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Chapter 1

General Introduction

This thesis focuses on patient participation in decision-making in the context of palliative chemotherapy in the last phase of life. This topic is studied from different perspectives and with different methodologies. Before describing the results of the study in the next chapters, this chapter introduces the concept of patient participation in health care decisions. This is followed by a summary of research findings on treatment decision-making in the advanced cancer setting specifically. The chapter will subsequently outline why a focus on participation preferences and experiences of advanced cancer patients is important and which needs for research can be identified. Finally, the objectives and methods of the study described in this thesis will be addressed.

BACKGROUND

Patient participation in medical decision-making

Prior to the 1980s, the most prevalent approach to decision-making in health care was paternalistic, with physicians assuming the dominant role [1]. In this doctor centered approach, disease and treatment were central. For most diseases, a single best treatment was assumed and physicians were supposed to be in the best position to make treatment decisions. Patients' illness experiences and their involvement in health care decision-making were not or less considered [2]. During the 1980s and beyond, the paternalistic role for physicians began to be questioned. At the same time, for an increasing number of diseases more treatment options became available. This evolved to a more complex decision context [1], in which different treatments had different tradeoffs between benefits and risks. Since the patient rather than the physician would have to live with the consequences of these tradeoffs, a plea for a more respectful, sharing and empowering approach of the patient developed [2]. At the same time, physicians started to emphasize the importance of understanding the meaning of illness for patients rather than merely diagnosing medical diseases [3] and a more patient centered approach evolved in medicine [3-5]. At the same time there are several reasons for this increased emphasis on patient autonomy described in the literature. People have become better educated and informed about health care issues, but also a shift in society's expectations of the appropriate role for physicians has occurred [4]. Placing the patient at the center of care [5] represents an approach to improve the quality of medical care [6]. Nowadays, patients are encouraged and expected to participate in decisions affecting their own treatment and care [7]. The shared decision-making (SDM) model is nowadays often considered ideal [8-11]. A central element of common definitions of SDM is on the information exchange between physicians and patients and on the involvement of both parties [8;12-14]. Stiggelbout and colleagues have

distinguished 4 steps in SDM [15]. 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 various options and their probabilities are explained to the patient, 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.

Extensive research has been done on patient preferences for participation in treatment decision-making. Preferences for participation in medical decision-making can be measured with tools such as the Control Preferences Scale (CPS) [16]. These tools measure the extent and type of influence patients want to have concerning treatment decision-making. Overall, it is found that most patients prefer a shared role in which patients and physicians share responsibility for the treatment decision [17-21]. However, differences are found between patient populations, related to demographic factors and educational level. For example, younger patients [22], higher educated people [20;23-25] and women often prefer a more active role in decision making [23]; older patients were found to prefer a more decisive role from their physician [26]. The phase in the disease trajectory also appears to influence patient preferences; patients in the beginning phase of the disease prefer a less active role [27] while patients with a longer disease history whose condition recently worsened want to be more decisive [28]. In addition, it is also important to know if the preference for a certain role in decision-making expressed beforehand is also realized in the actual decisions about treatment. A review on patient participation preferences in medical decision-making of patients with cancer showed significant discrepancies between preferred and perceived roles in decision-making and in the majority of studies, patients preferred to be more involved than they actually were [29]. Failing to meet patients' desired involvement has been shown to have a negative effect on patient outcomes such as satisfaction and anxiety [4]. Establishing preferences for involvement in treatment decision-making is important to make health care more sensitive to the needs and expectations of each individual patient [30].

Treatment decisions in the last phase of life of cancer patients

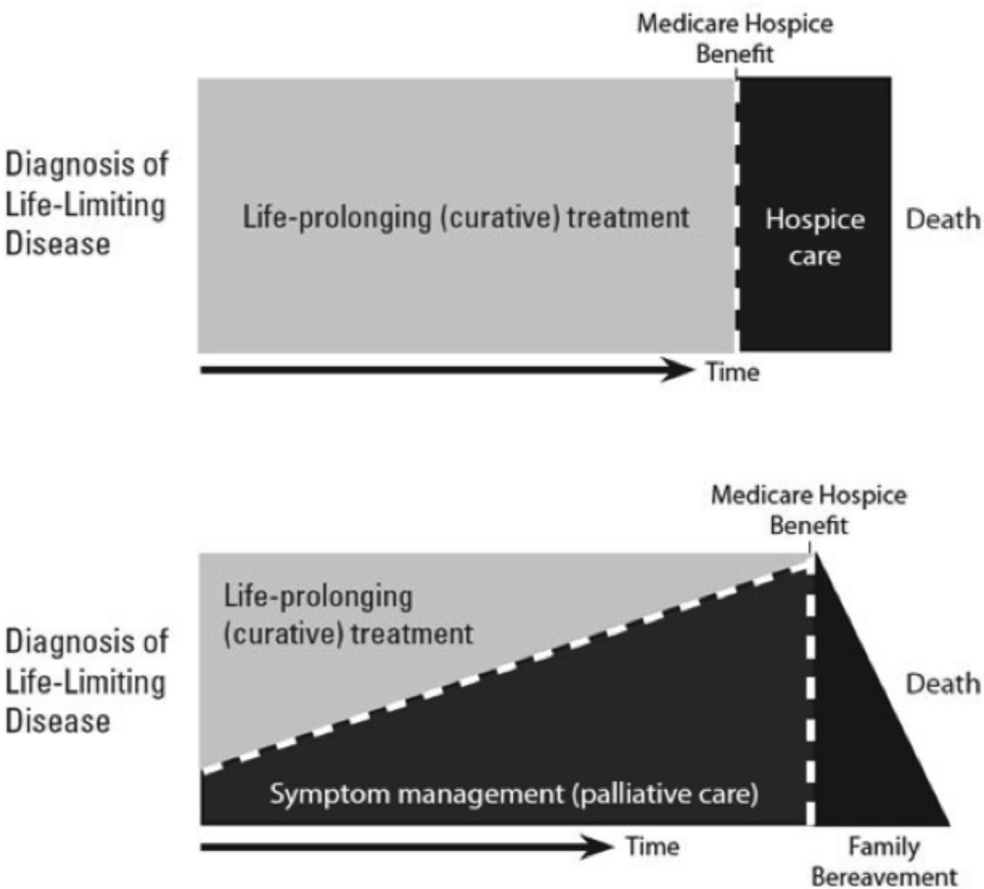
Most studies on patient participation in treatment decision-making are conducted in the curative setting where patients often have to choose between treatments that have both proven to be effective and have no clear-cut differences in survival outcome [31-36]. Curative treatments and life-prolonging treatments are treatments aimed at modifying the disease, as opposed to palliative

treatments, which focus on the management of pain or other symptoms but without any prospect of cure. In the last phase of life the trade-off between possible benefits of continuing treatment in terms of likely life prolongation and likely side effects of the treatment becomes more relevant. As treatment aims can change in time communication between physicians and patients on expectations and wishes are of utmost importance and can be achieved with SDM. However, available data show that SDM is not optimal in end-of-life care: A longitudinal study on terminally ill patients found that these patients did not perceive that their participation in treatment decision-making reflected their preferences [37]. A study on treatment goals in advanced oncology, in which consultations were tape-recorded, found that only 44% of patients was offered an alternative to anticancer treatment during those consultations, and only 30% were offered a choice [38]. A study on the actual decision choice in patients with metastatic cancer, also observed that the alternative option of “watchful waiting” was mentioned in only half of the consultations about palliative chemotherapy that they observed, while 87% of these patients preferred a strong role in decision-making [39]. Physicians should be aware that preferences of patients can change as death is approaching. Systematic literature reviews on topics such as prognosis disclosure and communication in advanced life-limiting illnesses conclude that patients will not necessarily bring up the issues they want to discuss, and that socio-demographic characteristics are not reliable predictors of information needs [40;41]. A timely and individually tailored exchange of information is therefore recommended [42].

Palliative care and palliative chemotherapy

Palliative care is an approach that improves the quality of life of patients and their families facing a life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual [43]. Until about 10 years ago, palliative care mainly focused on the care for terminally ill patients, and palliative and curative care were often seen as separate concepts. A current policy priority is the promotion of a timely start of palliative care, early in the disease trajectory, making the shift from curative care to palliative care more gradual (figure 1). In this approach, based on the model of Lynn and Adamson [44], treatment aimed at life prolongation may be given alongside treatment aimed at symptom management on all care domains (physical, psychosocial and spiritual). Moreover, further on in the disease trajectory the initial emphasis on life-prolonging treatments decreases gradually, shifting to an emphasis on palliation to maintain quality of life and management of pain and other symptoms. In this care continuum, palliative care starts early in the course of the disease and continues after the patient's death with aftercare for relatives.

Figure 1. Model of Lynn &Adamson 2003. The older “transition” Model of Care versus a “trajectory” Model of Care



In advanced cancer patients treatment often means palliative chemotherapy. Palliative chemotherapy can be aimed at delaying tumor growth, prolongation of life and/or maintaining or improving quality of life. Therefore, palliative chemotherapy makes treatment goals diffuse and implies a complex decision. In addition, in the last decade more treatment options have become available and deciding about treatment in the last phase of life has become a delicate process. Nonetheless, further on in the disease trajectory the effects on life prolongation decreases. Whether treatment with chemotherapy should be continued is not always evident. Studies are contradictory with respect to results of palliative chemotherapy. In some studies chemotherapy

appears to enhance patients' quality of life [45;46] while other studies found no improvement of quality of life or even decline [47-49]. Second and third line chemotherapy in the advanced cancer setting have a limited likelihood of response and only modest improvement in (progression-free) survival [50]. Various studies have shown a trend towards increasing use of chemotherapy for advanced cancer patients [51-53], often called "aggressive care". This aggressive treatment in the last phase of life has been identified as an indicator of poor quality of care [53]). In the Netherlands continuing treatment is an issue of public debate. A study indicates that physicians prefer to continue treatment, as they believe it is in the patients' best interest, despite sometimes doubting whether the treatment benefits would outweigh the burdens [54]. Physicians do not want to disappoint their patients by not helping them or by taking away their hope by giving them "nothing" [54;55]. It is also found that severely ill patients sometimes wish for chemotherapy even when such treatment is probably ineffective [56] or with small benefits [57], and that patients may consider quality of life of secondary importance [58]. Patients may be willing to tolerate the toxicity of chemotherapy in the expectation of some life prolongation, regardless of the fact that the cancer is not curable. However, other studies have shown that patients prefer quality of life over quantity of life [59;60]. For example, patients find it important not to be ill due to chemotherapy, to stay in control or not to spend valuable time in hospital [61]. Patients' attitudes and wishes vary widely when faced with a life-threatening disease. However, it is unclear to what extent patients participate or want to participate in these decisions in the last phase of life, which more often regard stopping or continuing a subsequent line of chemotherapy than choosing between treatments with equal outcome on survival.

Patients with advanced cancer and setting of this study

Every year about 101.500 people in the Netherlands are diagnosed with cancer [62]. Although chance of survival varies among type of cancer and stage of the disease, almost half of all the cancer patients die within 5 year after diagnosis. Many patients are treated with a potentially life prolonging treatment and are faced with situations in which decisions must be made whether or not to start a subsequent line of palliative chemotherapy.

This thesis focuses on two patient populations that are confronted with these decisions: patients diagnosed with glioblastoma multiforme (GBM) and patients with metastatic colorectal cancer. In these patient populations, the question is not 'if' the tumor recurs, but 'when' it recurs, so that decisions for further treatment need to be made.

GBM is the most common and most malignant type of primary brain tumor in adults. Brain tumors are relatively rare, every year 1100 people are diagnosed with a brain tumor. The median survival

for these patients is approximately 14 months after diagnosis [63]. At time of diagnosis the main aim of treatment is to prolong life, but since the treatment is not curative, morbidity during the remaining survival time is of utmost importance for both the patient and their relatives. Almost all patients diagnosed with GBM undergo postoperative combined chemo- and radiotherapy (64), so called first line treatment, as first line treatment has shown benefits in terms of survival (63). When progression of the disease occurs, a decision is often required on whether or not to start a (second-line) treatment aimed at prolonging life, but with the disadvantage of burdensome side effects. Although this treatment may lead to some life-prolongation, the response rate to a subsequent line chemotherapy is low [65;66].

Colorectal cancer is the third most common type of cancer in the Netherlands [62]. Every year approximately 13.000 patients are diagnosed [62]. At time of diagnosis over 20% has metastasis (stage IV). The median survival for these patients is 24-28 months with current standard care [67], and no more than 5-8% of these patients are alive at five years from diagnosis [67;68]. The aims of chemotherapy in this patient population are to prolong survival, control symptoms, and maintain or improve quality of life (e.g. relief of pain caused by tumor growth) [69]. Chemotherapy can be effective in prolonging time to disease progression and survival, but these benefits must be weighed against treatment toxicity and the effect on quality of life (e.g. nausea and fatigue) (69). These two patient groups are thus confronted with the complex decisions described in the former paragraph and are therefore chosen for studying the objectives of this thesis.

Need for research

As described above, patient participation in health care decisions is a research issue that is getting more attention. Existing studies on patient participation, however, have some shortcomings. Firstly, they examine mostly patients with a non-life-threatening disease or patient with (a potentially) curable cancer. Less attention has been paid to situations in which cure is no longer possible and the end of life is approaching and can only be postponed for a shorter or longer period. As these decisions differ substantially from those in a curative setting, the reasoning behind a patient's choice is of great importance to provide a better understanding. As mentioned before, decisions whether or not to start palliative chemotherapy are complex due to their different goals. Also, more treatments have become available with limited effects on survival, and therefore a well-considered treatment decision should be made whether or not to start palliative chemotherapy. Therefore more empirical research is needed to improve understanding and insight in patient participation in the last phase of life.

Secondly, many existing studies are retrospective or based on scenario cases. Hypothetical treatment scenarios preferences may differ from actual preferences of patients when they are confronted with specific treatment decisions in real life. Two reviews found that patients with cancer seem more likely to prefer a participant role in decision-making than people in the general population [19;70]. A better understanding of patients' preferences regarding participation in treatment decisions could help to improve patient-centered care and the quality of the decision-making process.

Thirdly, there is lack of a longitudinal perspective on patient participation. Most studies are cross-sectional and do not offer insight into possible changes in participation preferences over time or in course of the disease trajectory. Whether and how preferences change during the patient disease trajectory needs further research. Insight in changes in preferences could help physicians to adjust their communication to patients' preferences and wishes and optimise the decision-making process and therefore enhance the quality of decision-making and satisfaction.

Finally, to understand patient-physician communication both perspectives are needed. Up till now, most studies focus either exclusively on patient or the physician perspective. Integrate both perspectives may lead to a deeper understanding of the process of decision-making on treatment.

Objectives and research questions

The main aim of this thesis is to gain insight into patient participation in treatment decision-making in the last phase of life. Central in this thesis is the participation of advanced cancer patients in decisions concerning palliative chemotherapy.

The first objectives is to gain a deeper understanding of patient preferences regarding participation in palliative care situations. The second objective of this thesis is to gain insight in patients' and physicians' participation in actual treatment decisions whether or not to start palliative chemotherapy, according to the steps of SDM. Two studies have been conducted to reach this objective. A systematic review to gain insight in congruence between preferences and perceived participation was conducted and a longitudinal qualitative study was performed looking at patients' preferences, shared decision-making in the advanced cancer setting and mechanisms that could enhance continuing treatment. The objectives are worked out in the following research questions:

1. To what extent do patients prefer to participate in treatment decision whether or not to start palliative chemotherapy in the near future and what is the reason for this preferred role? (objective 1)
2. Is congruence found between patients' preferred and their perceived participation in medical decision-making and in case of mismatch, would patients prefer to participate to a greater or lesser extent when their preferences were not met? (objective 1 and 2)
3. Can steps of shared decision-making about second- and third-line chemotherapy be recognized in clinical practice and what is the impact on patient participation in treatment decision-making? (objective 2)
4. What are specialists' experiences with and views on shared decision-making, and how do they apply the 4 elements of the shared decision-making model? (objective 2)
5. What are mechanisms that contribute to the tendency of continuing with treatment in advanced cancer patients? (objective 2)

METHODS

In order to reach the objectives and to answer the research questions, we used qualitative research methods. We also conducted a systematic review. The methods are outlined here, but described in more detail in the separate chapters of this thesis.

Systematic review

In order to answer the second research question a systematic literature review was performed to identify studies that examined the congruence between preferred and perceived participation in medical decision-making among patients. Medline, PsycINFO, CINAHL, EMBASE and the Cochrane Library databases were searched up to September 2012 by use of a search strategy including search terms preference, patient participation and decision-making. The search strategy yielded a total of 4299 hits of which 44 articles were included because they reported on patient congruence between preferences and perceived participation in medical decision-making.

Qualitative studies

A longitudinal qualitative observational and interview study was performed among a group of 28 advanced cancer patients diagnosed with GBM or colorectal cancer who visited the outpatient clinic of a large university hospital. Observation of visits was used to get insight in actual communication between patients and physicians. In-depth interviews were used to get insight in

preferences and experiences of the participating patients and physicians.

The data collection period ran from May 2010 to February 2013. After inclusion, all patients were interviewed about their preferences for participation in treatment decision-making. The Control of Preferences Scale (CPS), developed by Degner [16], was used to start discussing the extent and type of influence patients wanted to have concerning medical decision-making in the near future. From that moment on, patients were followed in time as long as they visited the outpatient clinic. The researcher attended their outpatient clinic visits and had informal conversations with patients and relatives in the waiting room. The outpatient clinic visits were observed and digitally recorded. Both the patient and their treating physician were interviewed after treatment decisions were made (whether or not to start a life prolonging treatment) to establish their perceived role in the decision-making process. Again, the CPS was used to discuss the extent and type of influence they had had.

Furthermore, a multidisciplinary focus group meeting was organized with medical professionals who were involved in the decision-making process of patients diagnosed with GBM. A topic list based upon literature and the analysis of the former held interviews was used. Participants discussed the concept of shared decision-making and its elements when applied to the context of advanced GBM patients, and their ideal role in this process.

Interviews and observations of outpatient clinic visits and focus group were audio taped, transcribed verbatim (those visits in which treatment decisions were made) and analyzed [71].

Transcripts were first read and re-read to become familiar with the data, codes were ascribed to meaningful text units, and grouped together in order to identify themes.

OUTLINE OF THIS THESIS

Chapters 2 to 6 of this thesis are based on articles that have been published in a peer-reviewed scientific journal. This implies that various chapters overlap, especially with regard to the methods sections, which have been maintained in each chapter so that they can be read independently.

Chapter 2 describes the preferences of advanced cancer patients with regard to participation in treatment decision-making in the last phase of life.

Chapter 3 reports on the level of congruence between patients' preferred and their perceived participation in medical decision-making.

Chapter 4 focuses on daily clinical practice and examines whether and how steps of shared decision-making are recognized in decision about subsequent lines of chemotherapy.

Chapter 5 elaborates on experiences and views of health care professionals concerning the

implementation of shared decision-making.

Chapter 6 presents the results of a study investigating the mechanisms that contribute to the tendency of continuing treatment in the advanced cancer setting.

Finally, chapter 7 discusses the main findings. It addresses methodological considerations, main findings, implications for practice and policy, and suggestions for further research.

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