



Personal values and Shared Decision Making for people with Multiple Myeloma

A qualitative study about the role of personal values
in treatment decisions and its contributions in
Shared Decision Making

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Preface

Dear reader,

In front of you lies my master's thesis 'Personal values and Shared Decision Making for people with Multiple Myeloma'. This thesis has been written as my final effort before graduating the master's degree Health Economics, Policy & Law at the Erasmus University Rotterdam. Writing this thesis was challenging, but also a true learning experience which resulted in this final version where I am proud of. Whereas writing this thesis was academically seen a learning process, the interviews with several patients also taught me a lot on a personal level. I really admire how they view their life and enjoy it to the fullest. Having the opportunity to interview them was an experience I would never forget.

First of all, I would like to thank all the respondents for their openness, honesty, and willingness to participate in this study. I would also like to thank my supervisor Hedwig Blommestein for all the feedback and advice she gave me during the writing process. Last but not least, I want to thank my family, and especially my mother for all the advice, feedback, and on top of that mental support when I needed this the most.

I hope you will enjoy reading my thesis.

Sara Mostert

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Abstract

This study investigates the role of personal values in treatment decisions for people with Multiple Myeloma (MM) and how this contributes in Shared Decision Making (SDM). Nowadays, organizing care around a patient's personal situation is receiving much attention. For this, a shift has taken place from disease-oriented care organization towards person-centered care organization in which the patient's personal values are a central component. Treatment decisions might be influenced by what patients and professional caregivers value in treatment. In the Netherlands, a discrepancy shows that professional caregivers primarily focused on clinical health outcomes, while other values may be just as important for patients. SDM can help to realize to make treatment decisions that fit a patient's personal values. MM is a particularly relevant case considering the increasing incidence, the long period patients live with the disease, and the increased treatment options. This qualitative study consisted of semi-structured interviews with MM patients, physicians treating MM patients, and a nurse practitioner treating MM patients. Data was analyzed by open, axial, and selective coding. Patients' and professional caregivers' interviews were analyzed separately and afterwards compared. The results showed that patients' personal values are considered relevant in the treatment trajectory and decisions. They influence the patient-physician relationship, way of information exchange and shape the proposed treatments. Furthermore, for professional caregivers, knowledge about a patient's personal values allows them to zoom in on what is essential for an individual when proposing treatment and during the treatment trajectory. Although the importance of personal values in treatment decisions was recognized, a treatment's physical effectiveness remains highly relevant in the decisions made. The decision-making process was not entirely in line with the four steps recognized within SDM. Despite this, for patients, the way decisions were made had contributed to their involvement in their treatment trajectory, resulting in patients feeling heard and authorized to contribute to the decisions. Both physicians and patients recognized the positive effects of SDM. Nevertheless, SDM has several boundaries. This study contributes to the body of knowledge regarding the appearance of SDM in practice and the realization that SDM is about involving patients in their treatment trajectory to their preferred extent and goes beyond just the decisions made. Moreover, the recognition that for patients and physicians, whereas treatment effectiveness remains important, personal values partly shape the treatment trajectory, and subsequently, the decisions made. The findings of this study could help patients and physicians realize an increasingly satisfactory decision-making process for every individual. However, further research is needed to generate more generalizable and broad-based results.

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1. Introduction

'The question "what matters to you?" allows patients to disclose their interests, values and preferences – as full humans, not just as recipients of care' (Kebede, 2016). This quote clearly states the core of person-centeredness in healthcare, in which care is not merely organized around the disease but along the personal values of a patient. The question, but more important the answer to this question, is also considered relevant in the situation where a treatment decision has to be made. Therefore, person-centeredness is a great opportunity to improve patient satisfaction and to incorporate outcomes considered relevant by patients (Kebede, 2016). However, in the Netherlands many professional caregivers are still mostly focused on values like clinical health outcomes (e.g., biological response to treatment), while for patients other values like the ability to work, playing sports, level of pain, and sexual functioning may be just as important. This shows that patients and professional caregivers differ in the importance they attach to the variety of personal values. This might influence treatment decisions (Ministry of Health, 2018).

Although always more or less implicitly present in health care, the discussion around value in healthcare gained renewed attention in Porter's Value-Based Health Care (P-VBHC) framework. Within P-VBHC, value is defined as health outcomes per unit of cost. Value in healthcare is created around a patient's interrelated set of conditions, and therefore should be organized in an integrated way (Porter, 2008). P-VBHC is frequently used but also received some critical notes. Critics say that his definition is too narrow for the healthcare field since it neglects elements like patients' personal values and the relational value of 'caring' (Groenewoud et al., 2019; EXPH, 2019). Therefore, the Expert Panel on Effective Ways of Investing in Health (EXPH) of the European Commission defined value in VBHC more comprehensively. An important addition is the inclusion of personal values and their crucial role in treatment decisions. (EXPH, 2019). A requirement of receiving care based on personal values is Shared Decision Making (SDM). Making shared decisions in terms of examining what is most valuable for the patient and thereupon share the treatment decision as much as the patient wants, will lead to outcomes that fit patients' personal goals. (EXPH, 2019; Elwyn et al., 2012; Gafni & Charles, 2017). SDM has a lot of benefits for patients such as increasing respect for their autonomy and balancing benefits and risks according to their personal values. Furthermore, SDM could contribute to an increase in equity between patients with a high and low level of education. Therefore, SDM should be the norm, however this is not yet always the case (Stiggelbout et al., 2012).

In this thesis, Multiple Myeloma (MM) will be used as a case to investigate the role of personal values in treatment decisions and how personal values contribute in SDM. MM is a

hematological cancer type in which malignant plasma cells in the bone marrow multiply in an uncontrolled way. MM is a particularly relevant case in the light of the aging population since incidence is increasing with age (Kanker.nl, n.d.). So far MM remains incurable, but treatment and diagnostic opportunities have strongly improved over the past years. There are many treatment options and patients live a relatively long time with the disease¹ (Kanker.nl., n.d.; Brink et al., 2019). With improving treatment opportunities which can be given consecutive with increased five- and ten-years survival rates, the decision-making process for treatments becomes more relevant. For instance, there are changing treatment goals for less 'fit' patients with a greater focus on patient-centered outcomes such as quality of life, duration, and tolerability of the treatment. Furthermore, there is need for a more holistic approach concerning the individual, treatment side effects, information access, and provider-patient communication (Mateos et al., 2019; Cuffe et al., 2020). Considering the increasing incidence of MM, the improved and increased treatment options, and the relatively long period patients live with the disease, the decision-making process for these patients deserves further attention.

The aim of this research is to investigate which role personal values play in treatment decisions for people with Multiple Myeloma and how this contributes in Shared Decision Making. The main research question is posed as follows:

What is the role of personal values in treatment decisions for people with Multiple Myeloma and how does it contribute in Shared Decision Making?

The following sub-questions are formulated to answer the main question:

1. What are the personal values of people with Multiple Myeloma?
2. To what extent are physicians familiar with the personal values of their patients?
3. What is the role of personal values in the interaction between patient and physician, and subsequently the treatment decisions?
4. To what extent is the decision-making process in line with SDM?
5. How does the role of personal values in the decision-making process differ over time and between patient subgroups?

¹ After five years, approximately 54% of the MM patients are still alive. After ten years, this has become 30% of the MM patients that are still alive (Kanker.nl, n.d.).

The next chapter starts with an exploration of this study's central concepts, VBHC and SDM, after which there will be zoomed in on the application of these concepts in the Netherlands. This theoretical chapter ends with an overview of the body of knowledge about SDM, treatment decisions, and personal values in treatment decisions. Next, the methodological section will explain the qualitative study design and the data collection and analysis methods. Moreover, considerations regarding research ethics, and validity and reliability will be discussed. In chapter four, the field study results will be presented based on two main topics, personal values and treatment decisions. Ultimately, this study ends with an extensive discussion, after which a conclusion will be given.

2. Theoretical framework

In this chapter, the main concepts of this research, VBHC and SDM, will be elaborated further based on the available scientific literature. The link between both concepts and the application in the Netherlands will be described. Subsequently, the position of this research in the current debate on SDM, treatment decisions, and personal values in treatment decisions will be discussed by providing an overview of the existing knowledge and elucidating where knowledge is lacking.

2.1 Value-Based Health Care

The possibilities in healthcare in terms of diagnosis and treatment options are increasing rapidly. This results in a rising complexity of the healthcare sector and unsustainable high healthcare expenditures which is challenging in many countries. To encounter these challenges, Porter (2008) described a model in which the transformation of our healthcare towards maximizing the value of care according to the patient as well as the reduction of care costs are the core concepts. According to Porter, value improvement should be the goal of healthcare. He proposes the VBHC framework to improve the delivery system. By improving the delivery system, Porter aims to increase value in terms of outcomes per unit of cost, which is the first principle of P-VBHC (Porter, 2008).

The next element of P-VBHC has to do with the organization of care. Value is created around a patient's interrelated set of conditions, and therefore should be organized in an integrated way. Care delivery should take place in integrated practice units (IPUs). IPUs include all the necessary expertise and specialties for a medical condition. In case a patient has several co-occurring medical conditions, it depends on the commonness of the medical conditions whether a patient has a single or multiple IPUs. Organizing care into IPUs requires providers to transform their service lines. This will lead to care that is organized around patients' needs and will reduce fragmentation (Porter, 2008).

Value measurement in terms of outcomes and costs is the third element of P-VBHC. This measurement should take place at a level similar to that of the care delivery, so at the level of IPUs. Porter describes three outcome tiers which are considered relevant and need to be captured within outcome measurement. First, the patient's achieved health status. Second, outcomes related to the care itself like recovery time or complications. Third, the sustainability of the outcome in terms of long-term consequences and maintaining the health improvement. Moreover, by improving the second and third tier, the care costs will be reduced, for instance, when complications are diminished. Therefore, by measuring this comprehensive set of outcomes, quality will be improved and care will be less expensive (Porter, 2008).

Finally, in P-VBHC, reimbursement should be aligned with value creation. Therefore, VBHC requires bundled reimbursement which enables insurers, providers, and patients to benefit from improving value. Separate reimbursement in which reimbursement is structured around discrete services, works against value. It generates incentives to diminish the need for or complexity of care. As bundled reimbursement allows for reimbursement over medical conditions, the reimbursement system is aligned with value and is therefore a payment system where all involved parties can benefit from value improvement (Porter, 2008).

P-VBHC is embraced in many western healthcare systems but also received some criticism. Porter defined value from an economic perspective as outcomes per unit of cost. According to Groenewoud et al. (2019), this does not fit the healthcare context and may therefore cause some violations of medical ethical principles. As, in P-VBHC, treatment is considered as 'high-value care' when clinical outcomes are improved against acceptable costs, this does not account for the patient's personal values in life. Furthermore, P-VBHC neglects the relational value of 'caring'. Because of the merely instrumental and economical conception of value in which healthcare only adds value if outcomes are improved against acceptable costs, the relational value of caring is not included in P-VBHC (Groenewoud et al., 2019). Besides, The Expert Panel on Effective Ways of Investing in Health (EXPH, 2019) states that Porter's definition of value is '*too narrow*' for the healthcare sector since value is predominantly defined from a provider-centered approach. The definition misses elements of equity and therefore does not reflect the full health system and patient-centeredness. The EXPH therefore proposes to define VBHC as an exhaustive concept based on personal, technical, allocative, and societal values (EXPH, 2019). Within the EXPH's VBHC, care delivery should be in line with the patient's personal goals; best outcomes concerning the accessible resources should be attained; these resources should be distributed equitably; and healthcare should contribute to social involvement (EXPH, 2019). In this study, the main focus will be the pillar 'personal value'.

According to the EXPH, high-quality care will only be achieved if the care is in accordance with the preferences, goals, and values of a specific patient. Therefore, the personal values of individual patients should be used as fundamentals in the decision-making process. A decision itself may be optimized by taking into account the values, goals, and preferences of an individual patient (EXPH, 2019). To reach this goal, still a cultural shift in the patient-physician relationship is essential. This means that beyond the feasibility of treatment, the physician and patient need to talk about whether this treatment is valuable from the patient's perspective. Making an optimized decision in line with patient's preferences, goals, and values requires Shared Decision Making (EXPH, 2019).

2.2 Shared Decision Making

Since 1972 the term SDM is used in literature. Due to changing preferences in the patient-physician relationship, this is moving from a paternalistic way of communication towards an increasingly interactive and patient-centered relationship, in which the concept of SDM is very suitable. Within SDM, the focus is on the process leading to a treatment decision, not on just the content of this decision. SDM is about involving patients in their treatment trajectory and giving them space to make choices in line with their own goals, preferences, and values. The degree of SDM depends on the patient's preferences and treatment phase (Elwyn et al. 2012; Stiggelbout et al., 2015; La Grouw et al., 2019). Within SDM, four steps are recognized:

- First, the physician tells the patient that a decision is to be made and that their opinion is important.
- Second, the physician informs the patient about the options and their pros and cons.
- Third, the patient and physician talk about the patient's preferences and the physician supports the patient in considering the options.
- Fourth, the patient and physician talk about the patient's preferred role in the decision and the decision is made based on knowledge and preferences.

Nowadays, SDM is often considered the preferred model in decision-making (Gafni & Charles, 2017). If SDM is applied well, it has a lot of benefits for patients. Decisions will better suit the individual patient with respect for their autonomy and consequently, this will increase patient satisfaction. Furthermore, SDM will improve the patient-physician relationship and positively influence treatment adherence in the long term. Moreover, equity between less and more educated patients may increase. This is the case when both less and more educated patients are involved in their treatment decision to the same extent (Stiggelbout et al., 2015; Stiggelbout et al., 2012). As SDM is the preferred model in decision-making, in many countries it is listed on the policy agenda and there are various policy movements towards an increase of incorporation of SDM in daily practice. Initiatives to increase SDM consist of decision aids, educational and communication skill programs for health professionals, and enhancement in knowledge and awareness by policymakers, professionals, and patients (Politi et al., 2012; Stiggelbout et al., 2015; Gafni & Charles, 2017).

In contrast to the broad-based support of SDM in healthcare in general, the implementation in cancer care is not yet widely adopted (Steffensen et al., 2018; Kane et al., 2014). Several factors make it difficult to implement SDM in daily practice. There is often a lack of time in the consultation room to incorporate SDM and, especially in cancer care, the implementation is complex due to high levels of uncertainty and difficulties in considering the risks and benefits of different treatment

options (Légaré et al., 2014; Kane et al., 2014). From the patient perspective, Covvey et al. (2019), identified in a systematic literature review the main facilitators and barriers regarding SDM in oncology. The main barriers involved uncertainty or no reached consensus about the treatment decision, concerns about adverse effects, and poor communication. Main facilitators for patients involved physicians paying attention to their preferences, positive physician actions or behavior e.g., in terms of strong communication and the use of supporting systems (Covvey et al., 2019).

2.3 Implementation of VBHC and SDM in the Netherlands

In 2018, the Ministry of Health published a report about the program 'outcome-oriented care 2018-2022'. The goal of this program is to increase the quality of life of patients by taking their personal situation into account in treatment decisions and is based on Porter's VBHC framework. To reach this goal, four lines of improvement were developed (Ministry of Health, 2018). First, more insight into outcomes considered relevant by patients. Second, increase SDM. Third, outcome-oriented care organization and payments. Fourth, more accessible, relevant and current outcome information (Ministry of Health, 2018). The first two are considered important in this study. Nowadays, it is often unknown what patients value as important outcomes. This makes it difficult to make appropriate treatment decisions in line with the patient's personal goals and values, therefore more insights into outcomes considered relevant by patients are required (Ministry of Health, 2018). Next, SDM should be used more often based on the increasing availability of relevant outcome information. To stimulate SDM, activities such as the development and usage of decision aids, a campaign, and educational training programs for healthcare professionals are designed (Ministry of Health, 2018).

In 2019, La Grouw et al. have conducted a study about SDM in hospital practice in the Netherlands. In this case study in two Dutch hospitals, where data is collected in one department per hospital, they found that patients and physicians were willing to make a shared decision. Although the four steps of SDM were not followed, the wishes and preferences of the patients were considered and combined with the pros and cons of the treatment options. The physicians mainly applied SDM from their own convictions and in their own way, which was largely in line with the principles of SDM. SDM strengthens the position of the patient. Yet not every patient is willing to participate actively or prepare and inform him/herself in advance of a conversation with the physician. Overall, patients experience the process of SDM positively. They feel heard and seen as a person, which improves their treatment process satisfaction (La Grouw et al., 2019). Nevertheless, large-scale implementation of SDM remains tough due to barriers at patient, physician, as well as organizational levels. The outcome-oriented care program of the Dutch Ministry of Health is aiming to overcome these barriers and stimulate SDM (La Grouw et al., 2019; Ministry of Health, 2018).

Whereas the program of the Ministry of Health aims to implement VBHC in a specific way, this is not the only way VBHC can be understood. Steinmann et al. (2019) revealed that there are various interpretations of VBHC in the Netherlands. In a discourse analysis they disclosed four different discourses regarding the main intention of VBHC in the Netherlands. These show different insights regarding the main perceived objectives of VBHC in the Netherlands (Steinmann et al., 2019). First, patient empowerment discourse: VBHC as a framework that strengthens the position of patients regarding medical decisions. This discourse shows large similarities with the outcome-oriented care program of this Dutch Ministry of Health since it builds on the perception that patients are disadvantaged in the patient-physician relationship and their position needs to improve. Patients should be empowered by providing them relevant outcome information, such that they can make an informed treatment choice (Steinmann et al., 2019; Ministry of Health, 2018). Second, governance discourse: VBHC is identified as a toolkit to steer and incentivize providers towards higher value in terms of greater outcomes and lower costs. This discourse focuses on the financial aspect of VBHC and assumes that medical professionals do not automatically work towards optimal value. The VBHC payment structure, bundled payment is perceived as a tool to incentivize and stimulate the optimization of value (Steinmann et al., 2019). Third, professionalism discourse: VBHC is a model for the organization and improvement of healthcare delivery and is closely related with P-VBHC. This discourse assumes that professionals are intrinsically motivated to deliver care aligned with the interests of patients and therefore, deliver the best possible care. Improving patient value requires interprofessional learning (Steinmann et al., 2019; Porter, 2008). Last, critique discourse: VBHC as a dogma of manufacturability. This discourse assumes the healthcare sector to be too complicated to be able to standardize value. Instead, the focus should be on the individuals and their needs and preferences (Steinmann et al., 2019).

As can be seen, VBHC is a complex and constantly changing concept. Several discourses shape how value and VBHC are conceptualized and make clear that there is a great ambiguity of the definition of value in healthcare. However, in all the revealed discourses, SDM is seen as a crucial element of VBHC (Steinmann et al., 2019).

A recent contribution to this discussion was made by Ahaus (2020). In his oration he calls for strengthening the patient perspective in VBHC. In his description of the organization of VBHC from a patient perspective, four main parts of VBHC are distinguished: value for the patient, organization of care, costs, and steering on quality (Ahaus, 2020). These parts seem to overlap with P-VBHC to a large extent. However, Ahaus describes in the 'value for the patient' part, a Dutch turn of VBHC. Within VBHC, there is a shifted focus from process indicators to outcome indicators. These outcomes

can be measured as clinical outcomes and Patient-Reported Outcome Measures (PROMs), and patient experiences can be measured as Patient-Reported Experience Measures (PREMs). In the Netherlands, the aim is to apply PROMs in the consultation room. PROMs may provide meaningful input to the patient-physician conversation and thereupon, SDM (Ahaus, 2020). Ahaus finishes his oration with a plea for collaboration with patients in designing VBHC. Patient engagement on different levels is considerably important in designing VBHC since the patient knows best what is important or valuable for him/her. This could be on the micro-level between patient and physician, on the meso level where the patient could collaborate on the organization of quality improvements, but also on the macro level where the patient participates in policy development (Ahaus, 2020).

2.4 The application of VBHC and SDM in the Dutch healthcare institute's assessment framework

The implementation of VBHC and SDM also depends on the incorporation of these concepts into the general guidelines about quality standards for a healthcare organization. Since 2018, SDM related activities are part of the Dutch healthcare institute's assessment framework for quality and information standards (ZiN, 2018). This means that every Dutch healthcare organization is obliged to include statements about the way SDM is used in their institution and the use of any associated decision-support tools, such as decision aids in their quality standards. This concerns statements about the use of SDM and understandable information to enable SDM. For instance, about the role of the patient and healthcare provider and the position of patient's experiences, needs, norms, values, and preferences. Furthermore, the quality standard and/or associated decision-support instruments need to describe understandably the various options (including evidence) for diagnostics, treatment, guidance and care, and the associated advantages and disadvantages of these options from a client perspective. On top of that, the healthcare institute advises paying attention to organizing feedback moments about SDM, for instance guided by PREMs (ZiN, 2018). Moreover, the provision of care based on patients' personal situation and needs, also needs to be included in the quality standards of a healthcare facility. The quality standards need to stimulate care tailored to the individual situation and needs of the patient. These quality standards must not lead to 'standard care' (ZiN, 2018).

2.5 Existing knowledge about SDM, treatment decisions, and personal values in treatment decisions in cancer care

Stiggelbout et al. (2015) reviewed several studies and evaluated the occurrence of the SDM steps in practice. They found that the SDM steps do not seem to be applied very often in practice. For step one, the decision is often approached as a given fact, wherefore patients do not experience choice in treatment. For step two, often just one option is mentioned by the physician. Furthermore,

physicians' perception of the amount of information patients wish to receive is not in line with what patients would like to know, wherefore patients frequently feel uninformed. Besides, the provided information is often used to guide patients towards the physician's preferred treatment (Stiggelbout et al., 2015). For step three, patient preferences are not frequently illuminated either. Regarding the second part of this step, namely the support in considering the options, a lack of empirical evidence is encountered. For the final step, the patient's preferred role in the decision-making process is not asked for explicitly. However, this is possibly elicited more implicitly (Stiggelbout et al., 2015; Couët et al., 2015). From a broader perspective, the effects of SDM on health outcomes, especially patient outcomes, remain largely unaddressed in literature (Stiggelbout et al., 2015).

In recent years, a lot of research about SDM in cancer care, and for MM specifically, is conducted. For example, Tamirisa et al. (2017) studied patients and physicians views of SDM in cancer care. This study indicates that patients want to be involved in their treatment decisions. However, some barriers were found in terms of information and communication. First, there is a discrepancy in the level of desired and received information for patients (Tamirisa et al., 2017; LeBlanc, 2019). Often, physicians provide patients with information that is considered too detailed and not in line with their level of understanding. Moreover, patients frequently ask the physician to advise them about their preferred treatment option, in which the physician is often reluctant. This is because the patient expects the physician to take their personal preferences into account when recommending a treatment. However, not every physician is able to elicit patients' preferences (Tamirisa et al., 2017). Next, patient empowerment is found crucial in SDM and may improve health outcomes. Patients should acknowledge responsibility for their health and solve their issues with information, which is provided by their professional caregivers. Therefore, patients should think critically to make informed decisions. Moreover, their professional caregivers must admit patients are in charge of their care. However, health literacy and education are potential obstacles to patient empowerment, and subsequently, SDM (Kambhampati et al., 2016).

Whereas Tamirisa et al. (2017) found patients want to be involved in their treatment decision, Kehl et al. (2015) state patients vary in preferred level of participation in treatment decisions. However, regardless of the preferred level of involvement, patients who experienced SDM instead of physician-controlled treatment decisions were more likely to report excellent quality of care. Furthermore, patients who experienced SDM are more satisfied with the physician communication. Still, this is independent of their preferred role in the decision making. Thus, regardless of the patient's preferred decision role, SDM in cancer care is encouraged because of higher levels of quality of care and physician communication (Tamirisa et al., 2017; Kehl et al., 2015).

LeBlanc et al. (2019) reviewed existing literature about patient-centered communication for MM and other hematological malignancies. They indicate that for MM specifically, focusing on SDM is an opportunity to improve patient-centered communication. Because of the complicatedness of MM treatment decisions, an active discussion between physician and patient about patient's values, preferences and treatment goals is favored. Furthermore, most patients prefer a collaborative or active role in the decision-making process in which no differences in preferences between sociodemographic characteristics were found. Nevertheless, most patients still believe their physician decides for them and state their physician not properly facilitates their preferred decision role. In contrast to the patients' perceptions about who decides, the physicians suppose the patient decides. Furthermore, a discrepancy is found between the patient's values and goals in treatment and the physician's perception of these values and goals (LeBlanc et al., 2019).

A recent study by Pritlove et al. (2021) explored the implications for MM decision making by patients and their informal caregivers. Patients do not always choose the most effective treatment path. Instead, they sometimes choose a treatment that will reduce their symptoms or diminish the influence of their symptoms on their daily living (Pritlove et al., 2021). In line with these findings, Jen et al. (2020), found that alongside efficacy, other factors affect treatment decisions. For patients, the costs of the treatment and toxicity are mentioned as significant factors in coming to the decision. In addition, the physician's recommendation is considered crucial as well (Jen et al., 2020). Furthermore, Pritlove et al. (2021) have shown that patients sometimes decide on a treatment which minimizes the patient's workload of disease management and subsequently, the burden of illness. Therefore, it is considered crucial to take the work related to disease and treatment (e.g., medical tests, consults, travel time, adherence to drugs) into account within the process of SDM since this shapes treatment decisions (Pritlove et al., 2021). Whereas Pritlove et al. (2021) focused on the patient and their informal caregivers, Jen et al. (2020) also involved the physician perspective in their study. They found that for physicians, efficacy and treatment guidelines were of utmost importance in treatment decisions. Additionally, physicians indicate to take into account a patient's personal situation and characteristics to determine tolerability (Jen et al., 2020).

What matters most for persons with MM regarding their quality of life, is studied by Osborne et al. (2014). They found several main topics valued important by patients. First, symptom status and its influence on activities and participation in daily living. For instance, when someone is experiencing a lot of pain, this influences their mobility. Second, treatment factors and their impact on emotional status or activity and participation. For instance, having to undergo chemotherapy can cause frustration and anger. Third, treatment factors and their impact on symptom status, and

subsequently activity and participation. Next, someone's physical status and its influence on activity and participation, and later support factors. For instance, someone's physical status leaves them unable to work, which negatively influences their financial situation. To finish, adaptation and coping, expectations, and spirituality are considered crucial context factors in determining what is important for a MM patient (Osborne et al., 2014).

3. Research methods

In this chapter, the used research methods will be described and explained comprehensively. This chapter starts with discussing the study design. After that, the methods of data collection and analysis will be outlined. Thereupon, the research ethics will be discussed. This chapter ends with a discussion of the measures to improve validity and reliability.

3.1 Study design

Studying the decision-making process is complex, and the social interaction between physicians and patients requires an open design. Therefore, the research design consisted of a descriptive qualitative study. Qualitative research is unique in its research question phrasing and the methods of data collection. Qualitative research focuses on social processes and meaning from the perspective of the people involved (Mortelmans, 2018). In this study, in-depth qualitative data was needed to fully capture this study's social processes and interactions (Baarda et al., 2009). The importance of qualitative research in the healthcare field is explored and recognized by Renjith et al. (2021). Qualitative research is significant in understanding the complexity of human behavior, which is of utmost relevance when studying personal values and the decision-making process. Especially when examining the decision-making process, qualitative research helps understand the 'why' and 'how' of the decisions. Accordingly, qualitative methods are substantial in discovering and uncovering the thoughts and actions of individuals in a humanistic and person-centered way (Renjith et al., 2021).

For this study, semi-structured interviews were conducted. All interviews were recorded and verbatim transcribed afterwards. According to the respondents' preferences, the interviews were held via (video)call or a personal conversation. The interviews and transcripts are in Dutch since communication is more accessible in someone's native tongue. Quotes used in the results section were translated into English. After transcribing, the interviews were analyzed by open, axial, and selective coding. The coding process will be further explained in section 3.3.

3.2 Data collection

3.2.1 Literature search

In advance of the field study, a structured and targeted literature search was conducted to reveal the sensitizing concepts and compose the interview guide. PubMed and its Medical Subject Headings (MeSH) function was used to identify the most relevant articles while also ensuring feasibility. Additionally, the Erasmus university databank with its advanced search option was used to ensure that no vital literature was missed. Examples of searches in PubMed and the university databank are: value-based healthcare, shared decision making, treatment decisions, patient value, patient value in

treatment decisions, patient perspective, patient involvement. These terms were combined with: Multiple Myeloma, cancer care, chronic diseases. Moreover, there was occasionally focused on articles about the Netherlands. In addition, Dutch searches were conducted with the Dutch descriptions of SDM and VBHC. Preferably articles no older than 2010 were used. Furthermore, the grey literature of governmental programs and guidelines about SDM and VBHC in the Netherlands were investigated. The quality standards of the Dutch healthcare institute were considered as well.

3.2.2 Field study

The field study consisted of 13 semi-structured interviews with individual MM patients, physicians treating MM patients, and a nurse practitioner treating MM patients.

3.2.2.1 Target population and inclusion criteria

The respondents were selected out of the population MM patients, hematologists treating MM patients, and nurse practitioners treating MM patients. The target population consisted of patients and physicians because this research required information about patients' personal values and the relation and interaction between patients and physicians. The nurse practitioner was included in the study to gain information about their role in the decision-making process. A nurse practitioner has, just like a physician, an individual treatment relationship with a patient and partly performs tasks that would be performed by the physician otherwise. A nurse practitioner has a task substitution position (in Dutch: taakherschikking functie) (V&VN VS, n.d.). The sample selection was based on the following inclusion criteria: physicians and nurse practitioners needed to treat MM patients and have followed them over the treatment trajectory. Regarding the patients, the aim was to select a purposive sample. The criteria for being selected, additional to the diagnosis MM, were differences in age, time since diagnosis, treatment opportunities, and performed treatments.

3.2.2.2 Approaching and selecting

In April 2021, the target population was approached in various ways. The aim was to interview more patients than physicians since the main interest of the research lies in the experiences of patients. Patients were recruited by contacting the Hematon foundation, the Dutch patient organization for people with blood or lymph node cancer, by mail. This invitation letter can be found in Appendix A. To ensure enough respondents, patients were additionally recruited by a message in a private Facebook group for Dutch MM patients, and via physicians. The Facebook message can be found in Appendix B. To recruit physicians, the private and professional networks of the researcher were used. In total, eight MM patients, four hematologists, and one nurse practitioner have been interviewed. The interviews were held in the period between half May and half June 2021 via

(video)call or a face-to-face conversation and, on average, lasted for one hour. All the respondents gave permission to record and use the interviews for this study.

3.2.2.3 Interview structure and topic list

The interviews were conducted in a semi-structured way based on a pre-generated topic list. It is essential for an interviewer to have good listening and adaptation skills to generate insight experiences and knowledge about the subject. The semi-structured interviews guaranteed that in every interview, similar topics were discussed. Furthermore, there was space for the interviewer to ask questions not included in the interview guide to clarify issues or to go even more in-depth according to the interviewee's answers (Mortelmans, 2018). Three different interview guides, for patients, physicians, and the nurse practitioner, were composed based on the literature search. Each interview started with some general questions about the respondent. This was done to put the respondent at ease and gave possibilities during the interview to go back to what was said initially. Subsequently, there were some questions about the personal values, preferences, and goals of the patients. For the physicians and nurse practitioner, this part was about what they think the patients' personal values, preferences, and goals are, and whether or how they try to get familiar with them. Next, there were some questions about treatment decisions and SDM. Finally, the researcher asked some questions about the role in treatment decisions and SDM of the personal values which the interviewee had appointed. At the end of each interview, some adjustments to the interview guides were made to improve the upcoming interviews, which is a component of qualitative research's cyclic and iterative process (Mortelmans, 2018). These adjustments regarded the question phrasing and an increasing focus on experiences and concrete examples. The final interview guides can be found in Appendix C.

3.3 Data analysis

The analysis started with verbatim transcribing the interview recordings. Anonymity was guaranteed by removing mentioned names and other personal information. Subsequently, data was analyzed by open, axial, and selective coding using the software ATLAS.ti. The coding process was inductive to keep an open attitude towards the data, which fits the purpose of this study (Mortelmans, 2018). Professional caregivers' and patients' interviews were analyzed separately and afterwards compared. Within each group the analysis was a cyclic process in which data was compared continuously to develop coding and analyzing constantly (Mortelmans, 2018).

During the first phase of open coding, the transcripts were read closely, and every relevant piece of text was labelled. Within open coding the aim was to stick as close as possible to the data,

which resulted in 526 unique codes of in total 921 codes. Axial coding involved comparing and linking the labels from the open coding phase and altering them towards broader covering labels. During the phase of selective coding, 39 code groups were created, which cover almost all unique codes from the open coding phase. In this phase connections and patterns in the data were looked for in order to finally provide answers on the main and sub-questions (Mortelmans, 2018; Boeije, 2010). The codebook can be found in Appendix D.

3.4 Research Ethics

In advance of each interview, the interviewees were verbally asked for consent regarding recording and transcribing the interviews. The interviewees were informed that the gathered data will not be shared with any third parties. Further, every interviewee was asked for anonymous use of the gathered data for the aim of this study. In advance, the respondents were informed about the goal, structure, and time duration of the interviews. The respondents have had the opportunity to ask remaining questions in advance. Afterwards, they had the opportunity to ask remaining questions or complement on discussed topics. To finish, all interviewees had the opportunity to receive the interview transcript based on which they had the possibility to indicate whether all data was allowed to be used for the aim of this study.

3.5 Validity and reliability

Internal validity was improved by performing member checks. With a member check, interview transcripts were submitted to the respondents and by doing so they had the opportunity to correct or complement the content of the results. Prior to each interview, the researcher has asked whether the respondent wanted to use the opportunity of a member check. Six respondents wanted this and afterwards sent a message that the transcript was acceptable and could be used completely.

To improve the reliability of the research, an audit trail was used. This detailed description of the research process, including all developments and difficulties, was reported clearly in a logbook. By doing so, it can be concluded whether the research was conducted in a scientifically sound manner (Mortelmans, 2018). The audit trail was summarized and used as the basis of this chapter.

In this qualitative study, the role of the researcher was essential and should be reflected upon. As a researcher, I am aware of my subjective role in the research process and how my values and insights shaped the collected data and, subsequently, the results. With this and the meticulous procedure of data analysis and performed member checks, an attempt has been made not to miss out or misinterpret important information. To create transparency about the coding process, the

codebook is attached in Appendix D. The codebook involves the used code groups, and subsequently per code group the number of involved codes, frequency of occurrence, and the appearance in the different interviews. Furthermore, one interview was also coded by an associate qualitative researcher. That particular interview was coded independently by both the researcher and the associate researcher, whereupon the codes were compared and discussed. By doing so, the reliability of this study was improved.

4. Results

In this chapter, the results of the interviews will be presented. First, the respondent characteristics will be described. After that, the interview results will be presented based on two main topics: personal values and treatment decisions. All 39 code groups discovered in the data analysis phase, belong to one of these topics and subsequently, the accessory subtopics. The part regarding personal values is split up into the attention of professional caregivers towards patients' personal values, personal values in daily living, important concrete personal values, value in treatment, and the potential change of personal values over time. Treatment decisions will be discussed according to the four SDM steps, whereupon patients' and professional caregivers' opinion about SDM will be provided. This chapter finishes with addressing personal values in treatment decisions. In presenting the results, the perspective of the patients and professional caregivers will be intertwined.

4.1 Respondent characteristics

In total, eight MM patients, four physicians and one nurse practitioner have been interviewed. The nurse practitioner was included in the study to gain information about their role in the decision-making process. However, this role appeared to be smaller than expected, wherefore interviewing more nurse practitioners was unnecessary. The patient respondent group had a median age of 65, consisted of just as many males as females, and had a relatively large variation in the time since diagnosis. The professional caregiver respondent group mainly consisted of hematologists who had relatively little working time in the profession. An overview of the respondent characteristics is stated in table 1 and 2.

Respondent	Gender	Age	Time since diagnosis	Interview date
Pat-1	Female	66	2.5 years	21-05-2021
Pat-2	Male	65	11 years	24-05-2021
Pat-3	Female	56	2.5 years	02-06-2021
Pat-4	Male	53	Less than a year	02-06-2021
Pat-5	Male	60	3 years	03-06-2021
Pat-6	Male	72	8 years	15-06-2021
Pat-7	Female	75	13 years	18-06-2021
Pat-8	Female	-	6 years	19-06-2021

Table 1: Patient characteristics

Respondent	Gender	Profession	Working time in profession	Hospital type	Hospital region	Hospital area ²	Interview date
Phy-1	Female	Hematologist	February 2003	General	Gelderland	Urban	13-05-2021
Phy-2	Female	Hematologist	2015	General	Zuid-Holland	Urban	17-06-2021
Phy-3	Female	Hematologist	2018	General	Friesland	Rural	17-06-2021
Phy-4	Male	Hematologist	2019	Academic	Noord-Holland	Urban	18-06-2021
Nur-1	Female	Nurse practitioner	2019	General	Gelderland	Urban	21-05-2021

Table 2: Physician and nurse practitioner characteristics

4.2 Personal values

Patients and professional caregivers described various personal values. Values are personal and therefore some variation was noticed per individual. However, diverse similarities were observed between the patients' personal values as well as the patients' personal values according to the professional caregivers. Within the described personal values, a distinction can be made between personal values in daily living and personal values regarding treatment. The interviews showed these values are sometimes interacted and sometimes can be distinguished separately. For the patients, no clear pattern was observed in differences in personal values between patient subgroups, yet over time, values may change.

4.2.1 Attention to personal values

"Last time we went [SM: to the physician], and she said: 'what do you actually do during the day? How do you spend your days?'" – Pat -1.

Six out of eight patients think their physician (partly) knows what is essential in their life and treatment trajectory. This is considered vital for the relationship, way of information exchange, and proposed treatments. For instance, one patient indicated that she prefers a clear and action-driven way of communication. Her physician knows this and acts in this preferred way, due to which their communication is satisfactory. However, one patient mentioned that his physician is not familiar with his personal values and never asks these kinds of questions. This does not bother him, and he considers this course of action as a part of the professional patient-physician relationship.

² Based on the environmental address density (in Dutch: omgevingsadressendichtheid) (CBS, 2021; CBS StatLine, 2021).

Additionally, during the professional caregiver interviews, every professional caregiver mentioned that they try to discover the patient values. They indicated to ask questions about what the patient does or does not want, what the patient is able of, whether the patient can come to the hospital, what the patient is doing in his everyday life, and what is important in the patient's life. The interviews showed that these questions can be asked at the beginning of the treatment but discovering patients' personal values takes time. Therefore, these kinds of topics are gradually being discussed. Although every professional caregiver indicated to pay attention to what matters to their patients, some of them were reflective about their efforts and admitted this could be done more regularly.

"Yes, I always ask directly. So, I really start the conversation. Well, just like we sit here with each other now. Together, we will go on for a very long time. Unfortunately, this is a chronic illness, so you will never get rid of me again, and I mention that with a smile on my face. Together, we have to arrange it and that means we become a bit dependent and have to get to know each other. So, I would love to hear what your life is like. Can you tell me what is important to you, what hobbies you got, what passions you got, and what your view is on this disease and treatment." – Phy-2.

Several physicians indicated that with MM, at the beginning of the treatment and diagnosis process, there is often an urgent situation. Therefore, it is crucial to start treatment as soon as possible. Often in these situations, the conversation about what patients value cannot be held until the disease is stabilized a bit. Furthermore, patients differ, and the interviews showed physicians find it sometimes complex to disclose their patients' values. Several physicians mentioned difficulties in reaching the essence of patients. During the consultation, they experience issues with language, culture, and time. Especially during the Corona crisis, where consultations were frequently held telephonically or without family attendance, a lack of non-verbal communication and input from family were faced. In discovering what is essential for a patient, the interviews showed that the physician is frequently supported by a physician assistant, nurse practitioner, nurse, or case manager. Several physicians mentioned that often, these people have more time and therefore are very helpful, not just in the treatment trajectory but also in getting to the core in terms of what patients value in life. In case of a physician, who works in a hospital in Friesland, the physician assistant speaks the local dialect, which is very supportive in the communication since her patients favor communicating in the local dialect.

4.2.2 Personal values in daily living

Half of the patients and every professional caregiver mentioned that enjoying the simple things in life is important for patients. The patients indicated that they appreciate and enjoy matters like sitting in the garden, being able to do the groceries, or spending time with their children and grandchildren to a larger degree. The patients indicated that because of their disease they have realized how vital these simple things in life are. They enjoy every single day, appreciate what they have and can do.

"I enjoy every day and what I can do way more. And well, I am very grateful for that." – Pat-8.

The interviews showed these elements overlap to a large extent with the simple things in life the professional caregivers described as important for patients. Additionally, the professional caregivers mentioned that maintaining the position in their families, doing daily things without too many complaints, and having fun with their friends and family are crucial for patients.

"Children, grandchildren, vacations, being able to work in the garden. These kinds of simple things are essential for older persons."- Nur -1.

The patients indicated that these simple things in life can be enjoyed even more together with friends or family. Every patient mentioned their social interaction with friends and family as an important personal value in life. Connection with friends, family, and sometimes colleagues give them energy, trust, and safety. It is essential to be part of someone else's life and stay among people. Several patients indicated that these social contacts are the reason to continue with their treatment and do everything to stay with their loved ones for as long as possible. For example, Pat-5 described: *"Like I said: my wife, my daughter, and my grandchildren. I will do anything for them, and I will fight to keep them with me for as long as possible"*. However, the patient interviews showed that combining social life with their disease can also be complicated. Some patients indicated that their social life has shrunk as a consequence of their disease.

4.2.3 Important concrete personal values

Four patients and several professional caregivers stated that mobility is important in the patient's life. For some patients, this value has become more critical because they were not able to walk anymore at some point in their treatment. They described that being limited in their mobility has a significant influence on their freedom and autonomy. The patients indicated that remaining mobile is vital in their daily life. The ability to walk, go for a bike ride, or drive a car during treatment, is one of

the considerations which could influence the decision for treatment. This means that this value is not just a value in daily living but also important with regard to treatment.

"What is the point of cancer treatment when I am paralyzed in bed?" - Pat-1.

In line with the personal value mobility are the, sometimes implicitly, by patients mentioned values freedom and autonomy. Being in control of their life and treatment is crucial for some patients. However, their freedom is restricted because of their disease and accessory treatments. Therefore, they want to control their life and freedom as far as possible, for instance, by planning some appointments telephonically. For instance, Pat-8 described: *"I said, whether it is possible to do it telephonically (...) I said, well actually I prefer to have nothing to do with the hospital (...) So I apply it [SM: maintaining my freedom] and by doing so I win some time. I want to keep some distance from the hospital"*. Besides, patients indicated to sometimes choose a treatment in which they do not have to go to the hospital frequently or which limits their freedom because of many side effects.

Subsequently, a more occasionally described personal value by professional caregivers is independence, which corresponds to a large extent with the values freedom and autonomy mentioned by patients. Furthermore, the interviews with the professional caregivers showed that patients want to be identified as a person, not just as a patient. In this sense, it is crucial as a physician to consider which side effects are tolerable for an individual. The quote below expresses how this is considered.

"Many Multiple Myeloma therapies cause neuropathy, so nerve deafness. (...) For some patients, a bit deafness is accepted, but for others, for sure it is not.' (...) Look, it is unpleasant when you are working on the computer and your fingers are deaf. However, when you are a violinist, well then it is intolerable." – Phy-3.

4.2.4 Value in treatment

Five patients indicated that during the treatment trajectory, their most important value is the effectiveness of the treatment, so to make sure the blood values are stable for as long as possible. Even though side effects are sometimes highly unpleasant, they will deal with them and live for as long as possible with the disease. By way of contrast, the remaining patients mentioned that their tolerability of treatment has its boundaries. Two of them are also focused on their quality of life during treatment. Factors such as tiredness, mobility, and freedom were also mentioned as relevant during treatment. From a broader perspective, three patients stated that being heard by their

professional caregivers is of utmost relevance in their treatment process. Attention of a professional caregiver to the patient and their health status gave the respondents confidence throughout the process.

Whereas the patient interviews did not reveal a difference in treatment value by age, several professional caregivers mentioned during the interviews that they observe a difference in personal values in treatment between younger and older persons. Almost every professional caregiver said that the question 'do you want to be treated?' is unnecessary for a younger person. They stated that every younger person aims for the optimal treatment in order to be there for their families for as long as possible and be able to return to their jobs. In short, younger MM patients want to return to their former position in life. For older patients, quality of life was raised more frequently. The professional caregivers indicated that the question 'what do you consider as quality of life?' matters a lot to these persons. According to several professional caregivers, conversations about whether or not someone wants to be treated, until which point they want to be treated, and whether they are able to come to the hospital are of great importance.

4.2.5 Personal values over time

Patients' personal values may change over time. Within the interviews, there was no clear direction of this change over time. Several patients mentioned that before they got ill, they were primarily focused on their work and future, nowadays this has shifted to a focus on wellbeing, loved ones, and the appreciation of the simple things in life.

"I was a workaholic. I just thought my work was extremely important and the customer was number one, but now I am next to him (...) That has also reflected to me that I am really allowed, and have to put myself first." – Pat-3.

The patient interviews showed that unpleasant experiences with a professional caregiver or in the hospital caused some other changes in personal values. However, not every patient experienced a change in their personal values.

4.3 Treatment decisions

In this section, the decision-making process will be discussed according to the four steps recognized within the process of SDM. First, a short summary of the appearance of the SDM steps in the decision-making will be provided, after which there will be elaborated on these steps comprehensively. To finish, the respondents' opinion about the decision-making process and SDM will be discussed.

4.3.1 Degree of SDM summarized according to the four steps

Table 3 shows that the SDM steps are not always applied or experienced by physicians and patients. Especially the final steps did not always appear in practice, according to the respondents. However, this brief summary of the application of SDM serves only as a broad overview and therefore requires further explanation, which will be provided in section 4.3.2. In table 3, the nurse practitioner is not included since the interview showed that a decision is made by physician and patient, and the nurse practitioner is not present during these conversations.

SDM steps	Experienced by patients	Applied by physicians
Step 1. The physician tells the patient that a decision is to be made and that their opinion is important.	8 out of 8	4 out of 4
Step 2. The physician informs the patient about the options and their pros and cons.	8 out of 8	4 out of 4
Step 3. Patient and physician talk about the patient's preferences and the physician supports the patient in considering the options.	<i>Conversation about patient preferences:</i> 7 out of 8 <i>Support in considering the options:</i> 3 out of 8	<i>Conversation about patient preferences:</i> 3 out of 4 <i>Support in considering the options:</i> 2 out of 4
Step 4. Patient and physician talk about the patient's preferred role in the decision, and the decision is made based on knowledge and preferences.	<i>Explicitly:</i> 1 out of 8 <i>Implicitly:</i> 6 out of 8	<i>Occasionally:</i> 2 out of 4 <i>Implicitly:</i> 1 out of 4

Table 3: Occurrence of the SDM steps

4.3.2 Decision-making process and SDM

During the interviews, both patients and physicians seemed to be unfamiliar with the four steps of SDM, therefore the steps were explained and gone through during the interviews. Furthermore, several patients appeared not to be familiar with the concept SDM at all. For these patients, the concept was explained during the interviews.

4.3.2.1 Step one

4.3.2.1.1 Decision moments

The decision-making process starts when there is a choice to be made. However, many patients indicated that they did not experience any form of explicit choice or options in their treatment trajectory.

"Choice, that is a word I hardly know." – Pat-8.

By way of contrast, according to the professional caregivers, there are many decision points within the treatment trajectory. They mentioned some major moments of choice. The professional caregivers indicated this is at the beginning of the trajectory, when the disease relapses, and when a switch has to be made to a subsequent treatment line. Often, there is not much choice between treatments and the most logical choice is based on the guideline and potential contraindications because of co-morbidity. However, there is always a choice not to treat, although according to the professional caregivers, this is not considered a realistic option for many patients. Especially for younger patients, the choice of no treatment is denied. Apart from the major decision points, all professional caregivers mentioned continuous smaller decision points within a treatment. Every time the patient comes to the hospital, this is a short evaluation moment at which the treatment can be adjusted, for instance, because of intolerable side effects. The professional caregivers stated that these moments of choice are often implicit, not explicitly mentioned, and therefore not consistently recognized by patients.

"Anytime there is a treatment choice. There are some major moments where there is a moment of choice for everyone. However, it is not the case that there are no moments of choice in between."

– Phy-1.

Whereas the professional caregivers indicated that the beginning of the treatment trajectory is a major moment of choice, the patients experienced the least choice in this phase. Several patients indicated that at the starting phase of treatment and diagnosis, this was an urgent situation. They were seriously ill, and something needed to be done. Especially in this phase, they did not experience

choice or control about the decisions made. The patients mentioned being overwhelmed, and the only decision made was that they needed to be treated. Some patients indicated that this decision was even made for them.

"Well, at the first hospitalization, you got little or no choice. You get all kinds of drugs, and no one really asks do you want this or not?" – Pat-4.

Later, several patients experienced more involvement in the decisions made. Nevertheless, five patients still explicitly stated there was still no real choice about treatment opportunities. For them, just like the professional caregivers stated, it was only about going for the treatment or not, in which not going for the treatment was an unrealistic option. For instance, because they consider themselves to be too young to quit treatment. Besides, several patients mentioned there were no alternatives, and the only possibility is the standard protocolled treatment. However, when it is about possible adjustments in ongoing treatment, almost every patient perceived some leeway in the amount and/or kind of prescribed drugs. Although not every patient perceived this as a decision on which they could exert influence. By way of contrast, some physicians indicated that treatment choice increases as the disease progresses. They stated that for the treatment starting point, the treatment guideline is often leading. Later, options and choices increase, through which the options pros and cons can be listed and discussed together with the patient.

Remarkably, just one physician mentioned that there is more choice than just a treatment choice. This physician described the importance to consider with the patient how to shape their treatment. For instance, will the appointments be in the hospital or via (video)call? Does the patient want to receive the drugs at home or the outpatient daycare? These types of decisions are considered to be vital as well.

"For example, when you know a person has difficulties with the disease and this person wants to be confronted as little as possible with the presence of this disease. Well, in that case I could say: does that mean that you want to come to the hospital as little as possible?" – Phy-2.

When questioned directly, every respondent stated the first step of SDM was applied. However, this is somewhat contradictory since, as earlier stated, some patients mentioned that they did not experience many moments of choice. In this context, some patients indicated that the decision was not always marked as a choice. They were aware of the choice they got but did not experience it as a realistic choice.

"It is not marked as a choice because that goes without saying. But, of course, you can choose not to do it" – Pat-2.

4.3.2.1.2 Patients opinion about the decision

Several patients indicated that their physician always asks for their opinion about the proposed therapy. This gives them a feeling of being heard by their physician. In addition, some patients indicated their physician speaks in terms of 'we', which gives them the feeling of being in this together. Furthermore, all physicians indicated that they tell the patient their opinion is essential. In advance, they consider what the patient has told them about what they value as important. Then, during the conversation, they ask what the patient wants and take that into account.

4.3.2.2 Step two

When a major choice is to be made, the interviews showed that the physician often proposes one treatment option to the patient. Every professional caregiver indicated that a treatment proposal is based on a patient's characteristics, possibilities, and preferences. For instance, for a patient who cannot reach the hospital on their own, treatment is offered in which he or she does not have to come to the hospital every week. Often, the guideline is the guiding principle when a physician offers a treatment. However, the professional caregivers stated there is deviation from the guideline if this treatment does not fit the patient's personal situation. Initially, physicians propose the most effective therapy and discuss why this therapy is offered based on their personal situation. The physicians explained that often the treatment proposal is discussed with colleagues or during the multi-disciplinary consultation in order to offer the patient broad-based treatment.

"Based on the patients' wishes and social environment, you propose a treatment" – Phy-1.

From the patients' perspective, every patient described that their current physician informs them sufficiently about the trajectory, pro's, cons, and potential side effects. If there are alternatives or space for minor adjustments, patients indicated that they usually receive information about this, or they ask for it themselves. In some cases, the information supply was considered to be insufficient. Some patients described the delivery of this information as plain and clear, others as open and transparent.

During the interviews, the professional caregivers mentioned that in case there is just one 'most effective treatment option', the physician proposes that particular treatment and informs the patient why this is, in the physician's view, the best option. Some physicians indicated that they still give the patients alternative possibilities but do express their preference for the most effective option. Furthermore, physicians stated that they adapt their way of proposing a treatment on the patient's attitude. They indicated that a well-informed patient receives more information on the content than a less-informed patient, who will more easily put the decision in the physician's hands. Furthermore, the age of the patient matters in proposing a therapy. For older patients, physicians indicated to pay more attention to the option of no treatment and the treatment's effects on the patient's wellbeing.

"Based on your knowledge as a physician, I think you should do some preliminary work. Moreover, when there is a proportional choice, you should do it together [SM: with the patient]."

– Phy-3.

When it is about participation in an ongoing clinical study, the physicians indicated they inform their patient about the study and non-study therapy objectively. Five patients mentioned they got the opportunity to participate in a study. Remarkably, one patient stated that the study was proposed as the only opportunity and no alternatives were named. Furthermore, one patient indicated that he proposed participating in a study himself, after which his physician agreed. Finally, the interviews showed that two patients made the active choice not to participate in the proposed studies because of diverse reasons. They, however, indicated to be informed about both possibilities sufficiently.

4.3.2.3 Step three

All patients indicated that they feel like they can express their wishes and preferences to their physician. Just one patient mentioned that his preferences were not asked for, this was however not perceived a problematic issue.

"No, I think that is quite right due to this expertise and stature. (...) In retrospect, I thought someone with such status and such a leading hematologist does not need to ask: what do you want?"

– Pat-6.

Moreover, whether a patient feels he or she can express their wishes and preferences, has a lot to do with the patient's and physician's attitudes. Several patients indicated that the physician has an open attitude and shares doubts or considerations about proceeding or choosing the treatment. Some patients mentioned the attitude of the physician as patient-centered and objective. These patients feel involved in their treatment trajectory and stated that the physician is focused on their needs. In contrast to the physician's objective attitude, several patients stated their physician has preferences in the treatment trajectory and explained a guiding attitude.

According to the professional caregivers, their attitude is situation dependent. In general, the professional caregivers indicated an open, honest, and person-centered attitude within the treatment trajectory and decision-making process. Every professional caregiver stated that they try to adapt to an individual patient's situation and give the patient space for their own contribution and considerations. At a proportional decision point, when there is an equal choice between two or more treatment options, they attempt not to guide the patient and let them choose. However, many patients ask for the physician's treatment preferences. Besides, physicians indicated an enormous lack of knowledge among patients, and therefore they do not expect them to be able or willing to make the decision.

"I do not have a very paternalistic mentality, but I do not want to do everything shared decision making. Look, I discuss the choice in which we could take different routes. (...) But how is a layman able to choose between three different treatments?" – Phy-4.

Whereas professional caregiver attitudes vary, the interviews showed that patient attitudes vary as well. The professional caregivers remarked significant differences between patient attitudes. They treat assertive and less assertive patients and indicated significant differences between regions, type of hospital, background, and level of education. Still, many patients want the physician to decide about their treatment. The professional caregivers mentioned stimulating these patients to participate actively in the treatment trajectory and decisions made. Moreover, they try to convince these patients to go through this treatment process together.

"It is up to you, doctor. Well, I do not think so. We are doing this together, and you are, unfortunately, the one in front of me (...). Together we will make decisions, and you must support it." – Phy-2.

The following quote describes a patient with a resigned attitude during his treatment. Pat-4: *"You just assume that the physicians know what they are doing and that it is just the best thing for me."* However, the other patients showed a very assertive attitude in their relationship with their physician. They explicitly stated they want to be in control of their disease and treatment trajectory, for instance, by checking their blood tests in advance of the appointment with the physician or prepare themselves for an appointment by checking the internet for information about treatment opportunities and new scientific studies. They want to be in charge. The interviews showed that in some cases this is because things have gone wrong in the past, or they temporarily could not oversee their treatment trajectory.

Furthermore, in line with the differences in patients' and physicians' attitudes, patients have got different experiences in the degree of support to consider the options. Some indicated they did not need support in considering options. Others mentioned that the physician informs them, but they had to choose for themselves. Finally, someone else mentioned she gathers all information from her physician, and accordingly, she chooses herself. The experience of this patient is in accordance with a physician who mentioned that he helps his patients considering the options by answering their questions and adjusting his explanation to their level of intelligence. He also stated that he ensures them that there is no wrong choice. Another physician indicated to support her patient by going beyond side effects and effectiveness. Phy-2 stated: *"I try not just to explain the effectiveness of the treatment (...). Patients read and hear a lot about side effects. However, it is rarely about how this will affect my daily week."* To finish, the interviews revealed that all physicians attempt to zoom in on what is important for a patient in the support in considering the options.

4.3.2.4 Step four

Almost no respondents mentioned to talk explicitly about their, or their patient's preferred role in the decision. Both patients and physicians stated this happens more implicitly or automatically. By doing so, the interviews showed that every patient thinks their physician knows their preferred role in the decision. Several patients indicated to be outspoken, pro-active, or assertive. Via natural attrition, they think their physician knows they want to be involved in their decision. Some patients made their expectations or the importance of being involved clear. Furthermore, the physicians indicated to estimate during an appointment to what extent a patient can make the final decision. Besides, they mentioned that the patient is the one that has to undergo the treatment, so eventually, the one to say yes or no.

Next to this, one physician mentioned that talking with the patient about their preferred role in the decision is potentially a valuable step to undertake. Another physician stated that this step is further forward in the conversation.

As stated, there is often no explicit conversation about the patients preferred role in the decision. Next to this, it was also not perceived straight forward whether a decision is shared or belongs to the physician or patient. According to the professional caregivers this depends on the attitude, situation, and treatment phase. For example, the professional caregivers indicated, when it regards a study treatment or proportional decision, the decision belongs more to the patient. However, in an acute situation or prolonging treatment is considered ineffective or harmful, the decision belongs more to the physician. This is in line with the perception of the patients who experienced differences in decisions and the degree of influence they got in that decision. For instance, when it was about quitting treatment, this decision was perceived entirely as the patient's decision. Pat-7 experienced this in a situation where she got the opportunity to undergo very aggressive chemotherapy or quit treatment at all. She indicated to quit on grounds of having some more energy:

"I do not feel like it. I cannot manage it. If I opt for it, I must go to the hospital two times a week for two hours to receive the chemotherapy. So I said: I will not do it." – Pat-7.

Although patients experienced differences in the degree in which they can exert influence on the decisions made, almost every patient stated that the decision is a shared one. However, for these patients a shared decision does not mean that this is a balanced decision between patient and physician. Several patients stated that this 'shared decision' is mostly about being involved and being heard, though which decisions feel like a shared decision.

"When necessary, it was shared, and when not necessary or desirable, it was not shared (...). There were no points in time where I had the feeling that something was decided about me that I did not have had a say in, not at all." – Pat-6.

Among the patients who perceive the decisions to be shared, three of them mentioned the physician decides at some point in time and guides the decision. However, this was not considered negative. Moreover, this is in line with the interviews of several professional caregivers, who indicated they can guide a decision and that patients often agree with proposed therapies. Additionally, the professional caregivers mentioned that for many patients, it is too hard to decide. In

contrast, the other part of the patients considered the decision to be shared and entirely theirs at some point in time. Ultimately, every patient is satisfied with the decision-making process.

4.3.3 Opinion about SDM

According to several patients, a positive element of SDM is the involvement in their treatment trajectory. However, SDM has its boundaries. For example, some patients did not yet experience decisional space right now to make a shared decision. Furthermore, they are aware that the physician is the expert, and therefore, not every decision can be shared. Besides, SDM requires the patient to gather knowledge about their disease and, therefore, also involves the patient's responsibility, according to one patient.

"But I think it is debatable. Eventually, the physician is the expert and studied for this, and as a patient, I am... Yes, I am glad being involved, but she is the one to decide for me?"- Pat-6.

In accordance with the patients' opinion about SDM, the professional caregivers also stated that SDM is bounded. Particularly for MM, the physicians indicated there is not always a broad or equal choice between two or more options, which sometimes limits the possibilities to make a shared decision.

"You ask what the patient wants and take their wishes into account. (...) You explain and reason the proposed therapy. What is the disadvantage? Perhaps it is not possible for you at all, well that is it. I just think you can beautifully call it SDM, but it is just not possible." – Phy-1.

Furthermore, several interviews showed that not every patient is capable to decide or wants to make a shared decision. For the professional caregivers, SDM is mostly about transparency, explanation, information, and communication. Moreover, and in line with the patients' opinion, according to some physicians, SDM is also about the involvement of patients in their treatment trajectory, and subsequently empower and prepare them in the conversation with their physician.

Every professional caregiver described that they perform SDM based on intuition or personal beliefs, and therefore not step by step like the SDM model describes. Remarkably, although every professional caregiver stated making a shared decision is encouraged, they all initiated support from another association or group. For instance, by the professional group, scientific association, hospital, or during their study of medicine. Furthermore, the most experienced physician indicated that SDM

is already going on for years as transparency in the healthcare sector, whereas it is recently conceptualized as SDM.

4.4 Personal values in treatment decisions

To finish the conducted interviews, every respondent was asked what they think is the influence of SDM, or the way they handle with decisions, on the involvement of their (patients') vital elements in life in the treatment trajectory and decisions.

More than half of the interviewed patients mentioned that the way the decisions were made has positively influenced their involvement in the treatment trajectory, and subsequently the involvement of their personal values in the trajectory and the decisions made. Furthermore, several patients indicated that they feel heard and authorized to contribute to the decisions made. However, some patients did not think the interaction with their physician has mattered for the decisions made. To finish, one patient explained that for him the treatment trajectory and decisions are not about personal values and quality of life, since this disease is just a matter of life and death.

The professional caregiver interviews showed that several professional caregivers adapt to what patients value, and subsequently want, because of the way they interact and make (shared) decisions with their patients. This is perceived at every decision moment, but also during treatment, which according to some professional caregivers results in decisions and treatments increasingly supported by the patients. Furthermore, one physician stated that SDM has resulted in an increased dialogue, through which this physician is increasingly familiar with how her patient's life looks like. This allows her to zoom in on the impact of a therapy on someone's life. Almost every professional caregiver indicated these are positive effects of SDM, however one physician states this is not especially the effect of SDM since she has always acted in this way.

5. Discussion and conclusion

In this chapter, the research sub-questions will be answered. Moreover, this study will be positioned in the existing literature, and its contributions to the body of knowledge will be discussed. Further, limitations and strengths, practical implications, and recommendations for further research will be provided, after which a conclusion will be given.

5.1 Answers to the sub-questions

This study aimed to investigate which role personal values play in treatment decisions for people with Multiple Myeloma and how this contributes in Shared Decision Making. In order to answer the main research question, five sub-questions were formulated. Below, the combined answers to these sub-questions are described.

Patients in this study reported on a variety of personal values. For every patient, social interaction with friends and family is an important personal value that gives them energy, trust, and safety. Furthermore, enjoying the simple things in life, together with their loved ones, is essential for several patients. Lastly, mobility is considered a personal value; limited mobility significantly influences the patient's freedom and autonomy, which is deemed relevant in their lives. Even though professional caregivers faced some complexities when disclosing their patients' personal values, they are largely familiar with the personal values of their patients. Throughout the treatment trajectory, professional caregivers try to disclose the patient's personal values in several ways. The personal values described by patients overlap with the personal values the physicians defined to a large extent. Additionally, the professional caregivers identified a difference in personal values between younger and older patients.

Most patients described their personal values as vital for the patient physician relationship, way of information exchange, and proposed treatments, influencing the interaction between patient and physician. From the professional caregivers' perspective, knowledge about their patient's personal values allows them to zoom in on what is essential for a patient when proposing a treatment or supporting the patient in considering the options. In this way, patients' personal values partly shape the treatment decisions, and influence the way the treatment is designed. However, next to personal values, patients and professional caregivers also consider the effectiveness of a treatment as relevant in treatment decisions.

This study showed that both patients and physicians were not familiar with the four steps of SDM. However, except for the final steps, according to the patients' and physicians' description of the decision-making process, this was largely in line with SDM. The last step is applied more implicitly, in which physicians estimate to what extent patients are capable of making the final decision. Furthermore, although patients were not always offered various treatment options, there is asked for their opinion about the proposed therapy. To finish, patients and physicians also experienced that SDM has its boundaries through which not every decision can be shared.

Within the decision-making process, the role of personal values may differ between patient subgroups or over time. In this study, no significant differences in the role of personal values between patient subgroups were found. However, professional caregivers indicated to observe differences in personal values in treatment between younger and older patients. These professional caregivers indicated that whereas a younger person always wants 'the optimal' treatment, older persons also balance out their treatment choice with regard to their self-determined quality of life. Regarding the patients' personal values over time, some differences were found. Nevertheless, there was no clear direction in this change over time. Before and after the diagnosis, a shift in personal values from work to wellbeing, loved ones, and the appreciation of the simple things in life can be remarked.

5.2 Discussion

According to the Ministry of Health (2018), professional caregivers are still mainly focused on clinical outcomes. However, other values may be just as important for patients, and these values might affect treatment decisions (Ministry of Health, 2018). This study showed physicians often propose their patients the most effective treatment in accordance with the guidelines, however they appear not to be merely focused on clinical outcomes. Instead, physicians offer therapy based on a patient's characteristics, possibilities, and preferences. Therefore, they take the patient's personal situation and values into account and focus apart from clinical outcomes on outcomes considered relevant by their patients. Further, like the EXPH stated in their exhaustive conceptualization of VBHC, the crucial role of personal values in treatment decisions is recognized in this study's results (EXPH, 2019).

The focus of this study was mainly on the process leading to a treatment decision, and not just on the content of the decision itself. Prior to a decision, sufficient information about the options, side effects, and pros and cons of treatment is required. However, literature showed a discrepancy in the level of desired and received information for patients (Tamirisa et al., 2017; LeBlanc et al., 2019). In this study, this perceived discrepancy in information was only found when there was an urgency to

start a treatment. In these urgent situations, which mainly occurred at the beginning of the treatment trajectory, the patients indicated to be severely ill which meant that treatment needed to start as soon as possible. In this phase, some patients experienced little involvement and insufficient information supply. This limited extent of information discrepancy might be explained by the patient population of this study. Almost every patient indicated to be outspoken, pro-active, or assertive in which they mentioned to ask many questions themselves. Therefore, it could be the case that this patient population acts more pro-active when they perceive the gained information as insufficient. Because of this attitude, the interviewed patients potentially automatically ask for additional information or gather more information themselves, for instance by looking on the internet, which could explain that this study almost found no discrepancy between desired and received information for patients. Next, Kehl et al. (2015) indicated that patients often ask their physician for advice regarding their treatment decision (Kehl et al., 2015). The physician interviews showed that many patients ask their physician about their treatment preferences, and still many patients like the physician to decide for them, wherefore this study supports the findings of Kehl et al. (2015).

The desired and experienced level of involvement by patients is crucial in the decision-making process. According to the literature, patients often want to be involved in their treatment decisions (Tamirisa et al., 2017). The findings of this study confirmed this since several patients indicated they want to be involved in their treatment trajectory to control their disease. This involvement is also considered relevant within SDM. Several patients stated that SDM is mostly about being involved and heard in their treatment trajectory and not always about making a shared decision together with their physician. This was also found in the study of Stiggelbout et al. (2015), where the respondents felt heard and seen as a person, which was beneficiary for their satisfaction regarding the treatment process (Stiggelbout et al., 2015).

When taking the four SDM steps into account, this study has shown that, although physicians and patients were not familiar with the steps, the decision-making process was broadly in line with the elements of each of these steps. The existing literature has evaluated the appearance of these steps as well. Stiggelbout et al. (2015) addressed a knowledge gap in the third step of SDM, the step in which the physician supports the patient in considering the options (Stiggelbout et al., 2015). With the results of the current study, this gap may be filled with the findings that patients need different degrees of support to consider the options. Whereas not every patient needed help in considering the possibilities, others experienced the support as the physician who provides sufficient information after which the patients made the consideration, and subsequently the decision themselves. For physicians, this support consisted of zooming in on what is important for the patient, and sometimes,

go beyond effectiveness and side effects and talk with the patient about the therapy's impact on their daily week. Therefore, discovering a patient's needs about their preferred degree of support in considering the options may be just as important as informing them about the options.

Further, Osborne et al. (2014) studied what matters most for MM patients. Their findings show large resemblance with the findings of this current study. This research has discovered that for patients being able to do the simple daily things in life is of utmost importance. The literature described this as activity and participation, which is largely influenced by other disease and treatment-related factors (Osborne et al., 2014). This present study showed what patients define as quality of life and that this differs per patient and over time. Everyone values different elements in life as important and having a chronic disease may change what quality of life means to an individual. Yet, further research should explore how and in which direction the role of personal values and the meaning of quality of life alter because of having a chronic illness.

This study revealed some new insights that, to the researcher's best knowledge, have never been described before. First, the recognition from both patient and physician that, nowadays, SDM has its boundaries and is not applicable in every situation and for every patient. This study's interviews showed that these boundaries are predominantly found in situations in which a decision is required and where there is not much equal choice between two or more treatment options, in case therapies are medically not possible, or when patients do not have the capabilities to contribute to a shared decision. Furthermore, interviews with the professional caregivers showed that patients still have an enormous knowledge lack due to which they are simply not able to make some treatment choices.

5.3 Strengths and limitations

This study has at least four important limitations. First, this study's sample may not be representative for the MM patient population. The interviewed patients ranged in age between 53 and 75 and had a median diagnosis age of approximately 57 years. This is not representative for the MM population since the overall median diagnosis age is 70 years (Brink et al., 2019). Therefore, the findings of this study may not be generalizable to this older MM population. Furthermore, it can be imagined that the patients who participated in this study are not the 'average' patients but want to be active and involved in their treatment trajectory anyhow. This could have influenced the results and should be further explored in future research. The same applies to the professional caregiver respondents. Most of the professional caregivers were women, relatively young and new in the profession, and therefore not entirely representative for the professional caregiver population, which could have

influenced this study's findings. Nevertheless, a more experienced physician was interviewed which did not lead to an entirely different picture. The only outstanding differences were observed regarding her opinion about the conceptualization of SDM.

Another limitation of this study is the sensitivity of this research's topic. As a professional caregiver, the application of SDM and paying attention to a patient's personal values is highly desired and strived for. Therefore, this might lead to socially desirable answers in which professional caregivers appear differently than they really appear in daily practice. The researcher tried to avoid this phenomenon by frequently asking for concrete examples to come as close as possible to someone's experience. Besides, for the professional caregivers the tendency to present their course of action more positive than it is, is relatively low because of the scholarly basis of this study.

During the interviews, it became clear that most of the patients were not in the acute treatment trajectory phase where much equal choice between two or more treatment options was experienced. Due to this, it was harder to investigate the diversity within the different moments of the decision-making process. However, although patients did not always experience explicit decisions and moments of choice, the treatment trajectory consists of many implicit decision points. This is an interesting finding as well and potentially a valuable starting point for further research.

To finish, due to the corona crisis, almost all interviews were held via (video)call. Since semi-structured interviews were the primary data collection method, this is perceived as a limitation. With semi-structured interviews, the interaction between interviewer and interviewee is vital. Interviews in person stimulate trust between interviewer and interviewee and consequently generates interviews which gain more in-depth knowledge (Vogl, 2013). However, interviewing via (video)call increased the reliability of this study since in total more interviews could take place, as there was no travel time for both parties.

Notwithstanding the limitations of this study, this study also has several strengths. First, the nature of the interviews was semi-structured. This enabled the respondents to talk freely, and specifically for the patients, to tell their whole story. There was space to clarify matters for the interviewer or to go even more in-depth based on the interviewee's answers. Furthermore, there was space to ask audit questions to avoid potential misinterpretation, which improved the validity of this research. Moreover, all respondents have had the opportunity to receive the interview transcript to perform a member check, which improved the internal validity as well. Another strength of this research may be found in the coding process, which is partly performed together with another

qualitative researcher. By doing so, the reliability of the results was improved. Lastly, the patients' and professional caregivers' perspectives were integrated with this study. This resulted in a comprehensive view of the relation and interaction between both.

5.4 Practical implications

Next to the fact that this study emphasizes what patients value in life, their treatment trajectory, and subsequent treatment decisions, it provides insight into how the decision-making process unfolds in daily practice and into the boundaries of SDM. Not every patient wants or is capable to make their own decisions, not every decision can be made together with the patient and physician, and ultimately not every patient experiences moments of choice where they can exert influence on. However, for patients and professional caregivers, it is crucial to realize that SDM is not just about the patient making the treatment decision but about involving patients in their treatment trajectory to their preferred extent. In the involvement of patients, clear and transparent communication, and understandable information geared to the individual is of utmost relevance. Next to this, patients have to be aware that they always have a choice, even if this is just the choice of whether or not to undergo treatment. In the common situation where one treatment option is proposed, patients still have a choice, namely the choice not to do it. Hence, it is twofold. Patients should be empowered by their professional caregivers and empower themselves to participate in their treatment trajectory actively and recognize their role within this trajectory. On the other hand, physicians should allow their patients by adequate information and communication to participate in the treatment trajectory and recognize that SDM goes beyond just the decisions made. According to these findings, a practical implication for patients can be worked out via patient associations, for instance, Hematon for MM and related diseases. Patient organizations could be helpful to make patients increasingly aware of their role in the treatment trajectory and give them tools about how they could prepare themselves for a conversation with the physician in order to become involved in their treatment trajectory to their preferred extent. Moreover, physicians play an important role in empowering their patients. The results showed that for physicians making a shared decision is promoted via different routes. Therefore, it may be helpful to organize this in a more structured manner by focusing on one pathway, for instance the professional group. The professional group can be useful in several ways. First, to make the physicians aware that SDM goes beyond the treatment decisions itself. Second, to provide physicians with handholds for the conversation with the patient to make them increasingly able to assess a patient's preferred involvement. Third, to provide handholds to empower their patients and adapt information and communication strategies on the individual.

Another practical implication of this study is, in accordance with the discovered differences in patients' personal values and needs, that SDM should not be performed in one particular manner. Individual preferences regarding communication, level of information exchange, and desired involvement should be considered to adapt SDM to the individual. Practically, this could, again, be carried out by the physicians' professional groups to create awareness about the variety in patients' needs and preferences.

A final implication regards the current treatment assessment. Nowadays, the main focus is still on effectiveness. Although this study showed that effectiveness is still considered crucial by patients and physicians, other factors also play a role in determining whether a treatment is valuable. Whereas for some persons, the optimal treatment is related to the length of life, others may perceive treatment as optimal when maintaining their self-determined quality of life during treatment. What is considered as quality of life differs per individual. For instance, relevant factors of quality of life during treatment mentioned in this study were tiredness, mobility, and freedom. Therefore, it is recommended, especially for incurable diseases, to account for other factors besides effectiveness in assessing treatments.

5.5 Recommendations for further research

According to the results of this study, some interesting recommendations for further research can be made. First, as stated in the former section, SDM is twofold. Therefore, it would be interesting to investigate which way is most desirable to empower patients to become an increasingly active partner in their treatment trajectory. Furthermore, it is recommended to focus on patients with different characteristics, for instance, high and low educated, young and old, Dutch and foreign. Subsequently, the physician's role does not need to be underestimated. Therefore, it would also be interesting to investigate how physicians can be supported and empowered to apply SDM for various patient types.

Next, as mentioned in the limitations, the respondent group of this research is not representative of the MM population and physicians. This study's sample consisted of relatively few older patients, wherefore it could be the case that this study's results do not apply for the under investigated older patients. To find out whether these patients have different personal values or fancy to be involved in their treatment trajectory and decisions differently, it is recommended to perform a similar study and expand the study population to a more representable population to potentially generalize the results. Accordingly, the same goes for the investigated disease, MM. The results have shown that often the patients did not experience treatment choice, or equal choice

between two or more treatments. It would be interesting to investigate which role personal values play in treatment decisions when there is more equal choice between treatments. Therefore, it is recommended to perform a similar study for a chronic disease in which there is a more equal treatment choice.

5.6 Conclusion

This study has investigated which role personal values play in treatment decisions for people with MM and how this contributes in SDM. According to patients as well as physicians, personal values are considered relevant in the treatment trajectory and the decisions made. Personal values influence the patient-physician relationship, way of information exchange and due to this they partly shape the proposed treatments. For professional caregivers, the familiarity with a patient's personal values enables them to zoom in on what is important for an individual when proposing a treatment. Nevertheless, the treatment's effectiveness remains highly relevant in the decisions made.

Although the decision-making process was not entirely in line with the SDM steps, SDM is considered to contribute to the involvement of patients in their treatment trajectory. For several patients, the way the treatment decisions are made resulted in feeling heard and authorized to contribute to the decisions. For professional caregivers, the interaction with their patients allows them to adapt to what is important for them. Most professional caregivers consider this as a positive effect of SDM.

References

- Ahaus, K. (2020). *Organiseren van waardegedreven zorg vanuit patiëntperspectief*. Erasmus School of Health Policy & Management. Retrieved 29 April 2021 from <https://www.eur.nl/sites/corporate/files/2020-12/organiseren-van-waardegedreven-zorg-vanuit-patientperspectief.pdf>
- Baarda, D. B., de Goede, M. P. M., & Teunissen, J. (2009). *Basisboek kwalitatief onderzoek: Handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek*. Noordhoff Uitgevers.
- Boeije, H. R. (2010). *Analysis in Qualitative Research* (1st ed.). SAGE Publications Ltd.
- Brink, M., Korf - van Vliet, C. H., Plaisier, M., Sonneveld, P., Zweegman, S., van de Donk, N. W. C. J., ... & Dinmohamed, A. G. (2019). Multipel myeloom in Nederland, 2014-2017. Landelijk rapport van het hemato-oncologieregister van de Nederlandse Kankerregistratie. Utrecht: Integraal Kankercentrum Nederland.
- CBS (2021). Stedelijk gebied. Retrieved 2 August 2021 from <https://www.cbs.nl/nl-nl/onze-diensten/methoden/begrippen/stedelijk-gebied>
- CBS StatLine. (2021). Gebieden in Nederland 2021. Retrieved 2 August from <https://opendata.cbs.nl/#/CBS/nl/dataset/84929NED/table?ts=1627893821424>
- Couët, N., Desroches, S., Robitaille, H., Vaillancourt, H., Leblanc, A., Turcotte, S., ... & Légaré, F. (2015). Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expectations*, 18(4), 542-561.
- Covey, J. R., Kamal, K. M., Gorse, E. E., Mehta, Z., Dhumal, T., Heidari, E., Rao, D., & Zacker, C. (2019). Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 27(5), 1613–1637. <https://doi.org/10.1007/s00520-019-04675-7>
- Cuffe, C. H., Quirke, M. B., & McCabe, C. (2020). Patients' experiences of living with multiple myeloma. *British Journal of Nursing*, 29(2), 103-110.

- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., ... & Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of general internal medicine, 27*(10), 1361-1367.
- Expert Panel on effective ways of investing in Health (EXPH). (2019). Defining value in “value-based healthcare”.
- Gafni, A. & Charles, C. (2017). *Shared decision-making, decision aids, and the role of values in treatment decision-making*. In Kissane, D. W., Bultz, B. D., Butow, P. N., Noble, S., & Wilkinson, S. *Oxford textbook of communication in oncology and palliative care* (pp 23-27). Oxford University Press.
- Groenewoud, A. S., Westert, G. P., & Kremer, J. A. (2019). Value based competition in health care’s ethical drawbacks and the need for a values-driven approach. *BMC health services research, 19*(1), 1-6.
- Jen, W. Y., Yoong, J., Liu, X., Tan, M. S. Y., Chng, W. J., & Chee, Y. L. (2020). Qualitative study of factors affecting patient, caregiver and physician preferences for treatment of myeloma and indolent lymphoma. *Patient preference and adherence, 14*, 301.
- Kambhampati, S., Ashvetiya, T., Stone, N. J., Blumenthal, R. S., & Martin, S. S. (2016). Shared decision-making and patient empowerment in preventive cardiology. *Current cardiology reports, 18*(5), 49.
- Kane, H. L., Halpern, M. T., Squiers, L. B., Treiman, K. A., & McCormack, L. A. (2014). Implementing and evaluating shared decision making in oncology practice. *CA: a cancer journal for clinicians, 64*(6), 377-388.
- Kanker.nl. (n.d.). Multipel Myeloom (ziekte van Kahler). Retrieved 1 March 2021 from <https://www.kanker.nl/kankersoorten/multipel-myeloom/wat-is/multipel-myeloom-ziekte-van-kahler>
- Kebede, S. (2016). Ask patients “What matters to you?” rather than “What’s the matter?”. *Bmj, 354*.

- Kehl, K. L., Landrum, M. B., Arora, N. K., Ganz, P. A., Van Ryn, M., Mack, J. W., & Keating, N. L. (2015). Association of actual and preferred decision roles with patient-reported quality of care: shared decision making in cancer care. *JAMA oncology*, *1*(1), 50-58.
- La Grouw, Y., Kee, K., Ybema, S., Taverne., & Boonen, L. (2019). Samen beslissen in de praktijk. *Praktijkonderzoek i.o.v. het Zorginstituut Nederland*.
- LeBlanc, T. W., Baile, W. F., Eggly, S., Bylund, C. L., Kurtin, S., Khurana, M., ... & Fonseca, R. (2019). Review of the patient-centered communication landscape in multiple myeloma and other hematologic malignancies. *Patient education and counseling*, *102*(9), 1602-1612.
- Légaré, F., Stacey, D., Turcotte, S., Cossi, M. J., Kryworuchko, J., Graham, I. D., ... & Donner-Banzhoff, N. (2014). Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane database of systematic reviews*, (9).
- Mateos, M. V., Ludwig, H., Bazarbachi, A., Beksac, M., Bladé, J., Boccadoro, M., ... & Sonneveld, P. (2019). Insights on multiple myeloma treatment strategies. *Hemasphere*, *3*(1).
- Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health]. (2018). Ontwikkeling Uitkomstgerichte zorg 2018-2022.
- Mortelmans, D. (2018). *Handboek kwalitatieve onderzoeksmethoden* (5e dr ed.). Leuven: Acco.
- Osborne, T. R., Ramsenthaler, C., de Wolf-Linder, S., Schey, S. A., Siegert, R. J., Edmonds, P. M., & Higginson, I. J. (2014). Understanding what matters most to people with multiple myeloma: a qualitative study of views on quality of life. *Bmc Cancer*, *14*(1), 1-14.
- Politi, M. C., Studts, J. L., & Hayslip, J. W. (2012). Shared decision making in oncology practice: what do oncologists need to know?. *The oncologist*, *17*(1), 91.
- Porter, M. E. (2008). Defining and introducing value in health care. In *Evidence-based medicine and the changing nature of health care: 2007 IOM annual meeting summary* (pp. 161-72). National Academies Press.
- Porter, M. E. (2008). Value-based health care delivery. *Annals of surgery*, *248*(4), 503-509.

- Pritlove, C., Jassi, M., Burns, B., & McCurdy, A. (2021). The work of managing multiple myeloma and its implications for treatment-related decision making: a qualitative study of patient and caregiver experiences. *BMC cancer*, *21*(1), 1-11.
- Renjith, V., Yesodharan, R., Noronha, J. A., Ladd, E., & George, A. (2021). Qualitative methods in health care research. *International Journal of Preventive Medicine*, *12*.
- Steffensen, K. D., Vinter, M., Crüger, D., Dankl, K., Coulter, A., Stuart, B., & Berry, L. L. (2018). Lessons in integrating shared decision-making into cancer care. *Journal of oncology practice*, *14*(4), 229-235.
- Steinmann, G., van de Bovenkamp, H., de Bont, A., & Delnoij, D. (2020). Redefining value: a discourse analysis on value-based health care. *BMC health services research*, *20*(1), 1-13.
- Stiggelbout, A. M., Pieterse, A. H., & De Haes, J. C. (2015). Shared decision making: concepts, evidence, and practice. *Patient education and counseling*, *98*(10), 1172-1179.
- Stiggelbout, A. M., Van der Weijden, T., De Wit, M. P., Frosch, D., Légaré, F., Montori, V. M., ... & Elwyn, G. (2012). Shared decision making: really putting patients at the centre of healthcare. *Bmj*, *344*.
- Tamirisa, N. P., Goodwin, J. S., Kandalam, A., Linder, S. K., Weller, S., Turrubiate, S., ... & Riall, T. S. (2017). Patient and physician views of shared decision making in cancer. *Health Expectations*, *20*(6), 1248-1253.
- V&VN VS. (n.d.). Over de verpleegkundig specialist. Retrieved 1 August 2021 from <https://venvnvs.nl/venvnvs/over-de-verpleegkundig-specialist/>
- Vogl, S. (2013). Telephone Versus Face-to-Face Interviews. *Sociological Methodology*, *43*(1), 133 - 177. <https://doi.org/10.1177/0081175012465967>
- Zorginstituut Nederland. (2018). *Toetsingskader kwaliteitsstandaarden, informatiestandaarden & meetinstrumenten 2015*. Versie 2.1.

Appendix A: Invitation Hematon for participation in interviews

Geachte heer/mevrouw,

Mijn naam is Sara Mostert en ik ben bezig met afronden van mijn masterstudie Health Economics, Policy & Law aan de Erasmus Universiteit te Rotterdam (<https://www.eur.nl/en/master/health-economics-policy-law>).

Voor mijn masterthesis wil ik onderzoek gaan doen naar het besluitvormingsproces van behandelbeslissingen bij personen met Multipel Myeloom. Hierbij wil ik gaan onderzoeken welke persoonlijke voorkeuren, waarden en doelen voor patiënten belangrijk zijn en welke rol deze vervullen bij het nemen van behandelbeslissingen. Vervolgens wil ik onderzoeken in hoeverre de zorgverlener en patiënt gezamenlijk behandelbeslissingen nemen en welke rol de persoonlijke voorkeuren, waarden en doelen van patiënten hierin spelen.

Het besluitvormingsproces bij behandelbeslissingen omtrent de aandoening Multipel Myeloom is relevant aangezien er verscheidene behandelmogelijkheden zijn en personen vaak gedurende een langere periode met de aandoening te maken hebben. Meer samen beslissen (Shared Decision Making) is de komende jaren één van beoogde doelen van de overheid. Het, indien gewenst door de patiënt, maken van een gezamenlijke behandelbeslissing met inachtneming van zijn/haar persoonlijk wensen leidt in toenemende mate tot uitkomsten welke passen in bij zijn/haar persoonlijke waarden en doelen. Er is gebleken dat vrijwel alle patiënten graag betrokken willen worden bij een beslissing tot behandeling, echter wordt dit door patiënten nog niet altijd zo ervaren.

Voor mijn onderzoek zou ik graag door middel van interviews inzicht krijgen in dit onderwerp. Zou een bestuurslid van Hematon, als vertegenwoordiger van patiënten, bereid zijn om hierover met mij een interview in te plannen?

Om een compleet beeld te krijgen van het besluitvormingsproces, zou ik daarnaast ook graag interviews houden met personen met Multipel Myeloom en artsen die personen met Multipel Myeloom behandelen of behandeld hebben en hierover in gesprek gaan. Zou u als patiëntenorganisatie wat voor mij willen en kunnen betekenen bij het vinden van patiënten die bereid zijn tot een interview? Naar verwachting zal een interview ongeveer 30 tot 60 minuten duren en er zal natuurlijk rekening worden gehouden met de wensen en tijdsplanning van de geïnterviewde. Tevens zullen de interviewgegevens volledig geanonimiseerd worden en zal ik het gespreksverslag achteraf naar de geïnterviewde toesturen zodat hij/zij kan verifiëren of de inhoud overeenkomt met de versterkte en bedoelde informatie.

Ik hoop van harte van u te horen.

Met vriendelijke groet,

Sara Mostert

T: 06-52192706

M: sara_mostert@hotmail.com

Appendix B: Invitation Facebook group for Dutch MM patients for participation in interviews

Geachte heer/mevrouw,

Mijn naam is Sara Mostert en ik ben bezig met het afronden van mijn masterstudie Health Economics, Policy & Law aan de Erasmus Universiteit te Rotterdam.

Allereerst wil ik graag zeggen dat ik gezien de gevoeligheid van het onderwerp enige tijd heb getwijfeld of het gepast is om dit bericht in deze groep te plaatsen. Indien iemand uit deze groep vindt dat dit bericht hier absoluut niet thuis hoort, zal ik het bericht en mijzelf direct uit de groep verwijderen. Dit gezegd hebbende, zal ik de reden van mijn bericht en mijn thesis onderzoek toelichten.

Voor mijn masterthesis wil ik onderzoek gaan doen naar het besluitvormingsproces van behandelbeslissingen bij personen met Multipel Myeloom. Hierbij wil ik inzicht krijgen in wat voor personen met Multipel Myeloom belangrijk is in het leven op het gebied van persoonlijke voorkeuren, waarden en doelen en welke rol deze innemen bij het maken van behandelbeslissingen. Vervolgens wil ik onderzoeken in hoeverre er gezamenlijk met zorgverlener(s) behandelbeslissingen worden genomen en op welke manier de voor u belangrijke elementen in het leven terugkomen in deze beslissingen. Om dit te onderzoeken zou ik graag met personen met Multipel Myeloom in gesprek gaan over uw ervaringen met het nemen van beslissingen in uw behandeltraject. Zou u bereid zijn om in een interview van ongeveer 45 minuten hierover met mij te praten? Het interview kan naar uw voorkeur plaatsvinden via (beeld)bel-contact of een persoonlijk gesprek. Tevens zal ik achteraf de interviewgegevens volledig anonimiseren. Indien u nog vragen heeft, ben ik te bereiken op onderstaand telefoonnummer, mailadres en/of Facebook Messenger.

Ik hoop van harte van u te horen.

Met vriendelijke groet,

Sara Mostert

T: 06-52192706

M: sara_mostert@hotmail.com

Appendix C: Interview guides

Interview guide patients

Introductie

- Welkom
- Introductie onderzoeker
- Doel van het gesprek: *inzicht krijgen in het besluitvormingsproces voor behandeling bij MM patiënten en in gesprek gaan over de rol van persoonlijke waarden, voorkeuren en doelen van patiënten bij het nemen van besluiten.*
- Duur interview: 45 min
- Opbouw interview: *algemene vragen, vragen over de persoonlijke voorkeuren waarden en doelen van patiënten, vragen over behandelbeslissingen en SDM.*
- Audio opname, reden daarvan, toestemming daarvoor, anonimiteit
- Member check, behoefte daaraan
- Heeft u op dit moment nog vragen of zijn er dingen onduidelijk?

Algemene vragen

- Kunt u mij om te beginnen kort wat over uzelf vertellen?
 - *Naam, leeftijd, werk, familie*
- Kunt u mij wat vertellen over uw huidige gezondheid?
- Hoelang weet u al dat u de ziekte van Kahler/Multipel Myeloom heeft?
- Hoe ziet uw huidige behandeltraject eruit?
- Kunt u kort aangeven welke behandelingen u heeft gehad?
 - *Welke behandeling als zwaar ervaren?*
 - *Welke behandeling als lichter ervaren?*
- Wat bekent deze aandoening voor u en uw omgeving?

Persoonlijke voorkeuren, waarden en doelen

- Kunt u beschrijven wat momenteel in uw leven voor u het belangrijkste is?
 - *Denk aan: gezondheid, familie, hobby's, autonomie, vrijheid, sociale contacten*
- Welke persoonlijke doelen streeft u na in uw leven?
- Op welke manier past u deze genoemde dingen in uw leven in?
- Op welke manier worden deze dingen beïnvloed door uw ziekte of behandeling?
- Als u naar uw aandoening en behandeling kijkt, wat is daarin het belangrijkste voor u?
 - *Overeenkomstig met beschreven belangrijke elementen in het leven?*
- Op welke manier laat u dit naar voren komen in uw behandeltraject en behandelkeuzes?

Behandelbeslissingen en SDM

- Heeft u keuzemomenten, en zo ja wat voor keuzemomenten heeft u ervaren in uw behandeltraject?
 - *Wat voor behandelbesluiten zijn er genomen?*
- Welke personen waren of heeft u hierbij betrokken?
 - *Arts, verpleegkundige, familie, etc*
- Hoe heeft u deze keuzemomenten ervaren?

- Op welke manier heeft u zich voorbereid op deze keuzemomenten voor behandelbeslissingen?
- Kunt u omschrijven hoe behandelbeslissingen zijn gemaakt in het verleden?
 - *Eventueel a.d.h.v. een voorbeeld*
- In hoeverre had u het gevoel dat u echt de beslissing mocht maken?
- Hoe werd dit aan u duidelijk gemaakt?

De overheid streeft de komende jaren naar meer samen beslissen (SDM). Dit betekent het, indien gewenst door de patiënt, maken van een gezamenlijke behandelbeslissing. Het maken van deze beslissing met inachtneming van iemands persoonlijk wensen zal in toenemende mate leiden tot uitkomsten welke passen in bij zijn/haar persoonlijke waarden en doelen.

- Bent u bekend met het concept Samen Beslissen/SDM?
 - *Zo niet: uitleggen wat het inhoudt*
- Kunt u omschrijven wat dit volgens u inhoudt?
- Wat vindt u van Samen Beslissen/SDM?
- Als we naar het zojuist door u omschreven besluitvormingsproces bij keuzemomenten voor behandeling kijken. In hoeverre heeft u het idee dat u gezamenlijk met uw zorgverleners behandelbeslissingen maakt?

SDM kent een aantal stappen voorafgaand aan het nemen van een beslissing, ik zou deze graag aan u voorleggen en samen bekijken in hoeverre u deze stappen heeft ervaren (evt één beslismoment laten gebruiken + terugverwijzen naar eerder gezegde dingen).

- *Arts vertelt dat er een keuze gemaakt moet worden en de mening van de patiënt belangrijk is*
 - In hoeverre heeft de arts u duidelijk gemaakt dat er een beslissing gemaakt moet worden en uw mening belangrijk is?
- *Arts informeert de patiënt over de opties en de voor- en nadelen*
 - In hoeverre heeft de arts u geïnformeerd over de verschillende behandelmogelijkheden?
 - Houding arts bij bespreken mogelijkheden: Objectief? Subjectief? → gestuurd door voorkeur van de arts?
 - In hoeverre heeft de arts u geïnformeerd over de voor- en nadelen van de verschillende behandelmogelijkheden?
 - Geen behandeling als mogelijkheid?
- *Arts en patiënt praten over de voorkeuren van de patiënt en de arts ondersteunt de patiënt in het overwegen van de verschillende opties*
 - In hoeverre heeft de arts u geholpen in het overwegen van de verschillende mogelijkheden?
 - *Oog voor uw persoonlijke voorkeuren/waarden?*
 - *Voldoende informatie verstrekt?*
 - In hoeverre heeft de arts gevraagd naar uw voorkeur in type behandeling?
- *Arts en patiënt praten over welke rol de patiënt wil innemen in de besluitvorming en de beslissing wordt gemaakt*

- In hoeverre heeft u samen met de arts besproken hoe betrokken u wilt zijn bij het nemen van een beslissing?
- Hoe betrokken wilt u zijn bij het nemen van een behandelbeslissing?
- Indien niet zo betrokken of redelijk passieve houding ten tijde van een behandelbeslissing: in hoeverre heeft u behoefte om een actievere rol aan te nemen?
- Voelt u zich in de verstandshouding met de arts vrij om uw persoonlijke wensen en voorkeuren uit te spreken?
 - *Waarom wel / waarom niet?*
 - *Relatie met arts*
- Heeft u het idee dat uw arts weet wat voor u belangrijk is in het leven of in uw behandeltraject?
- Op welke manier heeft u dit kenbaar gemaakt? Hoe vraagt de arts dit uit?
- Welke invloed heeft dit op de interactie met de arts in de spreekkamer?
- Op welke manier spelen deze belangrijke elementen/waarden/voorkeuren in uw leven en behandeltraject vervolgens een rol bij het nemen van een behandelbeslissing?
- U heeft nu inmiddels ... jaren/maanden te maken met deze ziekte. Heeft u het idee dat er na verloop van tijd een verandering heeft plaatsgevonden in wat u belangrijk vindt bij een behandeling of behandelbeslissing?
 - *Zo nee: Waarom niet?*
 - *Zo ja: Op welke manier? Hoe is dit gekomen?*
- Wat vindt u hiervan?
- Bent u over het algemeen tevreden over dit besluitvormingsproces?
- Heeft u bij het nemen van behandelbesluiten op enig moment gebruikt gemaakt van 'keuzehulpen'?
 - *Zo ja: Heeft dit geholpen een keuze te maken? Werd dit gestimuleerd door uw arts?*

Persoonlijke waarden, doelen en voorkeuren en Samen Beslissen/SDM

- Wat voor invloed heeft Samen Beslissen/SDM volgens u op het betrekken van de voor u belangrijke dingen in het leven of in uw behandeltraject in uw behandelbesluiten?

Afsluiting

- Wilt u nog iets kwijt of heeft u nog een vraag voor mij?
- Bedanken

Interview guide physicians

Introductie

- Welkom
- Introductie onderzoeker
- Doel van het gesprek: *inzicht krijgen in het besluitvormingsproces voor behandeling bij MM patiënten en in gesprek gaan over de rol van persoonlijke waarden, voorkeuren en doelen van patiënten bij het nemen van besluiten.*
- Duur interview: 45 min

- Opbouw interview: *algemene vragen, vragen over de persoonlijke voorkeuren waarden en doelen van patiënten, vragen over behandelbeslissingen en SDM.*
- Audio opname, reden daarvan, toestemming daarvoor, anonimiteit
- Member check, behoefte daaraan
- Heeft u op dit moment nog vragen of zijn er dingen onduidelijk?

Algemene vragen

- Kunt u uzelf even voorstellen?
 - *Naam, werk, functie, ervaring*
- Kunt u mij wat vertellen over het type patiënten die u doorgaans behandelt?
- Welke ervaring heeft u met het behandelen van Multipel Myeloom patiënten?
 - *Hoeveel patiënten/aantal jaren*
- Hoe ziet het behandeltraject voor Multipel Myeloom patiënten eruit?
 - *Veel verschillende opties? Beslissingsmomenten?*
- Welke personen zijn er betrokken bij zo'n behandeltraject?

Het onderzoek is gefocust op Multipel Myeloom, maar aangezien ik mij kan voorstellen dat u een hoop verschillende patiënten behandelt met allerlei verscheidene hematologische aandoeningen, vroeg ik mij af of het lukt om dit interview enkel vanuit MM patiënten te benaderen, of dat uw voorkeur uitgaat om het interview breder vanuit al uw hematologische patiënten te benaderen?

Persoonlijke voorkeuren, waarden en doelen van patiënten

- In hoeverre probeert u te achterhalen wat voor uw patiënten belangrijk is in hun leven?
- Op welke manier probeert u dit te achterhalen?
- In hoeverre delen patiënten hun persoonlijke waarden, voorkeuren en doelen tijdens een consult?
 - *Invloed op de interactie met de patiënt*
- Hoe denkt u dat dit van belang is in het behandeltraject van uw patiënten?
- Kunt u een omschrijving geven van persoonlijke voorkeuren, waarden en doelen van patiënten die regelmatig naar voren komen?
 - *Op gebied van aandoening, behandeltraject en dagelijks leven*
 - *Overeenkomstig?*

Behandelbeslissingen en SDM

- Kunt u in het kort omschrijven of en zo ja, op welke momenten uw patiënten een behandelkeuze dienen te maken?
 - *HOVON-studies?*
- Kunt u omschrijven hoe een consult waarin een keuze gemaakt moet worden in zijn werk gaat?
- Op welke manier probeert u de patiënt te begeleiden bij het maken van een behandelkeuze?
- Als we dan naar dit besluitvormingsproces kijken, in hoeverre komt dit volgens u overeen met SDM?
 - *Wat is SDM volgens u?*
 - *Bekend met stappen? Worden deze doorlopen?*

- *Arts vertelt dat er een keuze gemaakt moet worden en de mening van de patiënt belangrijk is*
- *Arts informeert de patiënt over de opties en de voor- en nadelen*
- *Arts en patiënt praten over de voorkeuren van de patiënt en de arts ondersteunt de patiënt in het overwegen van de verschillende opties*
- *Arts en patiënt praten over welke rol de patiënt in innemen in het de besluitvorming en de beslissing wordt gemaakt*
- *Waarom wel/niet? → tijd*
- *Geen behandeling als mogelijkheid?*
- *Hoe is SDM geïmplementeerd in het ziekenhuis? Of, gebruik methode gestimuleerd door het ziekenhuis?*
- Hoe zou u over het algemeen de houding van uw patiënten omschrijven op het moment dat een behandelkeuze voor hen gemaakt dient te worden?
 - *In hoeverre komen de verschillende voorkeuren en waarden hierin naar voren? → invloed op interactie en uiteindelijke behandelbeslissing?*
 - *Verschil tussen patiënten op het gebied van leeftijd, tijd dat ze MM hebben, levensverwachting, behandelfase, behandel mogelijkheden etc.*
 - *Stimuleren patiënten om actief te participeren?*
- Bij wie ligt de beslissing voor een behandeling volgens u?
 - *Waarom*
 - *Verschillen tussen patiënten wbt voorkeur betrokkenheid → hoe vraagt u dit uit?*
- Stimuleert u uw patiënten gebruik maken van eventuele 'keuzehulpen'?
 - *Zo ja: heeft u het idee dat dit hen helpt om een keuze te maken?*
 - *Gebruik PROMs?*
- In hoeverre bent u tevreden over de manier waarop behandelbeslissingen worden gemaakt?
 - *Zou u bepaalde dingen liever anders aanpakken?*
- In hoeverre bent u tevreden over het concept SDM?
 - *Zou u bepaalde elementen van SDM liever anders aanpakken?*
 - *Voor- en nadelen?*

Persoonlijke voorkeuren, waarden en doelen en SDM

- Wat voor invloed heeft Samen Beslissen/SDM volgens u op het betrekken van de persoonlijke waarden, doelen en voorkeuren van uw patiënten in hun behandeltraject in uw behandelbesluiten?

Afsluiting

- Wilt u nog iets kwijt of heeft u nog een vraag voor mij?
- Bedanken

Interview guide nurse practitioner

Introductie

- Welkom
- Introductie onderzoeker
- Doel van het gesprek: *inzicht krijgen in het besluitvormingsproces voor behandeling bij MM patiënten en in gesprek gaan over de rol van persoonlijke waarden, voorkeuren en doelen van patiënten bij het nemen van besluiten.*
- Duur interview: 45 min
- Opbouw interview: *algemene vragen, vragen over de persoonlijke voorkeuren waarden en doelen van patiënten, vragen over behandelbeslissingen en SDM.*
- Audio opname, reden daarvan, toestemming daarvoor, anonimiteit
- Member check, behoefte daaraan
- Heeft u op dit moment nog vragen of zijn er dingen onduidelijk?

Algemene vragen

- Kunt u uzelf even voorstellen?
 - *Naam, werk, functie, ervaring*
- Kunt u mij wat vertellen over het type patiënten die u doorgaans behandelt?
- Wat is uw rol in de behandeling van MM patiënten?
- Welke ervaring heeft u met het behandelen van Multipel Myeloom patiënten?
 - *Hoeveel patiënten/aantal jaren*
- Hoe ziet het behandeltraject voor Multipel Myeloom patiënten eruit?
 - *Veel verschillende opties? Beslissingsmomenten?*
 - *Welke behandelingen ervaren patiënten als zwaar?*
 - *Welke behandelingen ervaren patiënten als lichter?*
- Welke personen zijn er betrokken bij zo'n behandeltraject?

Het onderzoek is gefocust op Multipel Myeloom, maar aangezien ik mij kan voorstellen dat u een hoop verschillende patiënten behandelt met allerlei verscheidene hematologische aandoeningen, vroeg ik mij af of het lukt om dit interview enkel vanuit MM patiënten te benaderen, of dat uw voorkeur uitgaat om het interview breder vanuit al uw hematologische patiënten te benaderen?

Persoonlijke voorkeuren, waarden en doelen van patiënten

- In hoeverre probeert u te achterhalen wat voor uw patiënten belangrijk is in hun leven?
- Op welke manier probeert u dit te achterhalen?
- In hoeverre delen patiënten hun persoonlijke waarden, voorkeuren en doelen tijdens een consult?
 - *Involed op de interactie met de patiënt*
- Hoe denkt u dat dit van belang is in het behandeltraject van uw patiënten?
- Kunt u een omschrijving geven van persoonlijke voorkeuren, waarden en doelen van patiënten die regelmatig naar voren komen?
 - *Op gebied van aandoening, behandeltraject en dagelijks leven*
 - *Overeenkomstig?*

Behandelbeslissingen en SDM

- Wat is uw rol in het besluitvormingsproces wanneer er behandelkeuzes gemaakt dienen te worden?
- Kunt u in het kort omschrijven of en zo ja, op welke momenten uw patiënten een behandelkeuze dienen te maken?
- Kunt u omschrijven hoe een consult waarin een keuze gemaakt moet worden in zijn werk gaat?
- Op welke manier probeert u de patiënt te begeleiden bij het maken van een behandelkeuze?
- Als we dan naar dit besluitvormingsproces kijken, in hoeverre komt dit volgens u overeen met SDM?
 - *Wat is SDM volgens u?*
 - *Bekend met stappen? Worden deze doorlopen?*
 - *Arts vertelt dat er een keuze gemaakt moet worden en de mening van de patiënt belangrijk is*
 - *Arts informeert de patiënt over de opties en de voor- en nadelen*
 - *Arts en patiënt praten over de voorkeuren van de patiënt en de arts ondersteunt de patiënt in het overwegen van de verschillende opties*
 - *Arts en patiënt praten over welke rol de patiënt in innemen in het de besluitvorming en de beslissing wordt gemaakt*
 - *Waarom wel/niet? → tijd*
 - *Geen behandeling als mogelijkheid?*
 - *Hoe is SDM geïmplementeerd in het ziekenhuis? Of, gebruik methode gestimuleerd door het ziekenhuis?*
- Hoe zou u over het algemeen de houding van uw patiënten omschrijven op het moment dat een behandelkeuze voor hen gemaakt dient te worden?
 - *In hoeverre komen de verschillende voorkeuren en waarden hierin naar voren? → invloed op interactie en uiteindelijke behandelbeslissing?*
 - *Verschil tussen patiënten op het gebied van leeftijd, tijd dat ze MM hebben, levensverwachting, behandelfase, behandelmogelijkheden etc.*
 - *Stimuleren patiënten om actief te participeren?*
- Bij wie ligt de beslissing voor een behandeling volgens u?
 - *Waarom*
 - *Verschillen tussen patiënten wbt voorkeur betrokkenheid → hoe vraagt u dit uit?*
- Stimuleert u uw patiënten gebruik maken van eventuele 'keuzehulpen'?
 - *Zo ja: heeft u het idee dat dit hen helpt om een keuze te maken?*
 - *Gebruik PROMs?*
- In hoeverre bent u tevreden over de manier waarop behandelbeslissingen worden gemaakt?
 - *Zou u bepaalde dingen liever anders aanpakken?*
- In hoeverre bent u tevreden over het concept SDM?
 - *Zou u bepaalde elementen van SDM liever anders aanpakken?*
 - *Voor- en nadelen?*

Persoonlijke voorkeuren, waarden en doelen en SDM

- Wat voor invloed heeft Samen Beslissen/SDM volgens u op het betrekken van de persoonlijke waarden, doelen en voorkeuren van uw patiënten in hun behandeltraject in uw behandelbesluiten?

Afsluiting

- Wilt u nog iets kwijt of heeft u nog een vraag voor mij?
- Bedanken

Appendix D: Codebook

Code group in Dutch	Code group in English	Number of codes involved in group	Frequency of occurrence	In number of interviews
Artsen: behandeling aanpassen	Physicians: adjust treatment	12	25	5
Artsen: kennis/achterhalen persoonlijke waarden patiënten	Physicians: knowledge/discover patient's personal values	44	99	13
Beginperiode ziekte	Initial period of the disease	1	6	2
Behandelkeuzes	Treatment choices	38	115	13
Belang weten persoonlijke waarden	Importance of knowledge about personal values	8	14	7
Beslissingsbevoegdheid	Decision-making authority	38	95	13
Betekenis aandoening	Meaning disease	5	10	4
Emoties	Emotions	10	15	6
Ervaring behandelingen	Experience with treatments	5	15	8
Gedragsverandering patiënten	Patients behavioral change	12	15	6
Houding arts	Physician attitude	38	67	11
Houding patiënt	Patient attitude	71	165	13
Informatie, communicatie en transparantie	Information, communication, and transparency	15	32	10
Invloed SDM op persoonlijke waarden	Influence SDM on personal values	1	14	13
Lastige elementen in aandoening	Difficulties in disease	4	4	1
Lotgenoten contact	Fellow sufferer contact	2	5	2
Mening besluitvormingsproces	Opinion decision making process	1	5	5
Moeilijkheden achterhalen persoonlijke waarden	Difficulties in discovering personal values	11	12	4
Omgeving	Environment	4	12	6
Omschrijving behandeltraject	Description treatment trajectory	2	11	5
Ondersteuning bij het maken van een keuze	Decision making support	4	8	5
Personen betrokken bij behandeling	Persons involved in treatment	9	26	7
Persoonlijke waarden in behandeling	Personal values in treatment	6	10	4
Persoonlijke waarden patiënten	Patients' personal values	36	85	13
Relatie met arts/patiënt	Relationship with patient/physician	16	46	10
SDM	SDM	54	151	13

Second opinion	Second opinion	1	3	2
Studie	Study	7	12	7
Tijd in spreekkamer	Time in consultation room	4	5	5
Urgentie beginperiode	Urgency initially	1	5	5
Verandering persoonlijke waarden	Change in personal values	9	17	6
Verantwoordelijkheid patiënt	Patient's responsibility	1	4	2
Vertrouwen	Confidence	4	22	7
Vervelende ervaring	Unpleasant experience	1	3	3
Voorbeelden	Examples	2	2	2
Vorbereiding op consult	Preparation on consultation	4	15	7
Waarde in behandeling	Value in treatment	26	38	13
Wensen en voorkeuren uitspreken tegen arts	Express wishes and preferences to physician	1	7	6
Wijze van behandeling voorstellen	Way of proposing treatment	20	52	13