

“Often Relatives are the Key [...]” –Family Involvement in Treatment Decision Making in Patients with Advanced Cancer Near the End of Life

KATSIARYNA LARYIONAVA,^{a,b} DANIELA HAUKE,^c PIA HEUßNER,^d WOLFGANG HIDDEMANN,^c EVA C. WINKLER^a

^aDepartment of Medical Oncology, National Center for Tumor Diseases, Programme for Ethics and Patient-Oriented Care in Oncology, Heidelberg University Hospital, Heidelberg, Germany; ^bInstitute for History and Ethics of Medicine, Centre for Health Sciences, Martin Luther University Halle-Wittenberg (Saale), Germany; ^cDepartment of Internal Medicine III, University Hospital Grosshadern; Ludwig-Maximilians University, Munich, Germany; ^dOncological Center Oberland, Hospital Garmisch-Partenkirchen, Garmisch-Partenkirchen, Germany

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Key Words. Family communication • Advanced cancer • Forgoing cancer-specific treatment • Family involvement • Qualitative interviews

ABSTRACT

Background. Family communication has been increasingly recognized as an important factor in decision making near the end of life. However, the role of the family in decision making is less studied in oncology settings, where most patients are conscious and able to communicate almost until dying. The aim of this study was to explore oncologists' and nurses' perceptions of family involvement in decision making about forgoing cancer-specific treatment in patients with advanced cancer.

Materials and Methods. Qualitative semistructured interviews with 22 oncologists and 7 oncology nurses were analyzed according to the grounded theory approach. The results were discussed against the background of the clinical and ethical debate on family role near the end of life.

Results. We could identify two approaches shared by both oncologists and nurses toward family involvement.

These approaches could be partly explained by different perception and definition of the concept of patients' autonomy: (a) a patient-focused approach in which a patient's independence in decision making was the highest priority for oncologists and (b) a mediator approach with a family focus in which oncologists and nurses assigned an active role to patients' family in decision making and strived for building consensus and resolving conflicts.

Conclusion. The main challenge was to involve family, increasing their positive influences on the patient and avoiding a negative one. Thereby, the task of both oncologists and oncology nurses is to support a patient's family in understanding of a patient's incurable condition and to identify a patient's preference for therapy. *The Oncologist* 2021;26:e831–e837

Implications for Practice: This study focused on oncologists' and oncology nurses' perceptions of family involvement in decision making about treatment limitation in patients with advanced cancer who are able to communicate in a hospital setting. Oncologists and oncology nurses should be aware of both positive aspects and challenges of family involvement. Positive aspects are patients' emotional support and support in understanding and managing the information regarding treatment decisions. Challenges are diverging family preferences with regard to treatment goals that might become a barrier to advanced care planning, a possible increased psychological burden for the family. Especially challenging is involving the family of a young patient because increased attention, more time investment, and detailed discussions are needed.

Correspondence: Eva Winkler, M.D., Ph.D., National Center for Tumor Diseases, Department of Medical Oncology, Programme for Ethics and Patient-Oriented Care in Oncology, Heidelberg University Hospital, Im Neuenheimer Feld 460, 69120 Heidelberg, Germany. Telephone: 49-(0)6221 56-36049; e-mail: eva.winkler@med.uni-heidelberg.de Received July 18, 2018; accepted for publication July 17, 2020; published Online First on October 26, 2020. <http://dx.doi.org/10.1002/onco.13557>

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INTRODUCTION

Discussions and decisions with patients about limiting cancer-specific treatment belong to one of the most difficult and stressful tasks in oncology practice. In the last years, the role of family communication has been increasingly recognized as an important factor in decision making near the end of life. The family can provide emotional support to patients and help them in decisions regarding further therapy. Furthermore, end-of-life discussions are integral for helping the family preparing for a patient's death. [1].

Studies show that the majority of patients with cancer want their family to be involved in discussions about limiting treatment near the end of life and that family involvement in decision making has been associated with greater patient satisfaction [2–4].

However, research suggests that there may be some variety among patients in attributed weight to family involvement in decision. Studies examining the role of patients' cultural background in end-of-life decision making demonstrate that certain ethnic groups (i.e., Asian and Hispanic groups) in comparison with white groups prefer more family involvement [2, 5–7]. Additionally, there are some sociodemographic characteristics that might influence patients' preference for family involvement; according to some studies, women, married patients, and older patients would rather involve their family in treatment decisions [2, 6].

Also, oncologists and oncology nurses recognize the important role of the family participating in treatment decision making [8, 9]. However, in spite of the fact that oncologists want to include family in decision making, studies demonstrate that family involvement is often limited in frequency and scope and often occurs too late in the course of the disease [10–13]. As a result, the family is often unprepared for the death of their beloved one and suffers from more depression and anxiety [11].

To date, most of the research on family involvement in decisions near the end of life has been done in the intensive care units, where most patients are unable to communicate on their behalf [3, 14–16]. The results of these studies show the importance of physicians' and family communication and collaboration in decisions about life-sustaining treatments [3, 15]. However, some studies demonstrated increased distress among family who were involved in end-of-life decisions at the intensive care unit [14].

The role of family in decision making is less studied in oncological care, where most patients are conscious and able to communicate almost until dying [10, 17, 18]. Previous studies have focused mostly on family involvement in cancer-specific treatment decisions in general [19, 6], highlighting the importance of the family in helping patients understanding information about therapy, their cancer diagnosis [20, 21], or family impact on decisions on complementary and alternative treatment [22].

One large cohort study with 5,284 patients with newly diagnosed lung or colorectal cancer demonstrated that the majority of patients would involve family members in treatment decisions [2].

However, such decisions may considerably differ from the decision-making dynamics near the end of life in which questions whether to withdraw cancer-specific treatment and hospice or palliative unit referral are up for discussion.

Thus, with a qualitative interview study, we aim to explore oncologists' and oncology nurses' perception of family involvement in decision making about treatment limitation in patients with advanced cancer who are able to communicate in the hospital setting. The following research questions guided this qualitative study. What challenges are encountered by oncologists and nurses when involving family into decisions about limiting of cancer-specific treatment? How do oncologists and nurses value the role of family in decision making and what are their involvement strategies? Empirical results will be discussed against the background of a clinical and ethical debate on family role in the care near the end of life.

MATERIALS AND METHODS

We used a qualitative approach based on grounded theory methodology, as it is well-suited to explore in-depth how oncologists and oncology nurses perceive family involvement in decisions to limit cancer-specific treatment. Ethical approval was obtained from the research ethics committee of the Munich University Hospital. Written informed consent was provided by all participants.

Setting

The study was carried out at the Department of Hematology and Oncology at the University Hospital of Munich, Germany. Oncologists and nurses from six hospital units (palliative care unit, an intensive care unit, and four general wards) were interviewed.

Procedure of Data Collection

We contacted interview participants first by e-mail and invited them to take part in the study. Those who did not respond were recontacted by telephone. Qualitative individual face-to-face interviews were conducted using a semistructured interview guide. All interviews were conducted by the primary investigator (K.L.), who is experienced in qualitative interviewing, and lasted 30–100 minutes. All interviews were digitally recorded. Demographic data were collected at the end of the interview.

Development of the Interview Guide

The interview guide was developed in a multistep process that included (a) developing interview questions based on the analysis of the existing literature, (b) pretesting the interview guide with oncologists and nurses, and (c) improving and developing a final version of interview guide.

Sampling Strategy

Purposive and theoretical sampling strategies were applied. Participants were purposely sampled to represent different hospital units, working experience, age, and sex to reflect a

wide range of opinions. We continued sampling until the theoretical saturation was reached: when no more new categories emerged and the relationships among categories were well developed [23]. Theoretical saturation was achieved with 29 participants. Throughout the data-collection phase, the interdisciplinary research group that consisted of a social scientist (K.L.), an experienced oncologist and medical ethicist (E.W.), and an experienced oncologist and psycho-oncologist (P.H.) met regularly to discuss data collection and emerging themes.

Sample Description and Participants

In total, 22 oncologists and 7 nurses were interviewed before the theoretical saturation was achieved. To insure sample heterogeneity, six hospital units and participants with different working experience and position (fellows and seniors) were included into study. Two nurses and 4 oncologists were from an intensive care unit, 3 nurses and 11 oncologists from a general ward, and 2 nurses and 3 oncologists were from a general ward for private patients. Three oncologists worked at the palliative care unit. One hemato-oncologist was from the bone marrow transplant station. The average age within the sample was 37 (range, 22–64). Sample characteristics are provided in Table 1.

Data Analysis

The collected data was analyzed using the three-steps approach of grounded theory methodology.

Open, axial, and selective coding strategies were applied. At the first level of coding (so-called open coding),

the focus was on each sentence to define categories and, consequently, working concepts. In axial coding, we examined how the identified concepts and categories were related. Subsequently, in the last step of selective coding, relations between the categories were validated and refined, and core categories were identified [24]. To insure the maximal objectivity of our findings and to minimize the bias, we constantly discussed the results of the analysis in our interdisciplinary team meetings. Performing analysis in an interdisciplinary team can contribute significantly to prevention of the personal bias of a single researcher from influencing the study results. MAXQDA software (VERBI Berlin, Germany) was used to assist with the coding and management of transcripts.

The empirical data were then evaluated against the background of the current ethical debate regarding end-of-life decision making.

RESULTS

The majority of oncologists and all nurses, independently of their working experience and age, indicated that it was important to include family in decisions about limitation of cancer-specific treatment. Family role was described as a supportive and accompanying one. The family was seen as helpful for patients in terms of understanding and managing information regarding treatment decisions. Furthermore, family members could even become a facilitator of discussions about limiting treatment if they had a realistic view on patients' prognosis and the same understanding of care goals as oncologists.

However, participants, along with positive aspects, also reported some challenges related to family involvement in decisions to limit treatment. It was noticed that family involvement could be associated with increased psychological burden for the family. Family members might suffer from emotional distress, fear, and helplessness even more than the patient did. Communication with distressed family was perceived sometimes as even more challenging as with patients and was described as stressful for the care team.

Furthermore, the family could become a considerable barrier to advance care planning if they dissented with patients' or oncologists' goals of care and strived for further tumor-specific treatment.

Positive aspects as well as challenges associated with family involvement in decision making about forgoing cancer-specific treatment with participants' citations are presented in Table 2.

Oncologists' and Nurses' Attitudes Toward Family Involvement in Decision Making

In spite of the fact that the majority of respondents attached importance to family involvement in end-of-life discussions, we could identify two attitudes toward family role in decision making on limiting cancer-specific treatment: (a) patient-focused approach and (b) mediator approach with a family focus

There was no difference in attitudes among participants based on working experience, position (senior oncologist or

Table 1. Respondent characteristics

Characteristics	No. (%)
No. of all respondents	29
Age, mean (range), yr	37 (22–64)
Units	
Intensive care unit (<i>n</i> = 1)	6 (21)
Palliative care unit (<i>n</i> = 1)	3 (10)
General oncology wards (<i>n</i> = 4)	20 (69)
Bone marrow transplant station (<i>n</i> = 1)	1
Participants' working experience, from 8 mo to 34 yr	
Low or novice level (<3 yr)	8
Intermediate level (3–5 yr)	4
High level (>5 yr)	15
Oncologists	
Male	13 (59)
Female	9 (41)
Position	
Fellows	13 (45)
Senior physicians	9 (31)
Nurses	
Male	1 (14)
Female	6 (86)

Table 2. Challenges and benefits of family involvement in decision making

Benefits and challenges	Participants' citations
Positive aspects	
Patients' emotional support	"...Simply accompanying, supporting emotionally, so that patient is not alone." "[Ph.14, General Ward, translated from German]"
A possible motivator and facilitator of discussions about forgoing cancer-specific treatment	"Often relatives are the key, because relatives understand often more than the patient does and they are likewise realistic about situation as we are. And relatives can also take an important task in following up on detailed conversation because they can simply discuss certain things with patients afterward." [Ph. 13, General Ward, translated from German]"
Support for patients in understanding and managing the information regarding treatment decisions	"Well, I think, it is simply a great support for patients if relatives participate. The patient is so overburdened, so that he cannot keep all the information in mind, so they think the relative who is present is just a second mind to think along and pays attention to what is being said." [Nurse 23, General Ward, translated from German]"
Challenges	
A possible barrier to advanced care planning in case of dissenting family preferences on treatment	"And the daughter did not accept it. She said: It cannot be, he must be further treated, she cannot let him go. It was quite bad. However, we had to do, and we did what the patient wanted and what was important for him." [Ph.14, General Ward, translated from German]" "I think it is often so, that patient is already so far: i.e., I do not want further therapy any more. I have actually concluded with my life. And in such situation family members cannot let patient go and cling to the patient and say: do not try this, try this or that and they cannot let a dying patient go." [Nurse 2, General Ward, translated from German]"
Possibly increased psychological burden for the family	"Yes, you can imagine, of course, cancer disease is very stressful for a partner because of the feeling of helplessness. The fact, that he or she cannot help the partner." [Ph. 6, ICU, translated from German]"
Stressful for the care team	"The most difficult situations for me are not with the patient himself but with the relatives. Simply dealing with the grief of the family is worse than interacting with the patient, as patients often say: Yes, it is good that we are allowed to leave now. And we are glad that we have got it made." [Nurse 14, General Ward, translated from German]"
Mediating conflicting goals of care between patient and family	"Relatives are especially difficult when they are of a different opinion than the patient. If the patient says, for example: so, I came to terms now with my illness. I can accept that I will die of it – maybe I will die even soon of it. And the cannot accept this. In the end, the patient's opinion counts and not the relatives' one. And then you are caught between two stools. One party wants this. The other party wants that." [Ph. 4, General Ward, translated from German]"
Increased attention, more time investment, and detailed discussions when involving family of a young adult patient	"If they are the parents of a very young patient, you must talk of course with them in much detail. They are always awful. They are deeply involved of course." [Ph. 1, General Ward, translated from German]"

Abbreviations: ICU, intensive care unit; Ph., physician.

fellow), age, or gender. Furthermore, we could not identify any differences between oncologists and oncology nurses. When nurses were talking about family involvement, they often referred to the role they ascribed to oncologists (how they should deal with family members) and not to their own role.

Patient-Focused Approach

If the family was involved in treatment limitation discussion, its role was generally limited to helping patients in understanding information about therapy and to supporting patients emotionally.

A part of interviewed oncologists avoided family involvement if they noticed that family influenced patient and had divergent views regarding further treatment. Some nurses also stated that family could hinder decision making about limiting treatment, demanding further treatment:

There are also sometimes conflicts, so that patient says, e.g., I cannot any more, I would not like to be reanimated, I don't want further therapy any more. However, family members would like to go on with the treatment and put patient under pressure: now you cannot give up etc. [Nurse 2, General Ward, translated from German]"

The family was seen by oncologists and nurses within this approach as "passive" participants with only an accompanying and supporting function in the decision-making process. Patients' treatment preferences were of the highest priority for oncologists. The patient was perceived as a self-determined decision-maker. Only if the patient was not able to communicate did the family become more important as an information source for oncologists:

They [family members] should be on board with us if that somehow works, be present as far as it is possible

so that they understand it, understand for themselves. But they only play a role for me if I cannot learn the patient preferences from the patient himself. [Physician (Ph.) 26, Palliative Care Unit, translated from German]

This is our decision [treatment limitation], if at all together with the patient; and family members are only allowed to participate as passive participants. [Physician 11, General Ward, translated from German]

Family involvement was not perceived as a special task for oncologists but rather as a task of psycho-oncologists' team:

We actually include family members to a lesser extent of course. However, I also think this is not my job. I am primarily responsible for the patient here, not for the family. We are happy to inform family of course and talk about it. So, working with the family is not my area. I do not do it at all. [Ph. 21, General Ward, translated from German]

Mediator Approach with a Family Focus

Within this approach, family was seen as an important indispensable part in decisions about limiting therapy. A special focus was put on timely family involvement. Both oncologists and oncology nurses stated that the family should be involved much earlier; namely, before patients did not respond to the treatment and all therapy options were exhausted:

As both for the patients and for family there is a feeling that now we give him up when he is doing worse. (...) Yes, to involve them at the earliest opportunity when I notice as a physician that my possibilities are exhausted. [Ph. 17, General Ward, translated from German]

Oncologists and nurses described the importance of developing a trustful relationship with family members. Family involvement meant, for them, presence of family members at different stages of decision-making process. Both the patient and the family should be prepared step by step for difficult decisions like those of limiting futile treatment. Oncologists conceived themselves as mediators between patient and family. Also, nurses saw oncologists as mediators within this approach, who should take an active role in communicating and building consensus between the involved parties: "One should get known become [family] before. Just figure out what every party really wants and holds for the right and then try to find a common denominator for all the parties." [Nurse 14, General ward, translated from German]

Such expressions as "to convince" and "to persuade" were used to describe communication with the family. Even if a patient did not express a direct wish for family involvement, oncologists and nurses suggested that it was important to take the initiative and to talk to the patient and

clarify the reasons why the patient avoided family involvement.

Oncologists and nurses saw their role in facilitating communication between patient and family as patients' family can serve as either a barrier or facilitator for decisions to limit tumor-specific treatment.

Preferably, one informs both together: the husband and the wife. Because, I think, that they [...] want to protect each other and cannot talk to each other frankly. And then you should try to bring them both at the same state of knowledge. And the wife must go along with it and she needs a support. [Nurse 27, General Ward, translated from German]

It was noticed that patients often did not want to involve family members because they wanted to protect them from bad news. Respondents reported that patients tried to conceal their emotions and preferred not to talk about the end of life. Some oncologists and nurses explained it partly by the existing cultural norms of our society. It is not common to talk openly about death and dying and to express sadness, sorrow, and suffering within the relationship. "It has to do with our socialization. We are socialized to protect each other in our relationships, yes, from difficulties, from worries. And it is the same when someone is dying." [Ph. 9, Palliative Care Unit, translated from German]

DISCUSSION

The results of our study showed differences in participants' perception of facilitating family involvement in decisions about limiting cancer-specific treatment

When asked about strategies for family involvement, nurses often referred to oncologists' role and not their own tasks. This might be explained by a perceived lower hierarchical position of nurses in Germany [25] and that they see oncologists as mainly responsible for family involvement in decision making.

We could identify two approaches, shared both by oncologists and oncology nurses: (a) a patient-focused approach and (b) a mediator approach with a family focus. One possible explanation for this observed difference in oncologists' and nurses' attitude toward family involvement could be partly explained in different perception and definition of the concept of patient autonomy.

The Patient-Focused Approach: Informed Consent and Respect for Patients' Autonomy

A patient-focused approach with an emphasis on patients' independence in decision making is well in line with a concept of respect for patient autonomy and self-determination as one of the principles of biomedical ethics.

It entails that individuals have a right to make their own decisions about medical treatment. Physicians are to respect patients' autonomy-based decisions. Oncologists should provide their patients with all necessary information regarding treatment risks and benefits. Patients should be

also informed about the alternative of no-treatment to make independent "informed" choices [25].

If autonomy is primarily understood as a result self-determined decision making based on individual values, the family could be seen as a possibly interfering with such decision making—especially if their values and agenda differ from that of the patient. Thus, oncologists' role would be to protect patients' autonomy from being endangered by too much involvement of the family and manipulative influence [26].

The Mediator Approach with a Family Focus: The Concept of Relational Autonomy

This approach is in line with how ethics of care (or care ethics) understands patient autonomy. This normative ethical theory was developed primarily by feminists and rejects classical Kantian conception of autonomy, which sees an individual person more as a separate autonomous agent independent from social relations. Instead, it holds that social and familial relations build an integral part of a person's identity. Hence, patients are embedded in social relationships especially with their family [24]. Against this background, patients autonomy is understood as "relational autonomy" [27]. According to an ethics of care, patients' decision making is a constant dynamic dialogue with a family and social environment [28]. Furthermore, patients' illness cannot be perceived isolated from a family. Cancer diagnosis means a stressful and challenging time for all family members. It influences deeply family coexistence and relationships. Thus, according to ethics of care, when family is not involved in the decision-making process, patients' relational autonomy and family well-being are neglected [25]. The idea of relational autonomy is also supported by recent research in cognitive psychology. It suggests that individuals make decisions not by themselves but rather in interaction with others.

Reasons For and Against Family Involvement in Decision Making about Limitation of Cancer-Specific Treatment

Focusing on the idea of a patient as an independent agent, oncologists may run the risk of neglecting the positive aspects of family involvement near the end of life: family members may help patients to identify and express their preferences and needs, strengthening in this way the patient's autonomy [29]. If provided patient permission, the family benefits from involvement in decision making. Many studies report a great need on the part of the family for disease-related information such as symptom control, details of care, course of illness, treatment options, and alternatives [30, 31]. Thus, family members' understanding of patients' care correlates with their satisfaction [30]. Furthermore, family members often experience patients' illness as a burdensome situation causing fear, anxiety, and depression [30]. Results of a qualitative study with 18 family caregivers demonstrated that family involvement in decision making contributed to illness adaptation of the family and bereavement and had a positive effect on family functioning [1].

However, involving family sometimes becomes a considerable challenge for decisions about forgoing cancer-specific treatment when treatment preferences of the family differ from those of the patient. This is especially likely when the family does not have a realistic perception of the patient's condition and deny imminent death of the patient. Oncologists and nurses in our study report that family in these situations often pressure patients and demand further therapy. In these situations, oncologists should be mindful of family influence on decision making, advocating for the patient and helping him to make an independent decision.

Because of their unique position between oncologists and patients with their families, nurses could become an important informational source for oncologists because they spent more time at the bedside with patients and their family and are often aware of existing interfamilial relationship and of possible family influence on patients' treatment preferences.

Furthermore, oncologists who focus only on patients need to be aware that even if family is not involved directly in decision-making process, they still may have an influence on patients' cognitive process. It was demonstrated that after encounters with oncologists, patients discussed the received information with their family and that this shaped patient preferences and decisions [32].

Against this background, a mediator approach seems to be best suited for decision making in the context of serious and life-limiting illness. It not only respects patients' autonomy as independent actors but also does justice to the embeddedness of end-of-life decision making into family contexts. It is necessary to listen to family concerns and to understand their reasoning to avoid misunderstanding between family, patient, and oncologist. This process might contribute to family coping with a terminal illness of their beloved one, to avoiding trauma and distress of family, and to handling the difficult situation when the decision of therapy limitation is not avoidable any more. Thereby, it allows to counteract negative influence of family on patients' decision making.

CONCLUSION

Based on the result of our interview study and comparison of the two identified approaches toward involving the family, we formulate the following recommendations for clinical practice for oncologists and oncology nurses: (a) Oncologists and nurses should capitalize on the positive aspects of family involvement: patients' emotional support, improved understanding of therapeutic options and treatment course, and recalling necessary information, as well as helping the family to prepare for patients' death. Furthermore, the family can also be a possible motivator and facilitator of discussions about forgoing treatment. (b) Oncologists and nurses should be mindful of families' influence on decision making, especially when family members do not have a realistic perception of the patient's condition and deny imminent death. (c) Oncologists should therefore support the family in understanding a patient's incurable condition and should offer to mediate between a patient and family members in cases in

which their views on further treatment are at conflict. (d) Strengthening working relationships between nurses and oncologists is necessary for successful resolving possible emerging conflicts. (e) Nurses should develop a rapport (i.e., a trustful relationship with patients and their families and be able to understand care needs of family members). Nurses can also take a mediator role, providing information to patients as well as communicating patient and family needs to the care team.

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AUTHOR CONTRIBUTIONS

Conception/design: Katsiaryna Laryionava, Pia Heußner, Wolfgang Hiddeman, Eva C. Winkler

Provision of study material or patients: Pia Heußner, Wolfgang Hiddeman, Eva C. Winkler

Collection and/or assembly of data: Katsiaryna Laryionava

Data analysis and interpretation: Katsiaryna Laryionava, Daniela Hauke, Eva C. Winkler

Manuscript writing: Katsiaryna Laryionava, Pia Heußner, Eva C. Winkler

Final approval of manuscript: Katsiaryna Laryionava, Daniela Hauke, Pia Heußner, Wolfgang Hiddeman, Eva C. Winkler

DISCLOSURES

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