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Chapter 5

Perspectives of medical specialists on sharing
decisions in cancer care: A qualitative study
concerning chemotherapy decisions with patients
with recurrent glioblastoma

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ABSTRACT

Background: In cancer care, difficult decisions concerning advanced treatment need to be made, weighing possible life prolongation against harmful side effects. Treatment is frequently started, showing the need to explore how decisions are made. Little is known about the perspectives of physicians on shared decision making with patients. This qualitative study aimed to describe the perspectives of medical specialists on the decision-making process with patients with glioblastoma concerning starting new treatment.

Methods: Qualitative interviews were held with medical specialists. One focus group was organized with medical professionals. Their opinions about elements of shared decision making and the applicability in the context of patients with glioblastoma were assessed. The topic list for the focus group was based on the analysis of the interviews. Qualitative analysis of the transcripts was performed by three researchers independently.

Results: 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 the 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.

Conclusion: Medical specialists recognized the importance of patient involvement but experienced difficulty in sharing decision making in practice. Elements of shared decision making are partly followed but do not guide decision making. To improve cancer care, education of medical specialists and adjustment to the elements are needed to involve patients.

INTRODUCTION

Shared decision making is currently presented as a promising approach to improve patient-centered care [1–3]. With this approach, physician and patient share information and treatment preferences, and both aim to reach mutual agreement about the steps to take in treating the disease [4,5]. Shared decision making is situated between the informed and paternalistic models of decision making. In the latter model, only the physician makes the decision, whereas the patient ultimately decides in the informed physician-patient relationship. According to Charles et al. [5], a shared decision is best because it respects both patient and physician involvement without a dominant role for one of them. Physicians can involve the patient in the decision-making process by following several steps, outlined by Stiggelbout et al. [6] in their model of shared decision making. The first step involves outlining all options, including the option of doing nothing 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 to support him or her in 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 responsibility for the decision by establishing an equal partnership and assessing the preferred role of the patient in the decision-making process. The shared decision-making model and its practical applicability are important when treatment decisions may have substantial consequences for patients [5]. This is the case in advanced cancer care, in which patients and physicians are faced with the question of whether to start advanced lines of non curative chemotherapy. Although first-line therapy is shown to be successful in life prolongation, second-line chemotherapy seems to be less effective in prolonging life [7–9]. Some studies show that after second-line therapy, approximately 20% of the patients are progression-free after 6 months [9–11]. Because chemotherapy may involve harmful side effects, its administration might result in serious discomfort for advanced cancer patients in their last phase of life [12]. Despite the side effects, a number of studies report that in practice, second-line chemotherapy is frequently started and even considered standard [12–15]. Furthermore, the decision to start chemotherapy is not always based on scientific evidence [9, 12, 16]. This raises doubts about how the decisions concerning subsequent lines of chemotherapy are made. Little attention has been paid to the perspectives of medical specialists on chemotherapy in the last phase of life and shared decision making. This qualitative study aims to assess the perspectives of medical specialists on the decision-making process concerning life-prolonging chemotherapy in the last life phase of patients with recurrent glioblastoma. The study aims to answer the following questions: what are specialists’ experiences with and views on shared decision making, and how do specialists apply the four elements of the shared decision-making model in practice? [6]

METHODS

Design

The present study is a qualitative study with in-depth interviews with medical specialists, followed by a focus group meeting with medical professionals based on the findings of the interviews.

Setting

The study is part of a longitudinal qualitative study [17] of the process of decision making for patients with advanced cancer. Patients diagnosed with glioblastoma, the most prevalent and malignant type of primary adult brain tumor, were included in the study after the start of first-line treatment. Glioblastoma is an incurable cancer type, and the median survival after diagnosis is 13–17 months [18, 19]. First-line treatment consists of surgery and chemo- and radiotherapy [18, 20]. Progression of the tumor occurs on average within 5–8 months, and patients and their medical specialists are faced with the decision of whether to start subsequent lines of treatment [15, 21]. Second-line treatment could consist of surgery and/or chemotherapy but with less evidence of life prolongation and a higher chance of harmful side effects [8, 22]. The most common side effects include fatigue, hypertension, nausea, diarrhea, and convulsion, but no neurological decline due to treatment has been reported [21, 23–25]. After tumor relapse and second-line treatment, median survival is shown to be 6–8 months, but it is unknown whether this is longer than survival for those with no treatment [21, 26]. The effects are unknown because of the lack of phase III trials addressing the effects of second-line surgery and radiotherapy and because no randomized controlled trials have been conducted comparing second-line treatment with no treatment [9, 26, 27]. Furthermore, many studies of the effects of second-line treatment are influenced by selection bias [11, 27].

Study Population

The interviewed medical specialists were neurologists, oncologists, and neurosurgeons who were all involved in the decision-making process. The medical specialists were asked individually about the process of deciding whether to start second or subsequent lines of treatment in general and in specific cases. Subsequently, a multidisciplinary focus group meeting was organized to further discuss the outcome of the analysis with medical professionals involved in the process of decision-making.

Recruitment and Sampling

For the interviews, medical specialists were recruited through the patients included in the longitudinal study and were from the neurology department of a large university hospital. Patients with

glioblastoma were recruited through consecutive sampling and included between May 2010 and February 2013 [17]. During the study of the patients' perspectives, 12 interviews were held with 10 medical specialists about the decision-making process with the included patient. Next, participants for the focus group meeting were recruited through purposive sampling from the neurology department of a large university hospital. The focus group was held with four participants—a neurologist, an oncologist, a radiotherapist, and a nurse practitioner—all of whom were regularly involved in the decision-making process. Although the nurse practitioner was not a medical specialist, his close involvement in the decision-making process and understanding of the preferred role of the medical specialist provided valuable insights; therefore, his perspective was considered equally important. Interviews The 12 in-depth interviews were held from September 2010 to September 2013 with three oncologists, six neurologists, and a neurosurgeon after second- or third-line treatment decisions were made with specific patients. All interviews took place at the involved department and lasted 25–40 minutes. The interview topic list included open-ended questions about patient participation, the role of the medical specialist, the decision-making process in general, and the decision made with the specific patient. All interviews were performed by one interviewer (LB) and transcribed with the consent of the medical specialist. The interviewer kept field notes with reflections on the interviews and the study.

Focus Group

The focus group meeting took place in April 2014 and used a topic list based on the literature and the analysis of the interviews, as shown in Table 1. First, the concept of shared decision making was introduced, and the four elements were explained, along with the analysis of the interviews with quotes from the medical specialists. Second, participants discussed the concept and the elements of shared decision making, as applied to the context of advanced glioblastoma patients, and their ideal role in this process. The meeting lasted 90 minutes and was led by an experienced moderator. All participants consented to the meeting being audio taped and transcribed for analysis.

Data Analysis

The study was explorative and used open coding, as described by Strauss and Corbin [28]. The transcripts were examined independently to create a list of codes (e.g., mentioning the option of not starting treatment, the role of the team meeting, discussing the poor prognosis, sharing responsibility, and the role of the patient). Three authors (JCDS-T, HRWP, and GAMW) subsequently compared their findings to reach consensus about the codes and to create narrative portraits of

the interviewed medical specialists, with a focus on the elements of shared decision-making. These portraits and the codes were used for further analysis and to construct a topic list for the focus group meeting. The analysis was iterative, with themes emerging from the interviews used in the focus group. The transcript of the focus group meeting was analyzed independently (JCDS-T, HRWP, and GAMW) to identify trends and agreement within the meeting about the topics discussed. The analysis was discussed to agree on the overall interpretation of both the interviews and the focus group and to choose quotations for illustration of the results. These quotations were translated by a professional translator. These findings were discussed by all of the researchers.

Ethical Considerations

The study was approved by the medical ethics committee of the VU University Medical Center Amsterdam. Patients consented to their medical specialist being interviewed about the decision-making process. Written consent was obtained at the start of the interviews and the focus group meeting.

RESULTS

Medical specialists expressed different views toward shared decision making. Some specialists emphasized the importance of involving the patient in the decision-making process. Others stated that sharing the decision making is not in the best interests of the patient because the patient does not have an adequate understanding of the disease and the treatment. Almost all medical specialists differentiated between first and subsequent lines of chemotherapy. Because the amount of expected benefit is limited in subsequent lines, physicians' preference to start treatment was less strong, and they gave more room for the opinion of the patient. In the interviews and during the focus group meeting, specialists' opinions about shared decision making were assessed, including the difficulties associated with each element of shared decision making.

Table 1 Topic list focus group

Elements of shared decision-making (6)	Points to discuss
1 Creating awareness of equipoise	<ul style="list-style-type: none"> - Presenting the option of treatment and of no treatment as equal - Role of team meeting - Treatment preference of both specialist and patient
2 Discussing pros and cons of each option	<ul style="list-style-type: none"> - Discussing the poor prognosis - Directing patients towards preferred option
3 Assessing patients' expectations and concerns	<ul style="list-style-type: none"> - Importance of knowing what patients want - Implicitly or explicitly
4 Sharing responsibility and exploring role of patient	<ul style="list-style-type: none"> - Equal partnership - Sharing responsibility to prevent problems afterwards - Who decides?

Creation of Awareness of Equipoise

The first element in the process of shared decision making is creating awareness of equipoise, which means that the options of treatment and no treatment are presented equally. The importance of offering both options was recognized by some respondents. For most, however, the option of no treatment was not perceived as equal to treatment because starting subsequent lines of treatment could possibly benefit the patient.

The concept of "no best option" is, in my opinion, somewhat theoretical because, in practice, there is often a best option based on the tumor and the status of patients.

[Oncologist focus group meeting]

Medical specialists reported that, in daily practice, options are already discussed in the multidisciplinary team meeting that takes place prior to the visit with the patient and that often results in advice for the patient. The team meeting is focused mainly on the medical possibilities because the specialists share what is or is not possible based on their expertise. Consequently, the option of no treatment is not strongly emphasized.

The focus is very much on, what can technically still be done? What's still possible?

*But the question of "maybe we should do just nothing" sometimes comes from the back of the meeting room [from the nurses during the team meeting]...there sometimes is too little attention to [it]. **[Nurse focus group meeting]***

Some medical specialists noted their responsibility to mention all options and to adjust the advice to the needs of the patient, whereas others stated that most patients will automatically follow the advice of the specialist.

Interviewer: But in general, you suggest what treatment should be given?

Respondent: Yes, I think so, yes.

Interviewer: But is this also because patients want to be treated anyway?

Respondent: Well, I am also thinking about why I do it...maybe because in the team meeting we mention by default what is possible, and then this becomes your starting point for the visit with patient and that "you can do nothing" comes only later instead of the other way around.

*Well, I actually don't know. **[Interviewed oncologist]***

Most specialists also noted the preference of patients to start or continue treatment, making it more complicated to offer the option of no treatment; therefore, awareness of equipoise was not regarded as a relevant issue in most cases.

The patient often wants chemotherapy at all costs, and then it is difficult to withhold it.

[Oncologist focus group meeting]

Mentioning Benefits and Harms

The second element is mentioning the benefits and harms of all options. Medical specialists considered informing the patient to be important; however, because specialists experienced difficulty with the option of no treatment, the information provided concerned the benefits and harms of treatment with chemotherapy. Medical specialists were aware they provided information in line with the preferred option they had in mind, that is, mostly treatment. In this way, they directed patients toward their preferred option.

Of course, you can steer it tremendously. Only by the way you sit and look, you can try to explain something with the same message while implicitly showing it would not be your choice and that that would be crucial for someone not to choose for it. [Interviewed neurosurgeon]

The preceding team meeting seemed to contribute to this approach because the benefits and harms of starting treatment have already been weighed there. Misunderstanding by the patient further complicates the second element of shared decision making because, according to several specialists, some patients are not able to maintain oversight and thus are not helped by a comprehensive outline of the pros and cons of all options.

I sometimes provide one patient with more information than someone else, but that is also because I sometimes feel that that is too much for some people, that they only get more confused. [Interviewed neurologist]

One of the reported barriers to discussing benefits and harms of treatment was uncertain and poor prognosis. Some specialists experienced difficulty discussing the poor prognosis or the limited benefit of therapy and feared taking away a patient's hope.

The problem is often that when we provide, by default, lomustine [chemotherapy], you then get a conversation about, "Yes, it does probably not catch on, etcetera." You then omit a bit of information because, yes, once you take that straw, it is kind of disingenuous to totally bend it afterward. [Interviewed oncologist]

Eliciting the Patients' Ideas, Expectations, and Concerns

The next element is clarifying the patients' ideas, expectations, and concerns about treatment options. Medical specialists seemed to recognize the importance of this element and noted patient motivation as a precondition for treatment. Several specialists explained that they do not ask for patients' ideas directly, and some stated that they already know what patients want.

In a first consultation, at which we see someone for quite some time,...one of the things you do is that you try to assess, between the lines, what kind of person is this? [Interviewed neurologist]

Again, the main barrier, according to the specialists, is that the patient cannot see all of the options and consequences; therefore, specialists did not consider the ideas of patients to be helpful in sharing the decision.

Some people do have all kinds of ideas about it, but in what they say, you notice that it does not match with the current information or that it does not correspond to their perception of their illness. When that is the case, I increasingly tend to take over the decision making. [Interviewed oncologist]

Furthermore, patients' wishes are not taken into account in the multidisciplinary team meeting, implying that medical specialists do not focus on this step. During the focus group, advanced care planning was mentioned as a solution to elucidate patients' wishes for the future, although finding a moment to discuss future situations appeared to be difficult. Medical specialists wanted to explore the wishes of the patient but without aiming to explicitly involve patients in the decision-making process.

Sharing Responsibilities

The fourth element of shared decision making is sharing responsibility, including developing an equal partnership with the patient. Medical specialists did not see equal partnership as a possibility because the physician has more knowledge about the disease and its treatment. Medical specialists further appeared to be reluctant in sharing responsibility. Some feared that sharing responsibility might lead to patients feeling guilty, and others assumed that most patients do not want any responsibility.

Only a few people really want to know the ins and outs, who really fit in these steps of sharing responsibilities, etcetera. [Radiotherapist focus group]

In contrast, several medical specialists indicated that they sometimes make the patient responsible to prevent problems afterward. This approach seemed to lead to shifting, rather than sharing, responsibilities.

You should have him involved when making decisions because if you are going to decide for the patient, then... look, these patients are always pleased with you as long as it goes well, and at the moment that it's no longer going well, their satisfaction level will decrease rapidly.

[Interviewed oncologist]

Some medical specialists considered it important to explore the extent to which the patient wants to share the decision. Most specialists said to do it implicitly, as they also seemed to do with the third element of exploring patients' wishes.

*I think it is important that you try to assess to what extent a discussion partner wants to be involved in the decision. ... I can be wrong, making an accurate assessment is difficult, but I do differentiate according to my own judgment if patients want to participate or not. But I don't know whether I always make the right assessment. **[Interviewed neurologist]***

Several specialists stated that in their daily practice they will make the final decision themselves. The reason is patients' lack of understanding. According to some medical specialists, this justifies a paternalistic approach toward their patients. Consequently, the last element seems to be hardly followed or followed only implicitly.

*I think they [patients] can't oversee it [the decision] well. I think that is too specialized because they don't know the ins and outs of the treatment. So I think they cannot be involved in deciding. I think the doctor should decide for the patient. **[Interviewed neurologist]***

DISCUSSION

This qualitative study aimed to assess how medical specialists experiences the process of decision making in advanced cancer care and what their views were regarding shared decision making. Although medical specialists considered the involvement of patients to be important, they had difficulty arriving at a shared decision in practice with patients with recurrent glioblastoma. The main barriers that were identified regarded the preferences of both patients and specialists for starting or continuing treatment and the assumptions of physicians about knowing what patients want. These barriers complicate the application of the elements of shared decision making [6]. The first element, creating equipoise, is not regarded as relevant by the specialists because of the preference for treatment by patients and specialists; therefore, the subsequent elements seem to

be focused mostly on the option of starting treatment only. Discussing benefits and harms and sharing responsibility are also not always considered to be in the best interests of the patient because patients are not able to maintain oversight of all of the options and consequences and do not always want responsibility for the decision, according to the medical specialists. The wishes and the desired role of the patient do not seem to be assessed explicitly, reducing patients' ability to participate in the process. Consequently, the four elements are applied in practice in a limited way, if at all.

Equipoise

The options of treatment and no treatment seemingly are not presented as equal because of both the specialists' and, according to the specialists, the patients' preference for treatment. This result has also been found in previous research [12, 29–31]. The difficulty of talking about not continuing treatment might be related to the perceived need to actively fight the disease and maintain hope [12, 29–32]. Buiting et al. [32] showed that physicians considered taking away hope to be harmful to patients' quality of life. De Haes and Koedoot [30] noted the physician and the patient being involved in this “coalition of hope” and how treatment supports survival and suppresses fears. Especially during treatment, mentioning poor prognosis and approaching death was reported to be difficult, in the present study and in previous ones [32, 33]. Because there is no convincing evidence that life expectancy will be prolonged substantially by second-line treatment for patients with recurrent glioblastoma, it is highly important to communicate this information [9, 17, 21, 25, 26]. If patients know that they may eventually benefit from treatment for only a few months, the decision not to start treatment may become more attractive. Nevertheless, longer expected survival does not mean that the physician can assume the patient wants treatment without sharing other options and the expected pros and cons. All options, including forgoing treatment, must be discussed to realize equipoise, even when both physician and patient have a preference for treatment, as shown in the current study. To ease the difficulty in addressing the end of life and the pros and cons of treatment and no treatment, medical specialists need to be trained to discuss future wishes with their patients; such discussion has been shown to improve the quality of care and prevent overtreatment in the last phase of life [34, 35]. Advanced care planning was mentioned in the focus group in the current study as a way to explicitly discuss patients' wishes for future treatment. This discussion might be held early after diagnosis, as it has positive effects on quality of life and survival, as shown by Temel et al. [35]. In this way, both the element of equipoise and the element of communicating pros and cons can be improved. 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 [6]. 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. As long as these are not known, it is impossible to decide which option is best for a particular patient. A study with general practitioners [36] found that they were positive about equipoise when defined as “portraying options in an open, nondirective manner.” The understanding of equipoise can be improved by both educating medical specialists and clarifying the original concept [6]. The option of no treatment might be discussed more often as specialists learn how patients want to live the last phase of life, and misunderstanding on both sides about treatment effects and future wishes might be ruled out. In addition, the option of no treatment can be offered more comprehensively not by explaining it as “doing nothing” but rather by defining it as starting palliative care, including symptom management and psychosocial support [35, 37]. This approach might be realized by including a clinical ethicist or palliative consultant in the team meetings at which the medical options for a patient are discussed so that the alternative option of palliative care has more attention. In this way, equipoise may be realized during the multidisciplinary team meeting, and end-of-life issues might be discussed more frequently [37–40].

The Patient’s Role

According to the medical specialists in this study, many patients do not prefer an active role in the decision-making process. This opinion is supported by previous research [12,30, 41]. It may be due to the specific patient population because glioblastoma patients sometimes suffer from cognitive impairment when the tumor is recurrent, complicating participation in the decision-making process [42, 43]. In the study of Buiting et al. [12], the preferred passive role was still considered as respecting patient autonomy because patients voluntarily took this role. Another reason for the passive role might be the difficulty with coping with end-of-life issues [12]. Nonetheless, several studies showed that patients with advanced cancer preferred an active role concerning treatment when the tumor is recurrent [44–48]. Because life expectancy is poor and uncertain for patients with recurrent glioblastoma, it is likely that they want to be actively involved in how to sustain quality of life in the last phase [9, 17, 21, 26]. Furthermore, Brom et al. [44] showed large variation in participation preferences among patients and during the disease trajectory. Consequently, medical specialists cannot simply assume that they know what patients would want without explicitly asking. They could be trained in how to explore the values and wishes of patients explicitly and how to accept full patient involvement when patients claim a large role because patient involvement requires flexibility in the physician, and shared decision making “implies giving up decisional power” by specialists [49].

Strengths and Limitations

The main strength of this study is the focus on medical specialists' perspectives, which have not been studied extensively before. The qualitative design provides in depth understanding of practice and of perceived barriers to involving patients in decision making. In addition, the multidisciplinary focus group improved reliability and supported the interpretation of the interviews, and this made the research an iterative process. The small number of focus group participants, however, was a limitation. Furthermore, the study did not provide information about the actual practice of medical specialists because medical specialists were interviewed and not observed. A future observational study in the clinical setting might provide information about this aspect.

CONCLUSION

This study showed that it is not easy to share the decision making process in practice with patients with recurrent glioblastoma because of the preference of both specialists and patients to start second-line treatment and the assumption of specialists about knowing patients' wishes. These barriers reduced the possibility of discussing all options (including no treatment) in an equal and open way and the explicit exploration of patients' wishes. Nonetheless, most specialists emphasized the importance of shared decision making and were aware of the need to involve patients in deciding about care. We recommend further development of the theoretical model of shared decision-making, taking into account the barriers encountered in practice, to provide a tool for specialists that enables them to "really put patients at the center of health care" [6]. This recommendation applies not only to the particular setting of patients with recurrent glioblastoma but also to all patients who face decisions about whether to start or continue advanced treatment.

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