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## Patient participation in treatment decision-making in the last phase of life

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# Summary

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This thesis focuses on patient participation in decision-making in the context of palliative chemotherapy in the last phase of life. When patients are not able to cure from their disease, a well-considered choice about invasive treatment or supportive care has to be made, which is often difficult and complex. Can patient decide about the treatment they would like to receive, and to what extent do patients wish to participate in the decision-making process? And how are decisions on whether or not to start a (new) palliative chemotherapy made in daily practice?

**Chapter 1** gives an overview of developments in patient participation within the last decades. Whereas the physician had a paternalistic role in decision-making before, a shift has occurred towards a more active role for the patient in the last 30 years. The shared decision-making (SDM) model is nowadays often considered ideal. A central element of common definitions of SDM is that physicians and patients are both involved and exchange information. In general, it is found that most patients prefer a shared role in which patients and physicians share responsibility for the treatment decision. However, differences are found between patient populations, related to demographic factors and educational level. For example, women often prefer a more active role in decision-making than man, the same accounts for younger patients and higher educated people. As more treatment options have become available in the last decade, deciding about treatment in the last phase of life has become an even more delicate process. Among 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. 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.

To answer the research questions two studies were conducted. A systematic review was performed to identify studies that examined the congruence between preferred and perceived participation in medical decision-making among patients. The second study was a longitudinal qualitative observational and interview study, performed among a group of 28 advanced cancer patients diagnosed with a malignant brain tumor, glioblastoma multiforme (GBM) or colorectal cancer. These patients visited the outpatient clinic of a large university hospital. In a first interview patients were asked for their preferences with regard to participation in future treatment decision-

making. From that moment on, patients were followed in time as long as they visited the outpatient clinic. When a treatment decision was made on whether or not to start a new palliative chemotherapy, both patients and physicians were interviewed to get insight in their perceived role in the decision-making process. Furthermore, a focus group meeting was organized with medical professionals who were involved in the decision-making process of patients diagnosed with GBM.

**Chapter 2** describes an interview study on patient preferences for participation and the reasons for patients' preferred role in treatment decision-making at the end of life. The interviews revealed that all patients wanted their physician to participate in the treatment decision-making process because of his/her expertise and experience. The extent to which patients preferred to participate themselves seemed to depend on how patients saw their own role or assessed their own capabilities for participating in treatment decision-making. Patients who doubted about their capacity to make treatment decisions preferred to give a more decisive role to their physician. Patients who wanted an active role in future decision-making had several reasons for preferring this role: some wanted to keep control over their own life, while others felt it was their responsibility to make treatment decisions themselves. The observed variation in preferred role and their reasons asks for different approaches and support from physicians in the decision-making process. Furthermore, it was found that patients foresaw a shift in their preferred level of participation to a more active role in the later phase of illness when life prolongation would become more limited and quality of life would become more important. Communication about patients' expectations, wishes and preferences for participation in upcoming treatment decisions is of great importance. An approach in which these topics are discussed openly would be beneficial.

**Chapter 3** presents the results of a literature review about the congruence between patients' preferences regarding participation and their perceived participation in treatment decision-making. In total 44 papers were included, which contained 52 different patient samples. The congruence between preference for and perceived participation in decision-making was 60% on average. In cases where no congruence was found, of 36 patient samples most patients preferred more involvement and of 9 patient samples most patients preferred less involvement. The most investigated factors associated with preferences were age and educational level. Younger patients preferred more often an active or shared role as also did higher educated patients. This 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

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during their illness trajectory.

The actual daily practice of decision-making is described in **chapter 4**. The longitudinal qualitative study described in this chapter examined whether and how steps of the shared decision-making model are recognized in decision-making in second- and third line chemotherapy. Patients appeared to be satisfied with the decision-making process, but the steps of SDM were barely seen in daily practice. The extent to which physicians created awareness about available treatment options was limited and, above that, treatment options were not discussed in an equal way. Patients' wishes and concerns were not explicitly assessed, which led to different expectations about improved survival from subsequent lines of chemotherapy. To reach SDM in daily practice, physicians should create awareness of all treatment options, including forgoing treatment, and communicate the risk of benefits and harms. Open and honest communication in which patients' expectations and concerns are discussed is needed. This could facilitate the difficult process of decision-making in the last phase of life and could strengthen a focus on the best care for that specific patient.

**Chapter 5** provides insight in the perspective of medical specialists on sharing decisions with patients with recurrent glioblastoma. Medical specialists considered shared decision-making to be important; however, they did not adhere to its elements. Stopping treatment was not considered equal to continuing treatment. Exploration of patients' wishes was done implicitly, and shared responsibility for the decision was not highly recognized. The main barriers to shared decision-making were preferences of both patients and specialists for starting or continuing treatment and assumptions of physicians about knowing what patients want. To improve cancer care, education of medical specialists is needed on how to involve patients in their treatment decisions and on how to discuss alternatives next to palliative chemotherapy.

Mechanisms that contribute to the tendency towards continuing chemotherapy in patients with advanced cancer are described in **chapter 6**. We uncovered four mechanisms in daily oncology practice that can contribute to the tendency towards continuing chemotherapy in patients with advanced cancer: (1) "presenting the full therapy sets the standard"—patients seemed to base their justification for continuing chemotherapy on the "standard" therapy with the maximum number of cycles as presented by the physician at the start of the treatment; (2) "focus on standard evaluation moments hampers evaluation of care goals"—whether or not to continue the treatment was mostly only considered at standard evaluation moments; (3) "opening question guides towards

focus on symptoms”— most patients gave an update of their physical symptoms as an answer to the opening question of “How are you doing?” Physicians consequently discussed how to deal with these symptoms at length, which often took up most of the visit; (4) “treatment is perceived as the only option”—patients mostly wanted to continue with chemotherapy because they felt that they had to try every available option the physician offered. Physicians also often seemed to focus on treatment as the only option. Discussing care goals more regularly with the patient, for instance facilitated by implementing early palliative care, might help counter the 4 above mentioned mechanisms and lead to a more well-considered decision. This could be either stopping or continuing chemotherapy.

The last chapter of this thesis, described in **chapter 7**, highlights the methodological strengths and weaknesses of the different studies. Furthermore, the main findings and interpretations were discussed and placed in a broader perspective. Recommendations for policy, practice and future research were made to enhance patient participation in treatment decision-making. Health care providers and patients both have an important role in this process. Shared decision-making can only take place if different treatment options were considered as equal and if a patients is given room to talk about wishes, goals of care and expectations.

