provide a small, personal instruction to the patient about the usage of the Treatment Passport and questionnaire. Additionally, it provides you with the opportunity to continue the conversation regarding the treatment preferences of the patient. In the period of May, you will receive a short survey where we ask you about the experience that you had with the usage of the Treatment Passport as a professional.

What is the additional value of participating in the pilot for you?

As general practitioner (and GP-practice), you provide input into the research about advancing the process and content of Advance Care Planning, from the perspective of the care recipient.

Furthermore, it provides you with a tool to start the conversation with your patient regarding treatment preferences, wishes and values in the last phases of life.

Naturally, you will receive the results and conclusions from this research, which will be available mid-2021.

Suggestions for instruction to the patient

- Introduce the Treatment Passport and explain that the patient/person will receive it freely, because a national research has been involved in the passports. Thus the person does not have to pay for it. The region of Mijnstreek participates in this research in collaboration with the Palliative Care Network, Living Lab in Aging and Long-term Care Maastricht/Maastricht University and the Dementia Support Network.
- Explain to the client why it is important to timely think about preferences and wishes regarding treatment. By being able to explain this sufficiently, it is possible to maintain your own control in life, even with possible acute situations in the future.

Suggestions after handing out the passport

- Try to keep track on the amount of passports that you distributed to specific clients/patient/persons. In addition, try to regularly check if the patient filled out the passport. Or how they fill out the passport.
- Ask the client and (involved family caregiver) to **always** fill out the questionnaire that has been delivered with the passport, even if the passport is only limitedly used or filled out. Also ask the person to return the questionnaire (by postal service or email). All information is from considerable importance for the research. Possibly, provide aid to the client by scanning and emailing the passport when emailing is a difficult task for him/her.

- If you know that the patient has filled out the Treatment Passport, this provides an opportunity to plan a follow-up conversation with the patient regarding the advance care planning. Document all information from this conversation in HIS.

Do you have questions?

You can contact Inge Jochem, chain director of 'Hulp bij Dementie Westelijke Mijnstreek/programme coordinator of 'Ouderenzorg Mijnstreek'. She can be reached by using the telephone number or email address: 06 517 44 388, or via e-mail: ingejochem@mcc-omnes.nl

Appendix 4: Instruction Form for Advisory Nurses & Specialised Palliative Care Nurses



Instruction for distributing Treatment Passports by advisory nurses and specialised palliative care nurses:

Besides the advancements for Advance Care Planning (ACP) by healthcare professionals in the regions of south-eastern Limburg and the region of the 'Westelijke Mijnstreek', it has become important to let the civilians take control about their treatment preferences, wishes and values for the last phases of life.

With the Treatment Passport, developed by Esther Bertholet, a tool has become available for civilians to timely think, discuss and document their treatment preferences in the last phases of life. When a civilian or care recipient cannot express his/her own thoughts or wishes anymore, the best prospective medical action can be taken according to the documented information in the Treatment Passport.

Therefore, a pilot of five months has been initiated in January 2021, which consists of the distribution of the Treatment Passports and a questionnaire to inventory the impact of the Treatment Passport from the perspective of the civilian or care recipient. The focus lays, among other persons, on people with dementia.

As APVZ/VS you contribute to the distribution and allocation of the (free-of-charge) Treatment Passports and the questionnaires in the regions of the Mijnstreek. The completed questionnaires will be collected, processed and analysed at a central organisation of the pilot. You will receive approximately 10 Treatment Passports and questionnaires to distribute to patients in your own caseload between the months of January and May 2021

Suggestions before distribution

- Read through the passport and try to imagine which answers could be given by patients.
- Do you have questions/uncertainties regarding the passport, please call or mail me: 06-30625588/ e.knapen@zuyderland.nl, before distributing the passports.

- Please select patients from your caseload that are still able to answer the questions in the Treatment Passports and questionnaires (optionally with support from trusted persons).
- Prepare your own way how to explain to the client that you are handing out the Treatment Passport to this specific patient.

Suggestions for instruction to the patient

- Introduce the Treatment Passport and explain that the patient/person will receive it freely, because a national research has been involved in the passports. Thus the person does not have to pay for it. The region of Mijnstreek participates in this research in collaboration with the Palliative Care Network, the Living Lab in Aging and Long-term Care Maastricht/Maastricht university and the Dementia Support Network.
- Extensively indicate that the Treatment Passport is a personal "dossier" for the client and family caregiver. The information that is filled out in the passport is **not** automatically documented in the care plan for homecare or patient dossiers from the general practitioner.
- Explain to the client why it is important to timely think about preferences and wishes regarding treatment. By being able to explain this sufficiently, it is possible to maintain your own control in life, even with possible acute situations in the future (optionally, explain, from the perspective of AVPZ/VS, to the person that the passport does not indicate that the end of life is nearing).
- Indicate that the responsibility for well-established communication lays with the client (and involved family caregiver) himself. Again, only filling out the passport does not mean that the information is automatically used to take actions according to the stated information. A suggestion can be: enquire a conversation with the general practitioner to discuss the treatment preferences (with the passport as founding grounds) and continuously carry the passport around, in case of acute hospitalization.

Suggestions after handing out the passport

- Try to keep track on the amount of passports that you distributed to specific clients/patient/persons. In addition, try to regularly check if the patient filled out the passport. Or how they fill out the passport.
- Ask the client and (involved family caregiver) to **always** fill out the questionnaire that has been delivered with the passport, even if the passport is only limitedly used or filled out. Also ask the person to return the questionnaire (by postal service or email). All

information is from considerable importance for the research. Possibly, provide aid to the client by scanning and emailing the passport when emailing is a difficult task for him/her.

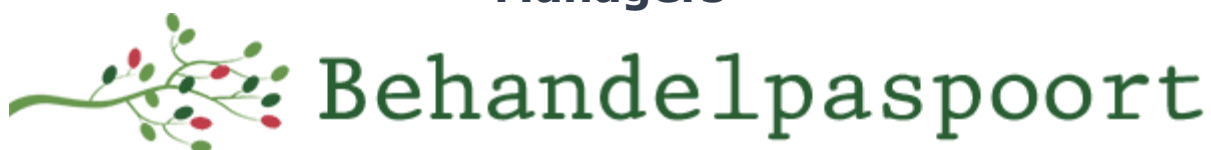
- If you know that the patient has filled out the Treatment Passport, this provides an opportunity to plan a follow-up conversation with you, as AVPZ/VS about advance care planning. Document all information from this conversation in your treatment plan or stimulate/help the client to share this information with the general practitioner.

Do you have questions?

If you have questions about the content or distribution of the passports or the questionnaires, please contact me. (e.knapen@zuyderland.nl / 06-30625588)

For more information about the Treatment Passport: www.behandelpaspoort.nl

Appendix 5: Instruction Form for Dementia Case Managers



Instruction for distributing Treatment Passports by dementia case managers

Besides the advancements for Advance Care Planning (ACP) by healthcare professionals in the regions of south-eastern Limburg and the region of the 'Westelijke Mijnstreek', it has become important to let the civilians take control about their treatment preferences, wishes and values for the last phases of life.

With the Treatment Passport, developed by Esther Bertholet, a tool has become available for civilians to timely think, discuss and document their treatment preferences in the last phases of life. When a civilian or care recipient cannot express his/her own thoughts or wishes anymore, the best prospective medical action can be taken according to the documented information in the Treatment Passport.

Therefore, a pilot of five months has been initiated in January 2021, which consists of the distribution of the Treatment Passports and a questionnaire to inventory the impact of the Treatment Passport from the perspective of the civilian or care recipient. The focus lays, among other persons, on people with a suspicion of/with dementia who live at home.

As dementia case manager you contribute to the distribution and allocation of the (free-of-charge) Treatment Passports and the questionnaires in the regions of the Mijnstreek. The completed questionnaires will be collected, processed and analysed at a central organisation of the pilot.

You will receive approximately 10 Treatment Passports and questionnaires to distribute to patients in your own caseload between the months of January and May 2021.

Suggestions before distribution

- Read through the passport and try to imagine which answers could be given by patients.
- If you have uncertainties, please try to discuss these with your chain director first before distributing the passports..

- Please select patients from your caseload that are still able to answer the questions in the Treatment Passports and questionnaires (optionally with support from trusted persons).
- Prepare your own way how to explain to the client that you are handing out the Treatment Passport to this specific patient.

Suggestions for instruction to the patient

- Introduce the Treatment Passport and explain that the patient/person will receive it freely, because a national research has been involved in the passports. Thus the person does not have to pay for it. The region of Mijnstreek participates in this research in collaboration with the Palliative Care Network, the Living Lab in Aging and Long-term Care Maastricht/Maastricht university and the Dementia Support Network.
- Extensively indicate that the Treatment Passport is a personal "dossier" for the client and family caregiver. The information that is filled out in the passport is **not** automatically documented in the care plan for homecare or patient dossiers from the general practitioner.
- Explain to the client why it is important to timely think about preferences and wishes regarding treatment. By being able to explain this sufficiently, it is possible to maintain your own control in life, even with possible acute situations in the future (optionally, explain, from the perspective of the dementia case manager, to the person that the passport does not indicate that the end of life is nearing).
- Indicate that the responsibility for well-established communication lays with the client (and involved family caregiver) himself. Again, only filling out the passport does not mean that the information is automatically used to take actions according to the stated information. A suggestion can be: enquire a conversation with the general practitioner to discuss the treatment preferences (with the passport as founding grounds) and continuously carry the passport around, in case of acute hospitalization.

Suggestions after handing out the passport

- Try to keep track on the amount of passports that you distributed to specific clients/patient/persons. In addition, try to regularly check if the patient filled out the passport. Or how they fill out the passport.
- Ask the client and (involved family caregiver) to **always** fill out the questionnaire that has been delivered with the passport, even if the passport is only limitedly used or filled out. Also ask the person to return the questionnaire (by postal service or email). All

information is from considerable importance for the research. Possibly, provide aid to the client by scanning and emailing the passport when emailing is a difficult task for him/her.

- If you know that the patient has filled out the Treatment Passport, this provides an opportunity to plan a follow-up conversation with you, as dementia case manager about advance care planning. Document all information from this conversation in your treatment plan or stimulate/help the client to share this information with the general practitioner.

Do you have questions?

If you have questions about the content or distribution of the passports or the questionnaires, please contact Inge Jochem, chain director Hulp bij Dementie Westelijke Mijnstreek/ program coordinator Ouderenzorg Mijnstreek. She can be contacted by phone via: 06 517 44 388, or via e-mail: ingejochem@mcc-omnes.nl

For more information regarding the treatment passport: www.behandelpaspoort.nl

The pilot is a collaboration between the Palliative Care Network Westelijke Mijnstreek en Oostelijk Zuid-Limburg, Burgerkracht Limburg, the Living Lab in Aging and Long-term Care Maastricht, the Dementia Support Network and Esther Bertholet.

Appendix 6: Coding Tree Care Recipient

<i>Axialcode</i>	<i>Open code</i>	<i>Quotes</i>
Nadenken over onderwerpen en behandeling en	Nog niet nodig om erover na te denken	<ul style="list-style-type: none"> • Ik ben momenteel gezond en wil er nog niet mee bezig zijn. • Ik ben er niet mee bezig • Op dit ben ik gezond!! • Ben ik niet mee bezig! • Nog niet nodig • Nog niet over nagedacht, nog niet aan de orde. • Ik ben er nog niet aan toe. • Ben ik niet mee bezig.
	Hulpmiddel voor nadenken behandelwensen	<ul style="list-style-type: none"> • Omtrent behandelwensen • Keuzes maken • In mijn leeftijd zal het moeilijk worden. • Nadenken tot welke keuze het beste is. • Dieper besef voor verantwoorde beslissingen. • Om tot een goede afweging te komen. • Ja, Stemt tot nadenken • Omdat de meeste mensen dan gaan nadenken om later nabestaande te ontlasten • Geeft meer inzicht en iets om over na te denken • Om na te denken over je wensen • Om erover na te denken • Blijven nadenken over de juiste beslissing. • Nadenken welke keuze het beste is. • Stof om na te denken. • Laat me weer nadenken over het leven en dan... • Ter overdenking. • Je gaat er bewust over nadenken en over praten. • Nadenken en vastleggen wat ik wil, duidelijkheid voor mijn familie. • Je wordt gedwongen erover na te denken.

		<ul style="list-style-type: none"> • Je wordt gedwongen na te denken hierover.
	Helpt nadenken over toekomst	<ul style="list-style-type: none"> • We willen het verschuiven maar eens moet je met de waarheid uitkomen. • Hoe ik verder wil. • Bewustwording weer. • Meestal wordt hier niet over gesproken. • Ja, Stemt tot nadenken • Geeft meer inzicht en iets om over na te denken • Je gaat nadenken en werkt naar iets toe • Om erover na te denken • Zet aan tot nadenken over de toekomst • Stof om na te denken. • Laat me weer nadenken over het leven en dan... • Voor de toekomst. • Ter overdenking. • Je gaat er bewust over nadenken en over praten. • Je wordt gedwongen erover na te denken. • Je wordt gedwongen na te denken hierover. • Ja, dan heb ik al een idee voor later. • Iedereen moet tijdig nadenken over zijn eind
	Belangrijk onderwerp	<ul style="list-style-type: none"> • Altijd belangrijk • Wel belangrijk op onze leeftijd • Het is handig en ook belangrijke informatie • Je stelt je eigen vragen • Belangrijk voor de toekomst • Altijd goed om alles te regelen • Belangrijk • Belangrijk • Belangrijk om over na te denken • Toch fijn om er eens over na te denken • Ja, Lijkt me belangrijk.
	Nadenken al gedaan	<ul style="list-style-type: none"> • Dat heb ik al gedaan. • Dat was al duidelijk. • Dat was al duidelijk. • Heb al nagedacht. • Dat deed en doe ik al.

Meerwaarde van gebruik		<ul style="list-style-type: none"> • Hier is goed over nagedacht en besproken. • Zie punt 9, al vele jaren geleden over nagedacht en geuit. • Dit heb ik al eerder gedaan. Was al eerder over nagedacht.
	Overzichtelijk	<ul style="list-style-type: none"> • Handzaam praktisch en overzichtelijk • Duidelijk handig • Het is handig en ook belangrijke informatie • Overzichtelijk document • Alles in een notendop, makkelijk te hanteren • Wordt duidelijk uitgelegd • Alles compact bij elkaar
	Ter controle	<ul style="list-style-type: none"> • Ter controle van datgene wat bij mijn notaris beschreven staat. • Het bevestigt wat ik al eerder wilde.
	Geeft inzicht in behandel mogelijkheden	<ul style="list-style-type: none"> • Over de mogelijkheden die er zijn. • Belangrijke info ter oriëntatie van het thema. • Dieper besef voor verantwoorde beslissingen. • Welke keuzes er zijn • Meestal wordt hier niet over gesproken. • Meer inzicht. • Geeft meer inzicht en iets om over na te denken • Meer inzicht en mogelijkheden die er zijn.
Het gesprek aangaan	Hulpmiddel wensen bespreken	<ul style="list-style-type: none"> • Na gesprek met casemanager wel tot behandelwensen kunnen komen. • Ik vind het moeilijk anderen te adviseren • Euthanasie aanvragen moeilijk • Je huisarts inlicht en je wensen toetst aan waar hij voor staat • Als tool om mee te werken vanuit de klankbordgroep • Je gaat er bewust over nadenken en over praten. • Door dit paspoort heb ik dit met mijn zoon besproken. • Met je naasten te bespreken

	<p>Bespreken al gedaan</p>	<ul style="list-style-type: none"> • Wij hebben dit al besproken. • Deze had ik al schriftelijk kenbaar gemaakt bij huisarts en gezinsleden. • Hier is goed over nagedacht en besproken. • Zie punt 9, al vele jaren geleden over nagedacht en geuit. • Heb al met mijn huisarts besproken in euthanasieverklaring. • Alles wat ik met huisarts besproken • Hier is goed over nagedacht en besproken. • Met naasten uitvoerig besproken. <p>Op het moment nog niet, behandelwensen zijn bij naasten bekend.</p>
	<p>Geeft rust</p>	<ul style="list-style-type: none"> • Kan even geruststellend zijn • Geeft een stuk duidelijkheid/rust als het op papier staat • Prettig te weten dat je wensen bekend zijn • Ja, Geeft rust in je hoofd. • Rust als er iets gebeurd • Geruststelling. • Geruststelling. • Het is een fijn gevoel dat mijn wensen op papier staan.
	<p>Duidelijkheid voor naasten</p>	<ul style="list-style-type: none"> • Duidelijkheid over mijn behandelwensen. • Dat ik mijn vrouw moet verzorgen. • Duidelijk. • Door dit paspoort heb ik dit met mijn zoon besproken. • Echtgenoot – bij ernstige lijden en geen uiteinde. • Ik kan duidelijk aangeven wat ik wil, naar de familie toe. • Dan weet iedereen wat je wil • Omdat de meeste mensen dan gaan nadenken om later nabestaande te ontlasten • Duidelijk voor jezelf en naasten • Duidelijkheid

		<ul style="list-style-type: none"> • Omdat ik het belangrijk vind voor nabestaanden • Duidelijkheid voor anderen • Duidelijkheid voor anderen • Voor duidelijkheid naar naasten • Geeft een stuk duidelijkheid/rust als het op papier staat • Is wel gemakkelijk voor de naasten • Dat ook anderen weten wat je wilt • Omdat het belangrijk is voor de nabestaanden • Zo dat anderen ook op de hoogte zijn • T.b.v. naasten • Nabestaanden niet met zoveel vragen komen te staan • Duidelijkheid. • Duidelijkheid. • Dan weten mijn dochters wat ik wil. • Ja! Om mijn wensen te vervullen en mijn nabestaanden moeilijke beslissingen te besparen. • Nadenken en vastleggen wat ik wil, duidelijkheid voor mijn familie. • In geval van nood, meer inzicht. • Gegevens zijn dan bekend. • Stuk zekerheid. • Dan zijn mijn wensen helder als ik deze niet meer zelf kan aangeven. • Als iets acuuts gebeurt dan weet men wat ik wil. • Duidelijkheid voor mijn kinderen.
	Duidelijkheid voor professionals	<ul style="list-style-type: none"> • Duidelijkheid over mijn behandelwensen. • Duidelijk. • Dan weet iedereen wat je wil • Duidelijkheid • Duidelijkheid voor anderen • Duidelijkheid voor anderen • Duidelijke afspraken voor degene die beslissingen moet nemen

		<ul style="list-style-type: none"> • Geeft een stuk duidelijkheid/rust als het op papier staat • Opdat de behandelaar weet wat wij willen • Dan is het duidelijk bij acute zaken • Zo dat anderen ook op de hoogte zijn • Duidelijkheid. • Duidelijkheid. • Dat er duidelijke afspraken staan. • Dat de arts kan zien wat de wensen zijn. • Het staat vast wat ik niet wil. • In geval van nood, meer inzicht. • Gegevens zijn dan bekend. • Dan zijn mijn wensen helder als ik deze niet meer zelf kan aangeven. • Als iets acuuts gebeurd dan weet men wat ik wil. • Dat ik kan aantonen wat er aan de hand is.
	Duidelijkheid voor mijzelf	<ul style="list-style-type: none"> • Duidelijkheid over mijn behandelwensen. • Dat ik mijn vrouw moet verzorgen. • Duidelijk. • Door dit paspoort heb ik dit met mijn zoon besproken. • Ik heb waardig geleefd en wil ook graag waardig sterven. • Als ik in een situatie kom dat ik geen leven zou hebben. • Dan heb ik al een idee voor later. • Duidelijk voor jezelf en naasten • Dat duidelijk is wat je eigen wensen zijn • Duidelijkheid • Geeft een stuk duidelijkheid/rust als het op papier staat • Prettig te weten dat je wensen bekend zijn • Duidelijkheid in proces • Ik heb levenstestament. Hierin niet beschreven wat ik qua behandelingen wel of niet wil • Duidelijkheid.

		<ul style="list-style-type: none"> • Duidelijkheid. • Dat er duidelijke afspraken staan. • Dan weten mijn dochters wat ik wil. • Het staat vast wat ik niet wil. • Ja! Om mijn wensen te vervullen en mijn nabestaanden moeilijke beslissingen te besparen. • Duidelijk aangeven wat ik wil. • Stuk zekerheid. • Nu minder maar waarschijnlijk wel in de toekomst. • In de toekomst • Dat ik kan aantonen wat er aan de hand is.
	Behandelwensen kenbaar maken	<ul style="list-style-type: none"> • Ik kan mijn wensen kenbaar maken. • Ik wil nergens meer aan geholpen worden. • Om op papier te zetten wat ik wil. • Geen reanimatie. • Ziekenhuisopname. • Ik wil nu ik nog gezond ben alle behandelingen ondergaan en hopelijk beter worden mocht ik ziek worden. • Ik heb waardig geleefd en wil ook graag waardig sterven. • Deze heb ik vermeld in de toelichting, wil op dit moment nog altijd alles. • Momenteel wil ik nog alles. • Kan de wensen kenbaar maken • Dat duidelijk is wat je eigen wensen zijn • I.p.v. Euthanasie • Je kunt je eigen grenzen aangeven en de wensen die je hebt • Omdat ieder zijn eigen keuze kan maken • Prettig te weten dat je wensen bekend zijn • Zo liggen mijn wensen vast • Wensen kenbaar maken • Wil kenbaar maken • Lijkt me tijd om de zorg die ik wel/niet wil ontvangen nu (nog) zelf kan bepalen

		<ul style="list-style-type: none"> • Ja, Dan staan je wensen duidelijk op papier. • Het kenbaar maken van eigen wensen • Hierin kan ik mijn behandelplan duidelijk vastleggen • Ik kan aangeven welke behandeling ik nog wil • Ik kan mijn wensen kenbaar maken • Ik kan aangeven welke behandeling ik nog wil • Ik kan aangeven welke behandeling ik nog wil • Ik heb levenstestament. Hierin niet beschreven wat ik qua behandelingen wel of niet wil • Mijn wensen liggen vast • Het staat vast wat ik niet wil. • Ja! Om mijn wensen te vervullen en mijn nabestaanden moeilijke beslissingen te besparen. • Ja, namelijk: Zodat vaststaat wat ik wil. • Kan ik mijn wensen kenbaar maken • Duidelijk aangeven wat ik wil. • Nadenken en vastleggen wat ik wil, duidelijkheid voor mijn familie. • Om mijn eigen wensen vast te leggen. • Om aan te geven wat je wensen zijn. • Wil kenbaar maken. • Dan zijn mijn wensen helder als ik deze niet meer zelf kan aangeven. • Gedeeltelijk en is ook een levenstestament • Mijn wensen worden zo kenbaar gemaakt. • Dat ik kan aantonen wat er aan de hand is. • Het is een fijn gevoel dat mijn wensen op papier staan.
Nadelen Behandel- paspoort	Vastlegging al gedaan	<ul style="list-style-type: none"> • Heb al met mijn huisarts besproken in euthanasieverklaring. • Had ik al gedaan: vastgelegd. • Mijn standpunten staan vast. • Alles was al eerder geregeld. • Zijn reeds vastgelegd. • Ik vind het dubbelop omdat de huisarts al op de hoogte is

		<ul style="list-style-type: none"> • Omdat ik al een wilsverklaring heb liggen bij de huisarts. • Ik heb al alle voorbereidingen al getroffen. • Ik heb een levenstestament. • Alles was al geregeld. • Maar ik heb al een levenstestament. • Heb al een levenstestament. • Mijn behandelwensen liggen reeds vast in wilsverklaring + levenstestament. • Alles als afzonderlijk geregeld, dus dubbel. • Zijn reeds vastgelegd • Gedeeltelijk en is ook een levenstestament
	Nadelen behandelpaspoort	<ul style="list-style-type: none"> • Te privacy gevoelig • Ik heb er totaal geen begrip van. • En dat paspoort altijd bij me hebben? Dat zie ik niet zitten. Hoe dat voor elkaar te krijgen? • Niet helemaal. Mis specifiek het onderdeel dementie. Dat is voor mij de uitzondering om niet verder te willen leven.

Appendix 7: Coding Tree Care Professionals

<i>Axialcode</i>	<i>Open code</i>	<i>Quotes</i>
Procesmatig gebruik behandelaspoot	Inzetten bij doelgroepen	<ul style="list-style-type: none"> • Ik geef niet iedereen zomaar het behandelaspoot. Ik heb de mantelzorger betrokken bij de klanten waarbij ik het heb ingezet. • Aan mezelf, vaker inzetten niet alleen bij de patiënt in laatste levensfase. Surprise question vaker stellen! • Bij kwetsbare ouderen of andere kwetsbare groepen • Bij cliënten met een beginnende dementie waarbij geen of nauwelijks sprake is van achterdocht • Het zou ook fijn zijn voor cliënten in het verzorgingshuis (indicatie zonder behandeling, de bewoners die onder de huisarts blijven vallen). Het is dan fijn als dit in de eerste 6 weken van opname al geïntroduceerd wordt. Bij het inhuizen in de zorgwoningen is het fijn als de wijkverpleegkundige kennis gaat maken en dan een situatieschets maakt. Ook hier zou het fijnst zijn om het behandelaspoot z.s.m. te introduceren.

		<ul style="list-style-type: none"> • Niet voor alle cliënten. Meerwaarde is er met name voor wilsbekwame cliënten, of cliënten met een wilsbekwame partner. Daarnaast heeft het vooral meerwaarde die lichamelijk al iets mankeren. • Persoonlijk denk ik dat het niet veel cliënten/mantelzorgers echt lukt dit Behandelpaspoort goed in te vullen. Zal hierbij altijd ondersteuning bij nodig zijn.
	Inzetten behandelpaspoort tijdens behandelproces of gesprekken	<ul style="list-style-type: none"> • Kijkend naar de cliënten waar wij komen als casemanager dementie is het belangrijk om tijdig een behandelpaspoort uit te delen of wensen te bespreken. • Dat je ruim tijd moet inplannen om het te introduceren • Het is dan fijn als dit in de eerste 6 weken van opname al geïntroduceerd wordt. Bij het inhuizen in de zorgwoningen is het fijn als de wijkverpleegkundige kennis gaat maken en dan een situatieschets maakt. Ook hier zou het fijnst zijn om het behandelpaspoort z.s.m. te introduceren. • Het gaat niet om het uitreiken van het paspoort maar om het gesprek wat er bij hoort.

		<ul style="list-style-type: none"> • Als ik het bespreek wil ik het ook zelf overhandigen. • Nee, omdat ik hiervoor liever ons eigen begeleidingsplan gebruik om het gesprek aan te gaan en de resultaten in te noteren.
	Openheid voor het gebruik	<ul style="list-style-type: none"> • Je dient de klant goed te kennen alvorens je hiermee aan de slag kunt gaan • Denk dat het erg afhankelijk is van de band met de patiënt, de kennis en ervaring. • Casemanagers dementie zijn denk ik juist hiervoor. Nadat het vertrouwen er is en de klant de CMD een beetje beter kent • Niet uitdelen in het traject van vertrouwen winnen • Je moet mensen al kennen en vertrouwen hebben opgebouwd • Onderzoek eerst of client/familie wel openstaat voor het onderwerp

Meerwaarde gebruik	Gebruik behandelpaspoort niet praktisch	<ul style="list-style-type: none"> • Ja, het is veel te klein van formaat, je moet er echt alles in kriebelen waardoor het niet meer goed te lezen is. • Maar ook wordt aangegeven dat het niet helemaal veilig is in de zin dat het wel hun handtekening kunnen zetten onder het paspoort maar dat in feite iedereen die het paspoort in handen kan krijgen • Echter merk ik bij sommige mensen dat ze het overbodig vinden om het paspoort bij zich te dragen. • Nee, want voor de patiënten te onduidelijk wat ermee te moeten doen • Nee, want ervaring is dat mensen het ergens in een kast leggen/kwijt raken en er niets meer mee doen. • Ik vind het aan de hoge kant w.b.t. de kosten
	Ter controle	<ul style="list-style-type: none"> • Ja, omdat mensen dan iets in handen hebben wat ze op een later moment nog eens kunnen inzien. • Het voordeel is wellicht het naslagwerk. • Ze kunnen dit later nog inzien of nalezen met hun naasten en helpt bij de onderwerpen waar ze over na kunnen denken. • Omdat het geeft een hulpmiddel als onderbouwing, naslagwerk

		<p>voor mijn gesprek en een hulpmiddel bij de huisarts als naslagwerk om het gesprek te voeren.</p>
	Tastbaarheid	<ul style="list-style-type: none"> • Doordat het fysiek boekje waarin voorkeuren vastgelegd kunnen worden • Het is fijn om iets tastbaars te kunnen overhandigen en hierbij het gesprek over aan te gaan. • De mensen iets in de hand te geven. • Geeft de mensen iets in de handen waar ze op kunnen terugvallen • Iets 'tastbaars' geven • Je hebt iets fysieks in handen • Cliënten vinden het fijn om iets te zien en vast te houden • Ja, omdat mensen dan iets in handen hebben wat ze op een later moment nog eens kunnen inzien • Het geeft de mensen iets in de handen
	Prettig om bij zich te dragen	<ul style="list-style-type: none"> • Bewaard kan worden in e.v.t. handtas mocht er eens iets onverhoopt gebeuren • Ze vinden het behandelaspaspoort dan wel nog toevoeging om iets te hebben wat ze bij zich kunnen dragen.
	Overzichtelijk document	<ul style="list-style-type: none"> • Zeer fijn en overzichtelijk om mee te werken • Zeker; Mooi en overzichtelijk document

Nadenken en praten over onderwerp en (behandel)wensen		<ul style="list-style-type: none"> • Het behandelpaspoort maakt het minder abstract voor de cliënt.
	Handzaam	<ul style="list-style-type: none"> • Ja, omdat het handig is, alle wensen bij elkaar • Ja, omdat het is een handzaam exemplaar en makkelijk aan te passen bij veranderende gezondheidssituatie. • Ja absoluut, een fijn en handzaam document om samen met de patiënt door te nemen.
	Creëert duidelijkheid voor professionals en familie	<ul style="list-style-type: none"> • Ja, omdat het handig is, alle wensen bij elkaar. Ook voor familie/contactpersoon duidelijk wat klant wilt. Het is een goed hulpmiddel om hun wensen duidelijk te krijgen voor zichzelf en te maken naar behandelaren en familie. • Er wordt meer met de kinderen en mantelzorgers gesproken over de wensen en aversies. Meer duidelijkheid en openheid m.b.t. wensen. • Ja, omdat het handig is, alle wensen bij elkaar. Ook voor familie/contactpersoon duidelijk wat klant wilt • Dat het ook voor kinderen zichtbaar is

	Behandelpaspoort motiveert tot nadenken	<ul style="list-style-type: none"> • Er wordt meer met de kinderen en mantelzorgers gesproken over de wensen en aversies. Meer duidelijkheid en openheid m.b.t. wensen. • Ja, omdat het handig is, alle wensen bij elkaar. Ook voor familie/contactpersoon duidelijk wat klant wilt • Dat het ook voor kinderen zichtbaar is • Ja, het bespreekbaar maken van het behandelbeleid geeft ook mantelzorgers een gevoel van dat zij straks niet alleen hoeven te beslissen. • Het is een goed hulpmiddel om hun wensen duidelijk te krijgen voor zichzelf en te maken naar behandelaren en familie.
	Behandelpaspoort biedt opening voor (ACP) gesprek	<ul style="list-style-type: none"> • Het is fijn om iets tastbaars te kunnen overhandigen en hierbij het gesprek over aan te gaan. • De ingang om advance care zorg bespreekbaar te maken. • Voor mij als casemanager hulpmiddel om het gesprek aan te gaan. • Het is een goed hulpmiddel om het gesprek hierover aan te gaan • Het geeft een ruimte/opening. • Doordat ik het paspoort gaf, kwam het gesprek vanzelf op gang.

	<ul style="list-style-type: none"> • Bij het starten van een ACP-gesprek ondersteund het behandelboekje het gesprek en ik zou er altijd voor kiezen om dit achter te laten bij de patiënt (met uitleg hierover). • Nee, want buiten het gesprek zie ik de meerwaarden niet • Gebruik het als een gespreksopener • Meer openheid om het gesprek hierover aan te gaan • Het biedt een opening om behandelwensen en wensen rondom levenseinde te bespreken. • Het is een meerwaarde omdat het gesprek erover dan meer aan bod komt. • Er ontstaat een gesprek tussen client en mantelzorger. • Behandelpaspoort kan een opening zijn in het gesprek over de laatste wensen. • Nee, ik heb het idee dat het paspoort niet de meerwaarde is maar wel de opening die het in de gesprekken geeft om over het gehele einde met al zijn facetten te praten. • Het geeft ruimte om er over te praten. • Het is een extra reden om het gesprek aan te gaan
--	--

(Behandel)wensen vastleggen	Vergemakkelijkt het gesprek	<ul style="list-style-type: none"> • Het maakt het gesprek wat laagdrempeliger • Het maakt het praten erover makkelijker. • Er wordt meer met de kinderen en mantelzorgers gesproken over de wensen en aversies. Meer duidelijkheid en openheid m.b.t. wensen • Ja, omdat dit het gesprek vergemakkelijkt en minder beladen is • Er ontstaat een gesprek tussen client en mantelzorger. • Het heeft meerwaarde voor partners die het onderwerp niet goed durven aan te kaarten of als client het er niet over wilt hebben. Dan is het een hulp middel.
	Paspoort ondersteund/structureert tijdens gesprek	<ul style="list-style-type: none"> • Door de unanimititeit van het boekje vinden mensen het minder een probleem hierover een gesprek aan te gaan • Onderlegger voor het gesprek • Extra handvat door het boekje stapsgewijs samen te doorlopen, soms in meerdere gesprekken. • Geeft dan een hulpmiddel als het gesprek gevoerd gaat worden. • Omdat het geeft een hulpmiddel als onderbouwing, naslagwerk voor mijn gesprek en een hulpmiddel bij de huisarts als

		<p>naslagwerk om het gesprek te voeren.</p> <ul style="list-style-type: none"> • Ja, omdat de cliënten het fijn vinden als handvat • Ja, omdat meer waarde hulpmiddel voor client om zijn wensen duidelijk te krijgen, zich voor te bereiden op een ACP-gesprek met huisarts. • Ja, omdat het een steun kan zijn bij het voeren en registreren van een gesprek. • Ja, omdat het een hulp middel kan zijn voor mensen om de wensen te bespreken • Daarbij geeft het hun letterlijk handvaten om na mijn gesprek met de huisarts een consult afspraak te maken en het boekje erbij te houden zodat het ook in het medisch dossier wordt vastgelegd. • Ja absoluut, een fijn en handzaam document om samen met de patiënt door te nemen. • Het gesprek wordt gestart en dan komen bepaalde zaken (wensen) boven tafel. • Toen namen we de praktijk over van onze voorganger en kwamen véél mensen hun wilsverklaring/ wensen bespreken met mij • En biedt gespreksstof met naasten • Het heeft mij deels ondersteund
--	--	---

	<p>Behandelpaspoort was niet altijd hulpmiddel</p>	<ul style="list-style-type: none"> • Behandelpaspoort heeft niet geholpen voor gesprek • Behandelpaspoort heeft niet geholpen voor gesprek • Behandelpaspoort heeft niet echt geholpen voor gesprek • Nee, want behandelwensen liggen vaak al bij de huisarts vast en in levenstestament • Anderzijds is het wel iets wat altijd al besproken wordt en waar cliënten goed in begeleid kunnen worden, ook zonder behandelpaspoort. • dat ze gesprekken over o.a. behandelwensen, euthanasie en reanimatie al gevoerd hebben met hun huisarts • Ook hoorde ik terug dat ze toch al alles besproken en geregeld hadden met CMD en huisarts. • Ik ging meestal al in gesprek met cliënten en naasten over behandelwensen en het belang dit vast te leggen. • Anderzijds is het wel iets wat altijd al besproken wordt en waar cliënten goed in begeleid kunnen worden, ook zonder behandelpaspoort. • Vele hebben wel al veel vastliggen bij huisartsen door eerdere gesprekken met casemanager dementie
--	--	--

		<ul style="list-style-type: none"> • Ook hoorde ik terug dat ze toch al alles besproken en geregeld hadden met CMD en huisarts.
	Hulpmiddel voor besluiten vastleggen	<ul style="list-style-type: none"> • Doordat het fysiek boekje waarin voorkeuren vastgelegd kunnen worden • Het gesprek wordt gestart en dan komen bepaalde zaken (wensen) boven tafel. • Ja, omdat meer waarde hulpmiddel voor client om zijn wensen duidelijk te krijgen, zich voor te bereiden op een ACP-gesprek met huisarts • Zodat in een rustig kader weloverwogen besluiten genomen kunnen worden • Het is een goed hulpmiddel om hun wensen duidelijk te krijgen voor zichzelf en te maken naar behandelaren en familie.

	Vastleggen al gedaan	<ul style="list-style-type: none"> • Nee, want er is al veel op diverse plekken vastgelegd • Er waren ook mensen die dit zelf als geregeld hadden. • De door mij benaderde cliënten zien de meerwaarde er hier niet van in. Degenen die oprecht wel geïnteresseerd waren hebben meestal al een levenstestament of zaken doorgesproken met familie/mantelzorgers en huisarts vaak ook.
	Vastleggen overplaatsen naar andere professionals	<ul style="list-style-type: none"> • Nee, want ik denk dat het effectiever is om het uit te laten reiken door de huisarts. • Maar uiteindelijk moeten zaken bij de huisarts vastgelegd worden. Het is voor cliënten dan ook duidelijker als daar het initiatief om erover na te denken vanuit gaat. • Bij de huisartsen zou dit mijn inziens beter thuishoren, vast leggen door de assistente. Huisarts/ assistente dienen dit telkens bij de casemanager te melden als dit is wat en ook wat is vastgelegd. • Uitreiken aan cliënten waarvan de huisartsen niet al met andere formulieren werken. • Daarnaast is het aan te raden om afspraken met de huisartsen te maken wie wat bespreek. Het is naar mijn idee een samenspel

		<p>van patiënt, arts en eventueel POH.</p> <ul style="list-style-type: none"> • Wel belangrijk dat huisarts hierover ingelicht wordt. • Wat mij opvalt is dat cliënten de behandelwensen, graag met de huisartsen willen bespreken. Ik als casemanager dementie, laat dit stukje bij de huisarts. Ik geef de huisarts wel een seintje dat client met deze vraag naar het spreekuur komt. Aan de andere kant merk ik dat de huisartsenpraktijken waarvoor ik werk, dat de behandelwensen een punt van aandacht zijn, I besproken worden met de client. Misschien is het een idee om de behandelpaspoorten ook met de huisarts te bespreken.
--	--	--