Chapter 7

General discussion
The general objective of this thesis was to gain a deeper understanding of patient participation in treatment decision-making in the last phase of life. We aimed to gain insight in patients’ preferences and physicians’ experiences with treatment decisions concerning whether or not to start palliative chemotherapy. The final chapter of this thesis will highlight and interpret the main findings described in the previous chapters. First, some methodological consideration will be formulated, followed by an overview of the main findings and interpretation of these findings. Subsequently, implications for policy, practice and further research will be considered.

METHODS AND METHODOLOGICAL CONSIDERATIONS

To answer the objective of this thesis two studies were conducted: a systematic review and a longitudinal qualitative study including observations, interviews and a focus group.

Systematic review

The systematic review provided an overview of the literature related to the congruence between patients’ preferences and their perceived participation in medical decision-making. Systematic reviews synthesize existing research findings at that moment, providing an overview of existing evidence for caregivers in the field, researchers and policy makers. A strength of our review is the broad approach since decision-making is relevant not only to cancer care. Therefore we also included patients with other conditions.

A limitation of the review we conducted is that we only included studies in which congruence between preferred and perceived participation could be calculated. Therefore, we did not retrieve all relevant studies regarding preferences. Furthermore, we transposed the reported data on patient participation which were coded on a 5-point scale into three categories (active, shared or passive) before calculating congruence; this may have caused an overestimation of congruence.

Longitudinal qualitative study

The longitudinal qualitative study was performed among a group of 28 advanced cancer patients diagnosed with glioblastoma multiforme (GBM) or metastatic colorectal cancer who visited the outpatient clinic of a large university hospital. In-depth interviews were used to get insight in preferences and experiences of the participants. From that moment on, patients were followed in time and accompanied by the researcher when they visited their physician(s) in the outpatient clinic. Observations provided insight in actual communication between patients and physicians and the process of decision-making in daily practice. In addition, informal conversations with patients
and relatives in the clinic waiting room were performed. Both the patient and their treating physician were interviewed after treatment decisions were made (whether or not to start a subsequent line of chemotherapy) to establish their perceived role in the decision-making process. Furthermore, a multidisciplinary focus group meeting was organized with medical professionals who were involved in the decision-making process of patients diagnosed with GBM. The focus group meeting provided an in-depth understanding of the practice and barriers physicians see in involving patients in the decision-making process.

A strength of this qualitative study was the longitudinal design which gave the ability to get insight in the process of decision-making. To capture the whole decision-making process, patients were followed in time as long as they were seen in the outpatient clinic. Information was gathered on preferences and experiences from patients’ own perspective and from their treating physicians using in-depth interviews. This approach enabled us to study decision-making processes and the roles patients wanted before treatment decisions were made and perceived afterwards. Additionally, we observed how decisions were made in daily practice by attending the outpatient clinic visits. In this manner we were able to get insight in the decision-making process in the last phase of life of patients with advanced cancer. The decision whether or not to start palliative chemotherapy is delicate, and often more than one conversation with the physician is needed. The longitudinal design gave insight into the process of decision-making including the phase in which progression of the disease was suspected, additional tests (CT or MRI) were done and patients were prepared for upcoming decisions.

A further advantage of the longitudinal approach was the opportunity to build a relationship and rapport with the patients and physicians which allowed the researcher access to their stories [1;2]. Data were collected by using observations of the visits and in-depth interviews (triangulation). In-depth interviewing enabled us to explore the subjective experiences and perspectives of patients and physicians in detail. Besides formal interviews data were also collected by informal talks with patients in the waiting room and when the researcher visited them when they were admitted in the hospital. During periods of stable disease the researcher also stayed in contact by telephone or by email. This intensive contact created a relationship of trust between the patient and the researcher and gave the opportunity to discuss sensitive and personal issues. Furthermore, this trustful relationship gave the opportunity to explore changing needs and experiences of patients [3].

By observing in the natural setting the validity of the data was increased [4]. We actually saw how ‘bad news’ was delivered by physicians, felt the tensions and disappointments of patients during
visits and actually heard how treatment options were presented to patients and how decisions were made. These observations were compared to the data obtained by the interviews with patients and physicians. Attending the outpatient clinic visits also enabled us to address situations that occurred in the outpatient clinic in the interviews. Thus, longitudinal observation gave valuable and additional information, but it also proved to be a time consuming activity.

The study had a relatively open explorative character: no explicit observational or coding scheme was used, and no hypotheses were tested. This had the advantage of getting access to considerations, attitudes and other factors that were not expected beforehand. For example, due to observations of the outpatient clinic visits we identified four mechanisms that can contribute to continuing treatment (see chapter 6). One of these mechanisms is the opening question. We observed that the opening question “how are you doing” leads to the discussion of symptom burden and treatment side effects while the question is probably meant to invite the patient to bring up any subject. As a consequence, more fundamental questions related to whether patients think they are still on the right track and what their ideas are about the ‘near future’, including preferences and care goals, were not immediately addressed by the patient, and not always discussed.

The open explorative character of the study also provided room for a shift in focus and to put our results in the context of shared decision making, a topic which receives much attention nowadays. As a consequence, one of the original questions is not analysed extensively in this thesis; the comparison between preferences for participation and perceived participation.

The longitudinal study also has some shortcomings. A limitation of the study is the sampling of patients. The group of respondents who participated in the study was a selective group. The patients were recruited in one large university hospital and all had a Dutch cultural background. From previous research it is known that patients with a Turkish or Moroccan background have different values and beliefs [5] which also is the case for the last phase of life. For example, talking about death and dying differs between cultures. This might influence the way decisions are made and how patients preferred to and could be involved. Also, patients treated in a university hospital might consciously choose that specific hospital because they wanted to try (experimental) treatments or to participate in clinical trials. However, in case of patients with advanced cancer they are often referred to a university hospital since smaller hospitals do not provide treatments for these specific patient groups; this is especially the case for patients diagnosed with GBM. In addition, patients diagnosed with GBM find themselves not only confronted with the diagnosis of
a life-threatening disease, but they also have a variety of neurological and cognitive problems. Besides that, fatigue, cognitive decline and changes in personality and behaviour are common in this patient group. The role of patients with cognitive decline might be different in the decision-making process than that of patients who are not confronted with these symptoms. Therefore the results of this study might not be applicable for all advanced cancer patients. We also may have selected relatively ‘good’ patients, particularly for the patients diagnosed with GBM. The median survival of patients diagnosed with GBM is 14 months, and our patients on average survived longer. At time of inclusion the patients already received the first part of their first line treatment (operation and radiotherapy combined with chemotherapy). Some GBM patients did not finish this first part of the treatment, because of the progression of the disease or a bad clinical condition, and were not eligible for our study.

Furthermore, patients were informed about the study by their treating physician, which may have caused selection bias. Two patients were not invited to participate because the physician said it was too burdensome for the patient to participate. This may have led to a selection of patients who were in a relatively stable and good condition, resulting in the fact that patients with a more complex disease trajectory were excluded from our study.

Observations also have some limitations. When the study started, the physicians seemed to feel somewhat uncomfortable with the researcher attending the outpatient clinic visits. They were aware of the researcher’s presence and may have adapted their behavior. To illustrate, a physician said after one of the first recorded visits that he felt pressed by the audio recorder and the attendance of the researcher to continue with chemotherapy although the patient was in a poor condition. Explaining the aims of the study and to get insight in the struggle that physicians feel in treating patients with a limited life expectancy was essential in our research. After all, when the physician understood the purpose of the recordings and trusted the researcher, this physician became a very important informant for the study. Yet, as each consultation during the disease trajectory of almost 30 patients was observed, physicians got used to the presence of the researcher and most likely returned to their normal behavior. Also, it concerned a large university hospital in which physicians are used to interns and co-assistants attending the outpatient visits. Taking this into account, it is not likely that we have observed adapted behavior.

A potential pitfall of longitudinal observations is getting too involved and loosing objectivity (going native) [1;2]. As a researcher, I got to know patients and built a relationship since I followed them in time. For example, one of the patients emailed me to tell me about the progress he made in his daily functioning: “Good news, I can ride my bicycle again!” They were willing to share their personal stories and let me enter into their lives. Whereas at the start of the study I felt I had to
collect data for my research, later on I felt like following ‘my’ patients in time. They were even willing to change their appointment if I wasn’t able to attend their next visit. One of the patients called me “his personal guide”. This made me feel special and I had the feeling I could mean something in this difficult period of a patient’s life. However, it also meant that when patients had progressive disease or had severe symptoms, I had to cope with feelings as well. For example, a patient and his partner got bad news and they didn’t expect this (the patient had no symptoms). They were shocked and couldn’t react to the news while talking with their physician during the visit. In the hallway they both started crying and felt into each other’s arms. I responded to their emotions and tried to comfort them but on the other hand I was still the researcher and therefore an outsider. To deal with these experiences and emotions I had regular contact with my daily supervisor. Also my colleagues in the end-of-life research group were willing to listen to my stories. By using research techniques such as member check and peer debriefing (discussion of the findings with all members of the research group) we tried to reduce subjectivity.

MAIN FINDINGS AND INTERPRETATION OF THE RESULTS

In this section, the main findings are summarized and interpreted.

Patient preferences concerning participation

In order to get an overview of the current literature on patient participation in decision-making, we conducted a systematic review (chapter 3). This review showed that the mean of congruence between patients’ preference for and perceived participation in decision-making was 60%. In case of no congruence, patients in general preferred more participation in the decision-making process than they perceived. Furthermore, the review showed that in studies in which preference was retrospectively measured, congruence was more often found, than in prospective studies. This suggests that in retrospective studies the assessment of preference probably includes an element of (positive) evaluation of the decision-making that occurred or a change in preference for participation based on experiences. Percentages of congruence were similar for patients with cancer and patients without cancer and also for preferences related to general and to specific treatment options. Several associations were reported with patient preference for participation in medical decision-making, most commonly age and education level, and most frequently reporting that older people and people with a lower education more often prefer a passive role. The review suggests that a similar approach to all patients is not likely to meet patients’ wishes, since preferences for participation vary among patients. Health care professionals should be sensitive to
patients’ individual preferences and communicate about patients’ participation wishes on a regular basis during their illness trajectory.

This variation in preferences was also found in the results of the qualitative study, described in chapter 2. After inclusion all patients were interviewed about their preferences for participation in upcoming treatment decision-making. We found that all patients preferred their physician to play a role in the treatment decision-making process. The extent to which patients themselves preferred to participate seemed to depend on how patients saw their own role or assessed their own capabilities. For example, we found that patients who preferred a more decisive role for themselves had different rationales for this choice: they either wanted to have control over their own life or felt responsible for making the treatment decision themselves without burdening the physician.

The finding that all patients wanted their physician to participate in the treatment decision-making process because of his knowledge and clinical experience, might be related to the complexity of the decisions in advanced cancer care. In fact, Beaver et al. [6] found that patient preferences depended on the type of decision as patients were more able to engage in decisions about the physical and psychological aspects of care than in treatment decisions. Some studies have suggested that increasing patient involvement in decision-making increases anxiety in cancer patients [7;8] or patient had decisional regret [9-11]. Balancing between quality and quantity of life requires skills from patients in which they can consider their needs, wishes and values.

Awareness of physicians of the different preferences for participation between patients is important, as they require different kinds of support. Patients who want to keep control need adequate information so they can outweigh their options and make a decision based on the provided information by their treating physicians. In patients who do not want to burden their physician, shared responsibilities of both parties need to be addressed.

Furthermore, we found that patients foresaw that their preferences for participation would change to a more decisive role as treatment goals shift further on in their illness trajectory. This is also confirmed by a studies performed in other cancer settings [9-11]. A possible explanation might be that patients were used to being ill [12;13]. Ongoing communication about patients’ expectations, wishes and preferences for participation in upcoming treatment decisions is therefore of great importance. An approach in which these topics are openly discussed would be beneficial.

Chapter 2 also described the finding that patients set limits for themselves to maintain quality of life. However, at the time of the first interview (beginning of first line chemotherapy) many patients considered that they had not reached their limits yet and still aimed for life prolongation. Patients’
idea of having a more active role later on in the disease trajectory might not be easy. The wish to continue with a subsequent line of chemotherapy also seems to be the result of a lack of alternatives (‘no treatment’ was not seen as an option). Patients may also have had difficulties in recognizing the stage of their disease. It is known that patients shift their limits and are willing to go on with burdensome treatments because they do not want to ‘give up’ and face death [14]. Patients want to hold on to their lives and are willing to accept intensive chemotherapy for a very small chance of benefit (15;16). Patients also rely on the physicians’ expertise (chapter 2) and trust them [17-19]. For this reason, physicians have to ask patients for their preferences on a regular basis since preference for participation can change over time and can depend on the situation and type of decision [12;20;21].

Patient participation in actual practice

To come to a well-considered decision, patients’ preferences and expectations should be taken into account in treatment decision-making in the last phase of life. Shared decision-making (SDM) is regarded as a way to give the patient a central role in decision-making and may be considered as ideal [22-26]. Stiggelbout and colleagues have distinguished 4 steps in SDM [27]. The first involves outlining all options, including the option of doing nothing or keeping the status quo and mentioning that there is no best option, thereby ‘creating awareness of equipoise’. In the second step, the risks and benefits of every option are explained to the patient and their probabilities, to support him or her in the consideration of the options. The third step is helping the patient in the exploration of his or her ‘ideas, concerns and expectations about the options’. The last step involves sharing the responsibility for the decision by establishing an equal partnership and assessing the preferred role of the patient in the decision-making process. To examine whether and how the 4 steps of SDM can be recognized in decision-making about second- and third-line chemotherapy, data were analyzed (observations and in depth interviews) of 14 advanced cancer patients who were confronted with these decisions (chapter 4). Our study showed that, although patients were overall satisfied with the decision-making process, the elements of SDM were barely seen in daily practice. The creation of awareness about available treatment options by physicians was limited and not discussed in an equal way. According to chapter 2, results showed that patients preferred a role for physicians in the decision-making process. In practice, physicians often steered decisions toward treatment without explaining alternatives which could lead to patients’ unawareness of available treatment and care options (chapter 4). It seemed that physicians had their own personal treatment preferences. Also, patients’ wishes and concerns were not explicitly assessed, which led to different expectations about improved survival from subsequent lines of chemotherapy.
To assess the perspectives of medical specialists about the decision-making process concerning starting second or subsequent lines of chemotherapy, and the role of SDM, a focus group meeting was held based on former interview data with medical specialists (chapter 5). We found that, although medical specialists consider the involvement of patients to be important, they have difficulty to arrive at a shared decision in dealing with patients with recurrent GBM. Medical specialists and professionals regard SDM as important. However, ‘no treatment’ is not seen as an option which might be equal to starting or continuing treatment. As a consequence, the subsequent elements of SDM (i.e. risks and benefits of all options and ideas of patients regarding all options) are mostly focused on the option of starting treatment only. Exploration of the patients’ wishes and participation preference is done implicitly, reducing patients’ ability to participate in the process. We concluded that the main barriers for SDM in daily practice are the initial treatment preference of both specialist and patient, and the assumption of physicians that they know what patients want. Medical specialists recognize the importance of patient involvement, but experience large difficulty to arrive at shared decisions in practice.

From previous studies it is known that physicians often adopt a paternalistic role [28;29]. Although all patients prefer a role for physicians in decision-making (chapter 2), our study also showed that physician still play a dominant or even paternalistic role. According to chapter 4, physicians stated that they already know what the patient wanted and they also offered treatment because they believed starting a subsequent line of chemotherapy was the best thing to do or because they followed treatment protocols. Physicians’ preference for opting for treatment was also found in our results of the focus group meeting (chapter 5) and in other studies [30-33]. Physicians often interpret decisions conflicting with their medical opinion as irrational and find it difficult to accept a patient’s refusal of further treatment [34]. They face a dilemma between the duty to care for a patient and respect for patient autonomy. Respecting the patient’s perspective is important for the physician-patient relationship. Education of medical specialists on SDM is needed to learn more on how to involve patients in the decision-making process, especially concerning the first step of creating equipoise.

**Feasibility of SDM in daily (advanced cancer) care**

It is questionable whether SDM is feasible in daily practice. Our results from the qualitative study indicate barriers that hampered SDM, especially considering the first step. Not only patients are willing to undergo a subsequent line of chemotherapy (because they believe they are still in the phase of possible life prolongation and cannot accept ‘doing nothing’), also physicians believe that
to continue with chemotherapy is the best thing to do (chapter 4 and 5). Moreover, awareness of equality in treatment options is lacking in patients and physicians. The et al. [35] described, in previous research, a collusion between patients and physicians in which they both didn’t put the truth on the table, although they both knew what the situation really was. Our study showed similar results in the communication between patient and physician. The focus on one specific treatment option, without outweighing alternatives might hamper the shift from a life-prolonging aim towards a focus on the quality of life and could also prevent patients from taking the lead in the decision-making process. According to chapter 4, some patients felt they had to try everything because they might experience regret if they decided not to start this new line of chemotherapy. The focus on treatment and the absence of addressing the provision of supportive care only has been reported previously [31;32;36]. Patients are unlikely to participate in decision-making if alternative treatments are not discussed with their physicians. The question whether in a situation in which physicians present treatment options in an equal way, outcomes will be different, remains. Moreover, will patients decide to stop or not even start a subsequent line of chemotherapy if just as much attention was paid to alternatives? It might be argued that when patients are better informed about the limited response probabilities of subsequent lines of chemotherapy and their impact on quality of life, more patients might decide to forgo further treatment. Therefore, more attention to advance care planning and palliative care is necessary. Advance care planning implies timely and regular involvement of patients and their proxies in decision-making with respect to the future goals of treatment and end-of-life care [37]. The studies of Temel et al. [38] and others [39;40] showed that earlier integration of specialist palliative care into oncology care fosters quality of life and quality of care. In these studies, attention was paid to assessing physical and psychosocial symptoms, establishing goals of care, assisting with decision making regarding treatment, and coordinating care on the basis of the individual needs of the patient. The specialist palliative care used guidelines for consultation with the palliative care team, which included five topics (understanding the illness, symptom management, decision-making, coping, and planning and referral) [41]. The discussion of longer term perspectives and care goals is facilitated by structuring the outpatient clinic visits around topics. This structuring and associated broadening of the visits might help counter the mechanisms that seem to promote continuing chemotherapy. A study evaluating advance care planning (ACP) in brain tumour patients demonstrated that the majority of patients is willing to discuss potential end-of-life scenarios and also the majority of patients prefer comfort care over life-prolonging treatment (42). Other studies show that patients who had end-of-life discussions with their physician were less likely to receive chemotherapy near death [40;43]. Patients who meet with a member of a palliative care team shortly after diagnosis and at least
monthly thereafter in the outpatient clinic until death had less chance of receiving chemotherapy [40].

Although there has been both an increased attention for SDM and substantial development of palliative care in the last decade [44], it seems that recommendations have not yet been adequately implemented and that little has changed in the last decade. Our results show that physicians still emphasize the medical aspects and pay less attention to daily functioning and quality of life. Palliative care involves not only complex medical information and a high emotional dimension, but also many options of care [44]. The dilemma of choosing between life-prolonging treatments with potential side effects or maximizing quality of life generates delicate discussions with patients. Although most patients with metastatic cancer choose to receive palliative chemotherapy, evidence suggests that most do not clearly understand that chemotherapy is unlikely to be curative [45]. Yet, for some it is a conscious choice to continue with chemotherapy. Moreover, most cancer patients are likely to choose chemotherapy expecting improved survival or quality of life. Patients are willing to accept chemotherapy in order to get just one extra week of life [46]. According to the result in chapter 4, patients fear regretting their decision later on and therefore want to start a new line of treatment. This anticipated regret has been reported before [52] and might explain the finding that all patients were satisfied with the way, and extent, in which they had been involved in the decision-making process. This may represent a cognitive justification: patients are satisfied with the process because they do not want to feel regret about the process or the decision made. They prefer to feel good about whatever decision being made, even when the disease progresses or chemotherapy does not improve their situation.

Mechanisms that contribute to continuing treatment

In the last two decades, the therapeutic possibilities for patients with advanced cancer have increased [47-52]. At the same time, the importance of high-quality end-of-life care, including end-of-life decision making, pain and symptom management, psychosocial support, and hospice care has been recognized [53]. In the last couple of years, continuing treatment is an issue of public debate in the Netherlands. A survey of the Royal Dutch Medical Association (KNMG) showed that 2 out of 3 physicians believed that patients were over-treated [54]. A national committee for appropriate care in the last phase of life (Passende zorg in de laatste levensfase) was set up in 2013 by the Royal Dutch Medical Association. The aim was to explore mechanisms that can explain the tendency to continue treatment and determine interventions which can prevent overtreatment. This thesis may shed some light on the tendency to continue treatment in the last phase of life. In our study we uncovered four mechanisms in daily oncology practice that may contribute to the
tendency towards continuing chemotherapy in patients with advanced cancer. The first mechanism is called: ‘presenting the full therapy sets the standard’. The second is: ‘focus on standard evaluation moments hampers evaluation of care goals’. The third mechanism we found is: ‘the opening question guides towards a focus on symptoms’. And the last mechanism we discovered was: ‘treatment is perceived as the only option’. The Royal Dutch Medical Association published a report about “appropriate care in the last phase of life,” describing 23 mechanisms that contribute to continuing with treatment on patient/physician level, institutional level, and national level. On the institutional level, they mention that treatment guidelines are focussed on continuing treatment. This mechanism resonates with mechanisms 1 and 2 we found on patient/physician level.

“Treatment is seen as the only option” is also described in the report, both on patient/physician level, and on a national level. The report concludes that this mechanism is dominant in the Dutch society. The report recommends creating more attention for accepting death and dying and setting up national campaigns stimulating advance care planning to promote appropriate care at the end of life. Discussing care goals more regularly with the patient, facilitated for instance by implementing early palliative care, might help counter the mechanisms and enable a more well-considered decision.

Appropriate care in the last phase of life

According to the results of chapter 4, patients’ expectations in terms of survival benefit of a subsequent line of chemotherapy differed from the physicians’ point of view. However, these differences in expectations were not openly discussed. Wright et al. [46] found that patients who had received palliative chemotherapy were significantly more likely to undergo mechanical ventilation or cardiopulmonary resuscitation in the last week of life and also to be referred to a hospice late. These outcomes have been associated with a poorer quality of life for patients and more distress for caregivers. Furthermore, receiving chemotherapy was not associated with longer survival [38;46]. The authors conclude that oncologists should be encouraged to discuss with patients the broader implications of palliative chemotherapy when decisions about treatments have to be made. The difficulty of talking about not continuing chemotherapy might be related to the perceived need of actively fighting the disease and maintaining hope [55-59].

To ease the difficulty of addressing the end-of-life and the benefits and harms of treatment as well as the alternatives, physicians need to be trained to discuss future wishes with their patients; this is shown to improve the quality of care and to prevent continuing treatment in the last phase of life [60;61]. Advance care planning implies timely and regular involvement of patients and their proxies in decision-making with respect to the future goals of treatment and end-of-life care. This might be
performed early after diagnosis, which has positive effects on quality of life and survival, as shown by Temel et al [61]. By this, both the element of equipoise and the element of communicating benefits and harms can be improved. These results show that SDM in advanced oncology is needed.

**IMPLICATIONS FOR POLICY AND PRACTICE**

In the light of the results of our study, the growing attention for palliative care in the Netherlands is timely. Several steps are taken by the Dutch Government to position palliative care in health care. The Dutch Ministry of Health, Welfare and Sports stated that every citizen in 2020, at the time of need, should be assured of good palliative care at the right place, at the right time, and provided by the right health professionals [62]. To accomplish this goal the National Program on Palliative Care started in 2014. The Foundation of Oncology Collaboration (SONCOS) stated in their annual report in 2014 that every hospital providing oncology care should have a multidisciplinary palliative care team within three years. Previous studies showed promising results of palliative care teams [38;40;41]. For example, the study of Temel et al. [38] showed that patients who were assigned to early palliative care had improved mood, more frequent documentation of resuscitation preferences, and less aggressive end-of-life care. On an institutional (hospital) level, palliative care teams might be helpful in addressing end-of-life issues and in training physicians how to start a conversation on the approaching (and inevitable) death and explaining the range of options, including only providing supportive care. From a recent national survey, it is known that all hospitals in the Netherlands have a multidisciplinary palliative care team or are establishing such a team [63]. In the light of the SONCOS report, which stated that every hospital should have a multidisciplinary palliative care team in 2017, palliative care in the hospital setting is gaining ground.

Recently, the Royal Dutch Medical Association developed an aid which focuses on early discussion of the last phase of life [64]. It consists of discussion points and information for a conversation about the impending death. In the light of our study, we recommend to specifically mention in this respect that in the discussion of treatment options, ‘doing nothing’ should be replaced by an approach focusing on quality of life. Adequate implementation of this tool in the advanced cancer care setting might support physicians in addressing wishes, expectations and concerns. In addition, Quill et al. provided examples of useful questions to ask patients in different situations [65]. They stated that you can only propose the possible treatment options that are consistent with the patient’s values and priorities when you know what the patient really wants. Physicians need to be trained in consultation skills, together with discussion of SDM in advanced cancer.

A further recommendation based on our study is to improve the implementation of SDM in daily
practice. First, a model of SDM that fits into daily clinical practice is needed. The struggle with the concept of equipoise, “explaining to the patient that there is no best choice,” seems to be partly due to resistance to the concept itself. Medical specialists consider treatment as the best choice in most situations. It should be clarified that the equality of options depends not only on medical facts concerning survival but also on side effects and patient wishes and values. Knowledge among physicians needs to be increased how to communicate available options and how to include all aspects of care. For example, a detailed description of what stopping or withholding palliative chemotherapy entails, will help to make a well considered decision. An explanation of supportive care would also be beneficial. In addition, clinical guidelines should pay more attention to treatment alternatives, including palliative care.

Secondly, physicians should be aware of the need to carefully present various options in the advanced stage of disease and discuss them with the patient. When benefits in terms of life prolongation are modest, alternatives should be explained more in detail. Although physicians are trained in how to deliver bad news, communication skills needed for reflection on and discussion of patient’ wishes, values and concerns should be further improved. Allowing time for reflection during outpatient clinic visits might counteract routine behaviour. This implies regularly discussing and re-evaluating the goals of care with the patient. Training physicians in creating moments of evaluation and starting a conversation on goals of care and questioning patients about their wishes, concerns and needs might be helpful in putting the subject on the agenda.

Thirdly, physicians should stimulate patients to participate in decisions and feel free and safe to discuss these topics with them. Good communication is identified by patients as one of the most important elements of end-of-life care [66] tailored to their information needs. One way to enhance communication is to provide written information. Written information has been shown to have many advantages, such as helping patients to obtain relevant information from the limited time with their doctor [67-69], increasing patient confidence in asking questions [67;68], keeping family, friends, and carers involved [70;71], anxiety and fear about cancer and its treatment decreased [72;73], and it improved the doctor-patient relationships [74]. A example of a useful method to involve patients is to “ask three questions” during the outpatient clinic visit [75]. The questions are: 1. What are my options? 2. What are the possible benefits and harms of those options? 3. How likely are the benefits and harms of each option to occur? These questions aim to elicit the minimum information needed for decision-making under conditions of uncertainty and to help organize the information that physicians give patients. Asking these three questions improves information given physicians and increased physician facilitation of patient involvement without increasing consultation length [75].
RECOMMENDATIONS FOR FURTHER RESEARCH

In our study we were not able to include patients with a non Dutch cultural background. It is important to gain insight in the process of decision-making of these patients since they have different beliefs and values [5;76]. Furthermore, the role of proxies is under exposed in our research. Proxies were a part of our study, as they accompanied the patients, but we didn’t report on them separately. We observed that proxies were regularly present, and when patients became more ill they always accompanied the patient. Their relationship changed as patients became more dependent on their partner or children further on in the disease trajectory. The interaction between patients and physicians is often a three-way communication. Sometimes the physicians asked the proxies how they experience the patients’ functioning in daily practice or explained medication use to them as well. Palliative care also aims at the wellbeing of proxies according to the definition of the World Health Organisation [77]. Future research should focus on the role of proxies in the decision-making process. To what extent are they involved (and experience involvement) in the decision-making process, how burdensome is it to take care of their loved one, and how can they be supported?

Multidisciplinary palliative care teams in hospitals are developing. It is important to structurally monitor the role of palliative and supportive care teams in hospitals and the effect on quality of care.

Another recommendation for future research is the usage of the Control Preference Scale (CPS) tool by physicians in the medical encounter in which the CPS would be used as a starting point to talk about patients’ preferences for participation. Not the choice for a certain card, but the conversation on preference for a particular role in upcoming decisions might provide insight in the patients’ values and needs. It also could give insight in how they asses their own capabilities in treatment decision-making and if and when preferences change in course of the disease trajectory. A study in which the CPS is used as a starting point for communication on wishes, needs and values needs to be evaluated to see if it has added value in the medical encounter. The above mentioned suggestions for training physicians and implementation of tools should be evaluated. For example, when physicians are trained in communication skills and supported by tools to adequately discuss end-of-life topics, one should investigate whether treatment decisions are well-considered and treatment outcomes are positive.
CHAPTER 7

CONCLUSION

This thesis provides insight in patients’ preferences for participation, in experiences of patients and physicians in treatment decision-making, and in actual decision-making in the outpatient clinic. Patients prefer to participate in upcoming decisions concerning subsequent lines of palliative chemotherapy. Yet, in daily practice, SDM is not realized. There is a lack of awareness of available alternatives to starting palliative chemotherapy, both on the side of physicians and of patients. Patients and physicians focus on continuing treatment without addressing expectations, values and needs, and alternatives. Open and honest communication is needed in which patients’ expectations and concerns are discussed. Through this, the difficult process of decision-making in the last phase of life can be facilitated and well considered decisions can be made, leading to the best care for the individual patient.
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General discussion


